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Chapter 1 Background

Introduction

- **Who are Gypsies , Roma and Travellers (GRT)**

The term Gypsy, Roma and Traveller has been used by policy makers to encompass a range of ethnic groups, and those with separate nomadic ways of life who are not from a specific ethnicity, such as showmen[1], and boaters.

In the UK the ethnic groups referred to are Gypsies , (including English Gypsies , Welsh Gypsies and Scottish Gypsy Travellers) , Irish Travellers , and Roma (Gypsies who have more recently come from East Europe to the UK) . Showmen should also now be included but not under the umbrella of GRT as they consider themselves to be a separate group even though they do have strong links with the Gypsy and Traveller communities and face many of the same barriers.

Most English and Welsh Gypsies are happy to be called Gypsy or Romany Gypsy, although some prefer the term Travellers . In Scotland the term Gypsy/Traveller is used , but most Irish and Scottish Travellers use the term Travellers.

To be inclusive I will usually refer to all these ethnic groups by the term Traveller in this report, affording it the entitled capital letter as all the groups included are recognised as ethnic groups by the Equality Act 2010.

- **Demographics**

Nationally, the census recorded 58,000 people as Gypsy or Traveller in 2011 in England and Wales, with a further 4,000 recorded in Scotland. The Government acknowledges that this to be an undercount because so many Travellers don't self- ascribe. The usual quoted estimates for the size of the Gypsy Roma Traveller (GRT) population in the UK is between 120,00 and 300,000. Many, including Travellers, think that this is also now an underestimate , not

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[1] The UK's Showmen have recently been recognised as both an ethnicity and an occupation in the 2021 national census, for the first time .

least because this estimated upper figure has not been revised for many years since it was originally estimated in 1987. [i]

The census[ii] also reveals that the age demographic of Gypsies and Travellers is much younger than the rest of the English and Welsh population, with a median age of 26 and nearly 40 per cent of the population being under 20 years old. Although it is likely that more Travellers in the younger age groups would be likely to complete a census return and self -ascribe, the evidence for a young age demographic is also indicated by a baseline census study in Leeds [iii] which showed that only than 2.5% of Gypsies and Travellers were over 60 years, compared to 20% of the total Leeds population.

One of the reasons that there are no accurate numbers is because so many Travellers don't self- ascribe , due to the fear of prejudice towards them .

As it is so difficult to provide accurate numbers we only have anecdotal evidence from local knowledge . Based on available data, the estimated GRT population of the Northwest is 38,976 out of 7,224,000 – that is equal to 0.5%. Extrapolated to Morecambe Bay CCG, that would give an estimated GRT population of around 1,700 - 1,900.

In Morecambe Bay area, as elsewhere, the GRT population live either in houses, on privately owned caravan sites or on the one council owned caravan site. Although they are ostensibly 'settled' in houses or on sites, many spend at least some part of the year travelling, either for work purposes, for cultural fairs or events or to be with extended family elsewhere .

GRT health – National Picture

The NHS National Data Dictionary does not include Gypsies and Travellers alongside the 16+1 other ethnic categories which are currently monitored. This means the NHS is unable to collect nationally representative data on the health needs of these ethnic minority groups.

Although only a proportion of Travellers identified themselves as such in the 2011 census, of those that did 14% of Travellers described their health as " bad "or "very bad". This compared with 5.9% of White British and 9.2% of White Irish people.

There is a dearth of robust research on the health and wellbeing outcomes of Gypsies and Travellers with the only large-scale epidemiological study being carried out by the University of Sheffield, funded by the Department of Health, in 2004.[iv] This study indicates that, as a group, their health overall is poorer than that of the general population and poorer than that of non-Travellers living in socially deprived areas or in certain other minority ethnic groups. It also found an inverse relationship between health needs and access to healthcare.

The starkest health inequality evident from the study was mental health , with Travellers found to be nearly three times more likely to be anxious than others, and just over twice as likely to be depressed. Mortality data published by the ONS are collected from the information provided at death registration but as this information does not include the ethnicity of the deceased, there are no official data on deaths by suicide among Gypsies, Roma, and Traveller (GRT) individuals in England and Wales. However high rates of suicide among Gypsies and Travellers in Britain were reported in a 2009 Equality and Human Rights Commission (EHRC) review of inequalities experienced by Gypsy and Traveller communities[v], which confirmed anecdotal evidence of a disproportionately high suicide rate amongst this group. In Ireland it has been possible to measure the suicide rate amongst Travellers , and the 2012 All Ireland Traveller Health Study (AITHS) [vi] shows that Travellers experience a 6.6 times higher suicide rate when compared with non-Travellers, accounting for approximately 11% of all Traveller deaths.

Although there have not been any large-scale studies after the Sheffield study, local authorities and clinical commissioning groups (CCGs) have a responsibility to prepare Joint Strategic Health Assessments (JSNAs) for their area . These are written jointly between local NHS services and local authorities. There is significant variation across England in how JSNAs are produced and updated . Some are regularly updated and deal extensively with Gypsy, Roma, and Traveller issues, but according to the 2009 EHRC review, this seems to be the exception rather than the rule. A few have carried out separate JSNAs for their GRT populations whilst a small number have included chapters on Gypsy and Traveller health needs. They all acknowledged the difficulty of obtaining GRT health data and have either referenced the Sheffield University study or other studies for health data, while others have carried out stakeholder interviews to obtain a local picture, but all confirm the picture of poorer health and poorer use of health care services. A selection of those that are publicly accessible online are referenced here. [vii] [viii] [ix] [x] [xi] [xii]

Findings in the qualitative arm of the Sheffield study gave indication of reasons for poor use of primary health care services .

Self-reliance, stoicism, fatalistic health beliefs and avoidance of thinking about or discussing feared diseases such as cancer may also be linked to ignorance of the long-term implications of initial symptoms, making it easier to tolerate conditions if symptoms are manageable. The combination of lack of knowledge, low expectations and fear, reduces the likelihood of seeking early treatment, particularly for those conditions (e.g., cancer and heart disease) where early detection has the greatest impact on prognosis.

Fears around death and dying were strongly associated with a dread of a diagnosis of cancer, which was seen as an inevitable ‘‘death sentence’’, and this seemed to be confirmed by experience for most respondents in the study . People therefore avoided any possibility of hearing that diagnosis. The fatalistic attitude that ‘‘nothing can be done’’ for cancer was frequently described, which in turn is likely to increase the chances of a terminal prognosis

More recently, the House of Commons Report on Tackling Inequalities faced by Gypsy and Traveller communities[xiii] also found that one of the most frequently cited healthcare problems facing Gypsy, Roma and Traveller people is in accessing primary and secondary health services. Several submissions to the review reported the tendency to use emergency services such as A&E rather than any structured approach to healthcare, due to previous poor experiences. Dr McFadden gave an explanation about poor experiences leading to mistrust in her reporting to the review

You might have your very close-knit community; your friends or your relatives have had that experience, and then that becomes a story. They're spread by social media. Historically, there's even worse, so there's a cultural memory about health services. So that all has a huge impact on trust.

Policy context

The Health and Social Care Act 2012 introduced the first legal duties about health inequalities. It included specific duties for health bodies including the Department of Health, Public Health England, Clinical Commissioning Groups, and NHS England which require the bodies to have due regard to reducing health inequalities between the people of England.

Since the 2004 Housing Act it has been a statutory requirement for local authorities to respond to the accommodation needs of the Gypsy and Traveller communities living in their areas as part of their wider housing strategies and the Regional Housing Strategy.

Although guidance on carrying out an assessment of the accommodation needs of Gypsies and Travellers (GTAAs) does not specifically include assessment of health needs , it does suggest inclusion of relevant questions : Does anyone in your household have a disability or serious illness? Does anyone in the household have health needs for special or adapted accommodation which need to be addressed? Is the proximity of a hospital or doctor a reason why a household lives where it does? [xiv]

Lancashire Sub-Regional GTAA in 2007 [xv]did include survey questions on health and housing related support issues. They found that out of the total sample, 52 households (24.8%) reported that someone in the household had a disability or long-term illness. The type of illness that households experienced varied. Complaints such as asthma, diabetes, heart problems and arthritis were particularly common. In addition, households reported incidences of cerebral palsy, hip and leg problems, and hearing problems.

A subsequent GTAA for Lancaster in 2017 [xvi] , caried out by a different organisation did not include any survey of health .

As mentioned earlier , there is also a statutory responsibility for local authorities with CCGs to carry out JSNAs, with the purpose of improving the health and wellbeing of local communities and to reduce health inequalities for all ages . Although the guidance doesn't specifically include mention of GRT communities, there is further guidance in 'Commissioning Inclusive Services' [xvii] from the Royal College of General Practitioners (RGCP), via the National Inclusion Health Board where Gypsies, Roma and Travellers are one of the four groups specifically targeted . It states

To do this, the JSNA must include those in disadvantaged areas or vulnerable groups who experience health inequalities, such as those who find it difficult to access services and those with complex and multiple needs, when considering the current and future health and social care needs for all the local population.

The JSNA for Lancashire 2014 [xviii] did not include any reference to GRT health needs . In its Annual Commentary: A compendium of key issues for health, wellbeing, social care and the wider determinants of health [xix] it did make reference to the impact of ethnicity on health:

"Changes to the ethnic mix of the county have an impact on health since certain ethnic groups are more susceptible to develop various health conditions such as diabetes and stroke."

However, when reporting on the ethnic mix it showed no recognition of GRT ethnicities , and therefore GRT groups were not included as being at risk of that negative impact in the report, as it stated

“At the time of the 2011 Census, the largest ethnic group in Lancashire was white (92%) with the remaining 8% being from black and minority ethnic (BME) groups.”

The report of the Director of Public Health 2019/20 also made no reference to ethnic health inequalities but focussed on deprived communities by place.

There has never been a separate JSNA for GRT health in Lancashire. The House of Commons report : Tackling inequalities faced by Gypsy, Roma and Traveller communities 2017-19 stated

“ *We are concerned that many JSNAs are currently not complying with the Public Sector Equality Duty. It is unacceptable that the* [GRT] *Communities continue to be overlooked, given that they have the poorest health outcomes of any ethnic group.”*

The Government response to the report [xx] made several recommendations , including :

- *The new assessment of needs for CCG resource allocation should include an explicit section for CCGs to outline the needs of Gypsy, Roma and Traveller people in their local areas. This need should be taken into account by NHS England when it is allocating funding to CCGs (Recommendation 25).*

Local health services structure

Lancashire and South Cumbria Health and Care Partnership is the name of the Integrated Care System . There are five Integrated Care Partnerships (ICPs) in Lancashire and South Cumbria, which have four main roles:

- To support and develop Primary Care Networks.
- To simplify, modernise and join up health and care.
- To understand and identify people and families at risk of being left behind and to organise proactive support for them.
- To coordinate the local contribution to health, social and economic development to prevent future risks to ill-health.

The ICP serving Lancaster and Morecambe is the Bay Health and Care Partners (BHCP) . It is made up of a range of local health and social care services, including University Hospitals of Lancaster County Council, Lancaster City Council , Morecambe Bay NHS Foundation Trust (UHMBT) , Lancashire and South Cumbria NHS Foundation Trust, covering mental health services, and Morecambe Bay CCG , which work together across North Lancashire, South Cumbria, and Furness.

Morecambe Bay CCG are responsible for commissioning planned and emergency hospital care, rehabilitation, most community services, and mental health and learning disability services. It is also responsible for engaging with local people to ensure that services meet the health needs of the community.

There are also eight Integrated Care Communities (ICCs) in Morecambe Bay . Each ICC employs a Development Lead whose principal role is to build strategic-level relationships with local partners – including community groups, public services, third sector organisations and housing.

The Development Lead combines information from a wide range of sources to learn about problems affecting local communities that may be impacting on people's health; including risk stratified population data, information about individuals being referred to care coordinators and through conversations with cohorts and groups within the community, asking them what they understand the issues to be.

In July 2019, every GP practice became a member of a Primary Care Network (PCN), which work together to provide care for their local populations. Within BHCP there are eight PCNs that build on the core of current primary care services and enable greater provision of proactive, personalised, coordinated and more integrated health and social care. The two PCNs serving Lancaster and Morecambe are Lancaster Primary Care Network and Morecambe Bay Primary Care Network.

Project background

In 2018 , following work with Traveller community commissioners and supporters in the Morecambe Bay Poverty Truth commission (MBPTC),   discussions took place with Andy Knox , Director of Population Health and Engagement in Morecambe Bay CCG with a view to exploring ways work more effectively with the GRT community regarding their health needs.

In April 2019 the first meeting of the newly formed Gypsy Traveller health Forum was convened by Andy Knox. It brought together a range of representatives from different local organisations to formulate a plan on how to engage with the GRT communities in Morecambe Bay about their health needs. Subsequent meetings included GRT members, and the third and last meeting was held in January 2020, before the covid pandemic took hold.

CancerCare, a local charity dedicated to the support of cancer patients , their families and carers and for those bereaved by cancer in North Lancashire and South Lakeland, was one of the allied organisations who were keen to reach out to and work more effectively with Travellers and their families . Cancer is one of the biggest single causes of death in Morecambe Bay, and the evidence referred to earlier, in ‘what we know about GRT health and health needs’, showed that this is a significant issue for Travellers. The extreme fear of a cancer diagnosis, combined with their lack of knowledge about cancer, often leads to the experience of late diagnosis within the community. This in turn has led to an assumption that a cancer diagnosis is an inevitable death sentence – and even that the act of receiving the diagnosis can be blamed for a fatal outcome.

In September 2020 CancerCare was successful in securing funding for this project from the MSD Cancer Community Grants Programme, to try and help to find a new approach to working with the GRT community around cancer. The aspiration was to design a project not by doing something to this community, but by establishing a genuine new partnership through co-designing new ways of tackling cancer together. The bulk of the funding was for an action researcher to deliver the project aims over twelve months, eventually producing a co-designed model to overcome the barriers for GRT communities in obtaining earlier diagnosis and treatment.

Original Project Aims

The aims of the project were to work with members of the local GRT community with the aim of building trust with primary care services, increasing screening rates, improving prevention, effecting earlier diagnosis, and more effective treatment and recovery – or, indeed, palliative care. This was to be achieved by:

- Establishing a project steering group , with most members being from the GTR community.
- Engaging with CCG, GPs, and secondary health professionals to understand their perspective.
- Establishing data access routes with health providers and any others identified.
- Working with the GTR community to build trust and develop ways of working and understand the issues for the community that impede their early access cancer services from health professionals and CancerCare
- Co-producing and designing the engagement model with the GTR community and bring together a wider group of the GTR community, health professionals and CancerCare staff to jointly test the model to see if it is viable

Project Challenges

The major challenges to achieving the project aims were a result of the project commencing in October 2020 during the Covid pandemic.

Ideally, if it were not for the restrictions enforced due to the pandemic it would have been possible for the action researcher to go with trusted intermediaries, either from the GRT communities or from those who already knew or worked with the communities, to be introduced to and get to know members of the GRT community . This would have been a prerequisite to explaining the project and seeking members to help to form the project steering group.

The restriction enforced due to the pandemic also made Traveller engagement particularly difficult and limited though the necessity of communicating remotely by telephone, email, or video technology once an introduction was made. The intended launch events for the communities to stimulate engagement were also not possible, and the intention to recruit Travelers as community researchers was not realised.

Even without the pandemic there would have been more difficulty because there are no existing groups or forums in Lancaster and Morecambe where Travellers regularly come together. In areas where such groups do exist those groups have usually been instrumental in developing such initiatives around health or other areas of concern for Travellers.

In common with so many in the wider community the covid pandemic had an impact on Travellers families as they had family members who became infected, and some very seriously or fatally. Travellers having such large and close extended families meant that it was more common for individual in the Traveller communities to have someone close to them that was affected. Caring for family members and keeping family members safe was inevitably their main priority and taking part in a project either as a steering group member or as a participant in any other way was not something that most would contemplate at such a time.

After considerable time spent in trying to engage potential steering group members from the GRT communities, some Travellers did agree to become members, but there was fluctuating attendance and involvement , invariably due to health or other family crises that understandably took precedence. No Traveller member was able to manage consistent attendance and there were two steering group meetings when no Travellers were represented..

Those that were willing to attend did not always have appropriate technology to enable them to participate and it was necessary to obtain the loan of tablets and dongles to enable remote participation by Zoom.

Another challenge was the focus on cancer, particularly the ability to raise this issue in isolation in interviews with Travellers with someone that they hadn’t had a chance to get to know gradually. It was agreed by the steering group that the focus of the project should be widened to look at prevention and early detection of all health condition, in acknowledgment that the project aims of building trust in health care services generally would be more likely if cancer was not singled out specifically.

The combination of all these challenges led to delays and to inevitable revision of the original project milestones as it progressed.

Project Steering Group

The roles of the steering group were :

- To guide the delivery of the project
- To review and evaluate progress and change the design as required
- To facilitate access and engagement with health professionals and GRT populations

The first project steering group met by Zoom on 17th November 2020 , with one Traveller member of the five originally recruited . Other original members included the director of client services in Cancer Care , the development leads for Lancaster and for Bay ICCs , a health visitor , a population health manager and communication and engagement officers from the CCG, a teaching assistant from the Lancaster GRT Achievement Service (education) who is also a member of the GRT community, and the action researcher .

Four subsequent steering group meetings were held, and different new members were co-opted, including a newly recruited Traveller member, although there was no meeting where more than three members from the Travelling community were present at any one time.

The main agenda item at the first steering group meeting was the exploration of feasible methods to gather baseline health and evaluation data

Baseline data gathering

- **Obstacles**

Although it was considered unlikely that many Travellers would have their ethnicity recorded on their health record as Gypsy or Irish Traveller it was important to find out how many were recorded. When representatives from each PCN reported back they revealed that the numbers were even smaller than anticipated, with only eight in total ; four in each PCN.

Meanwhile , as lack of hard data had been anticipated as an obstacle to baseline data gathering, it was arranged that the action researcher would deliver an education session in each PCN, to explain the need for this project and the importance of identifying GRT patients by recording their ethnicity. Confirmation of the importance is evident from the House of Commons report on Tackling Inequalities experienced by GRT and its consequent recommendations:

> *The lack of consistent data collection on Gypsy, Roma and Traveller people means that public bodies are failing to tackle inequalities that are clearly evidenced in academic research and in work being carried out by grassroots organisations.* (Paragraph 48)
>
> *Gypsy, Irish Traveller and Roma categories should be added to the NHS data dictionary as a matter of urgency.* (Paragraph 49)

> *The Race Disparity Unit should review all the Government and public datasets that currently do not use the 2011 census ethnicity classifications and require their use before the end of 2019* (Paragraph 50)

- **Example of good practice in recording GRT ethnicity**

Although the ethnic codes for Gypsy and Irish Traveller are not included in the 16+1 other ethnic categories which are currently monitored they are hidden among numerous other read codes[2] that have to be searched for. It is possible for them to be added in some way so that they are visible as a choice without separate searching , depending on the integrated clinical IT system that is used. An example was given at the education sessions of how this was done in county Durham, where most practices in each CCG used the IT system called ' System One.' This example demonstrated how the coding was then used to show comparative data from the Quality Outcomes Framework (QOF) between patients coded as Gypsy or Irish Traveller and the whole patient population in the combined CCGs covering County Durham [xxi] (see table 1)

The value of this was evident, as the comparative data confirmed in county Durham what had been found in the epidemiological Sheffield study and in some JSNAs , i.e. that the prevalence of mental health conditions, particularly depression, is significantly higher in the GRT population , while there was significantly lower prevalence of atrial fibrillation, cancer, chronic kidney disease and hypertension (see table 2) . This lower prevalence of conditions that are more silent in the early stages reinforce the indication that Travellers present less readily with symptoms of early disease than the majority population.

The added value of recording ethnicity and running the comparative data is that it would be possible to later evaluate any progress on addressing the late presentation of conditions such as hypertension, and cancer .

However, there are caveats to replicating this example of good practice currently in Morecambe Bay , as it is acknowledged that there are factors that made the practice of recording GRT ethnicity in county Durham easier.

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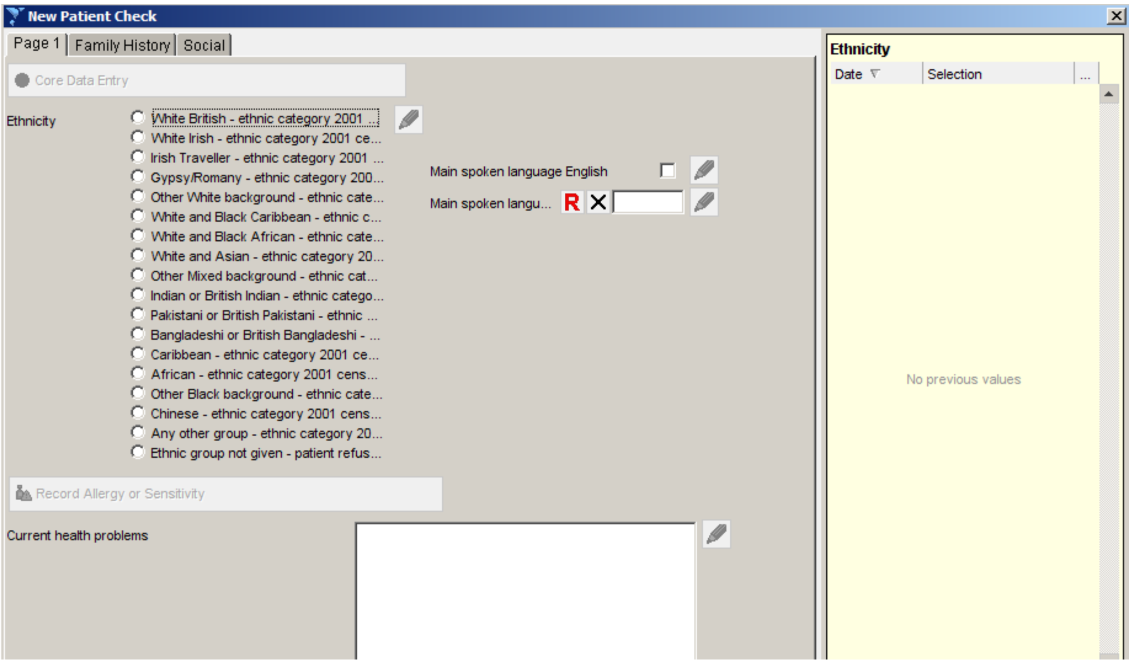
[2] Read codes are a comprehensive list of clinical terms intended for use by healthcare professionals to describe the care and treatment given to patients, but also included are ethnic group categories beyond the 16+1



Ethnicity

○ White British - ethnic category 2001 ...
○ White Irish - ethnic category 2001 ce...
○ Irish Traveller - ethnic category 2001 ...
○ Gypsy/Romany - ethnic category 200...
○ Other White background - ethnic cate...
○ White and Black Caribbean - ethnic c...
○ White and Black African - ethnic cate...
○ White and Asian - ethnic category 20...
○ Other Mixed background - ethnic cat...
○ Indian or British Indian - ethnic catego...
○ Pakistani or British Pakistani - ethnic ...
○ Bangladeshi or British Bangladeshi - ...
○ Caribbean - ethnic category 2001 ce...
○ African - ethnic category 2001 cens...
○ Other Black background - ethnic cate...
○ Chinese - ethnic category 2001 cens...
○ Any other group - ethnic category 20...
○ Ethnic group not given - patient refus...

Main spoken language English ☐

Main spoken langu...

Current health problems

Ethnicity

No previous values

Table 1. Ethnic codes main list with Gypsy and Irish Traveller codes included on System one in Durham CCGs

The first is that it is easier to add the Gypsy and Irish Traveller codes to the 16+ 1 drop down list on System One than it is on EMIS , which is the system used in practices in Morecambe Bay.

The other major factor is that in county Durham there is a specialist nurse for the GRT communities who is trusted and has the extra time to ask Travellers if they are willing to have their ethnicity recorded. She is also able to access the IT system used by the GP practices to record this.

The advantage of having a trusted person to ask this question, and to explain the reasons is recognised in the House of Commons report on Inequalities faced by GRT

"*Even when categories are available for public services to record Gypsy, Roma and Traveller ethnicities, there is a fear by the Communities that disclosing this information will lead to discrimination. In order for this to change, trust must be built between data-collectors and the Communities.* (Paragraph 52)

	2013-14 QOF Results				Practices 2013-14 QOF			GRT Primary Care Extract			Difference	
	NHS England	Durham, DarlinGRTon & Tees Area Team	DDES CCG	North Durham CCG	Population	List Size	Practices Prevalence	Sample Size*	GRT Data	GRT Sample Prevalence	Practices vs GRT Sample % points	p value from z-test (α p≤0.05)
Asthma	5.9%	6.2%	6.5%	6.4%	95,377	6,033	6.3%	220	21	9.5%	+3.2	0.10
Atrial Fibrillation	**1.6%**	**1.7%**	**1.8%**	**1.7%**	**95,377**	**1,664**	**1.7%**	**220**	**1**	**0.5%**	**-1.3**	**0.01**
Cancer	**2.1%**	**2.1%**	**2.3%**	**2.4%**	**95,377**	**2,236**	**2.3%**	**220**	**1**	**0.5%**	**-1.9**	**0.00**
Chronic Kidney Disease (18+)*	**3.2%**	**3.1%**	**3.4%**	**3.6%**	**76,118**	**2,882**	**3.8%**	**152**	**2**	**1.3%**	**-2.5**	**0.01**
COPD	1.8%	2.7%	3.2%	2.4%	95,377	2,754	2.9%	220	4	1.8%	-1.1	0.24
Coronary Heart Disease	3.3%	4.5%	5.3%	4.4%	95,377	4,892	5.1%	220	8	3.6%	-1.5	0.24
CVD - Primary Prevention	2.8%	2.9%	3.5%	0.5%	95,377	2,939	3.1%	220	6	2.7%	-0.4	0.75
Dementia	0.6%	0.8%	0.8%	0.8%	95,377	945	1.0%	220	2	0.9%	-0.1	0.90
Depression (18+)*	**5.2%**	**6.0%**	**6.3%**	**7.0%**	**76,118**	**5,896**	**7.7%**	**152**	**37**	**24.3%**	**+16.6**	**0.00**
Diabetes Mellitus (17+)*	5.0%	5.3%	5.9%	5.4%	76,977	5,898	7.7%	152	8	5.3%	-2.4	0.19
Epilepsy (18+)*	0.6%	0.8%	0.8%	0.7%	76,118	835	1.1%	152	3	2.0%	+0.9	0.44
Heart Failure	0.7%	0.9%	1.0%	0.9%	95,377	1,069	1.1%	220	2	0.9%	-0.2	0.74
Hypertension	**13.7%**	**15.5%**	**16.9%**	**15.4%**	**95,377**	**15,069**	**15.8%**	**220**	**15**	**6.8%**	**-9.0**	**0.00**
Learning Disabilities (18+)*	0.4%	0.5%	0.6%	0.5%	76,118	574	0.8%	152	2	1.3%	+0.6	0.54
Mental Health	0.9%	0.9%	0.9%	0.8%	95,377	1,056	1.1%	220	6	2.7%	+1.6	0.14
Obesity (16+)*	7.7%	10.5%	12.0%	10.2%	78,149	10,840	13.9%	152	24	15.8%	+1.9	0.52
Peripheral Arterial Disease	**0.6%**	**0.9%**	**1.1%**	**0.8%**	**95,377**	**1,181**	**1.2%**	**220**	**0**	**0.0%**	**-1.2**	**n/a**
Rheumatoid Arthritis (16+)*	**0.6%**	**0.7%**	**0.7%**	**0.6%**	**78,149**	**696**	**0.9%**	**152**	**0**	**0.0%**	**-0.9**	**n/a**
Stroke & TIA	1.7%	2.1%	2.3%	2.1%	95,377	2,183	2.3%	220	5	2.3%	-0.0	0.99

Table 2 QOF comparative data in CCGs in Durham

Qualitative Interviews

Considering the inability to gather baseline data from ethnic coding on GP records , there had to be reliance on qualitative interviews with GRT and with health staff to gain a current picture of GRT health.

Qualitative interviews were also important to capture the views of health staff and of GRT themselves of their health needs and use of health care services and the challenges that each group faced .

During the pandemic, with the health burden, the restrictions, and with the extra workload for health services it was to be expected that recruiting participants for interviews in both groups would be difficult.

- **Sampling and achieved samples of health staff**

There was an attempt to interview as wide a range of staff roles as possible in primary care . Information about the GRT health project was delivered to clinical staff in each PCN at one of their monthly education sessions.

Initially GPs and nurses who attended the education sessions were asked to volunteer for interview and several did so. Some of these staff then asked non- clinical staff to participate. Oncologists were approached by CancerCare and volunteered to be interviewed.

Although it had been expected that the onerous workload due to the pandemic would make it more difficult to recruit health staff , the fact that they could be interviewed by zoom, at convenient times when staff were off duty, made this easier. There were however several more staff who had been willing but were unable eventually to make time for interview.

Sixteen health staff were interviewed of which three were oncologists and one was member of staff from CancerCare. Of the other twelve, there were five general practitioners, a patient care coordinator, a practice manager, a patient care administrator, a practice nurse, two health visitors and a school nurse.

All the interviewed health staff were willing to be interviewed by Zoom and all but one for their interviews to be recorded for transcribing and coding purposes.

- **Sampling and Achieved samples from GRT communities**

In contrast to the advantage of zoom for recruiting health staff , the need to interview by zoom or telephone made it much harder to recruit Travellers for interview. Not only was the lack of personal face to face contact an issue but being unable to be introduced by a trusted person, and to get to know each Traveller before starting to interview them, made it very hard to find willing volunteers. Steering group members from education and health did attempt to recruit from other Travellers that they saw or knew in the course of their work but were largely unsuccessful, with very few indeed coming via those routes. Mainly the Traveller interviewees were steering group members or indirect contacts from them.

Eleven Traveller women were interviewed; six by zoom and five, more recently, face to face when covid restrictions were more relaxed . They ranged in age from 18 years to 60 years old. All but one were mothers and four of these were also grandmothers. Six lived on local authority sites and five lived in houses. All but one Traveller were happy for their interviews to be recorded for transcribing purposes , whether by zoom or face to face.

- **<u>Topic guides</u>**

Topic guides for interviews were developed from existing knowledge. Non−directive interview questions allowed exploration of health behaviours, beliefs and barriers to access and use of health services. Additional issues that arose spontaneously, such as pertinent information about Gypsy Traveller identity and culture, and suggestions for improved service provision, were explored and incorporated in subsequent interviews.

Health staff topic guides varied slightly according to the roles of different health staff , clinical and non-clinical . They broadly covered:

extent of awareness of their GP patients ,

asking about and recording of ethnic identity,

knowledge of GRT culture,

range and scale of health problems seen among Traveller patients ,

whether seen on an urgent basis or at timelier appointments,

attendance for screening, chronic disease management , immunisations and for follow up appointments.

awareness of any unspoken or spoken fears of Traveller patients or any other any challenges in treating them.

Finally, for those who didn’t spontaneously raise the subject of the goal of seeking further funding for a worker specifically for the GRT community, views were also sought about this.

Topic guides for Traveller interviews mirrored the health staff guides to some extent . They covered:

health of the interviewees and their families ,

views on what affects their health ,

extent of awareness that GRT have poorer health,

major health issues that they worry about and what first steps they take if they have any health worries ,

how they gain health knowledge ,

impressions of, and experiences of, attending a GP surgery,

views on screening and on immunisations, extent they felt that health staff understand their culture,

feelings about being asked and revealing their GRT identity.

Where relevant and appropriate, some specific questions were asked about cancer and cancer journeys, and also about pregnancy and antenatal care . Travellers were also asked their views on potential funding for a health worker for GRT community .

- **Analysis**

The interviews were transcribed and coded by themes. In presenting the findings below the views and experiences of Gypsy Travellers and health staff are combined and covered under each theme.

For reasons of confidentiality and the possibility of identification from a small sample , all quotes are completely anonymised . Health staff are also anonymised , with quotes from non-clinical staff only being referenced as such. as any quotes referenced by role, except for GPs and health visitors, would make the staff concerned easily identifiable.

Chapter 2 Findings

Reported Health of Gypsies and Travellers

Although three Gypsies and Travellers reported that they were healthy and spoke of no specific health issues, others reported health problems but still stated that they were healthy. In addition to reports of physical health problems, including arthritis, asthma , and high blood pressure, half of those interviewed spoke about their mental ill health, with reports of suffering with nerves, panic attacks, or suffering from 'mental health'. All of them had sought medical help for these conditions.

When asked about their wider family's health, the extent of poor health in the community was more apparent, with reports of family members who had heart disease, diabetes, arthritis and anxiety. There were several reports of deaths from cancer and also from heart disease and at a relatively young age. One Traveller reported that a living relative, had heart bypass surgery in her late thirties.

Most clinical staff each spoke of seeing very few Traveller adults

> *I wouldn't say there's been a pattern in the ones that I've seen, apart from this readiness to bring their children.*

Those who had seen more Traveller adults reported "normal women's health problems", childhood illness problems, cardiology problems , including early diagnosis of heart trouble, in young men, and in some of the younger women, extreme mental health problems with addiction problems relating to that, and chronic pain problems.

Very few Traveller men attended except on an extremely urgent basis, although there was one surprising report of a Traveller man attending the Doctor for anxiety. However, it turned out that he attended initially only because he thought he was having a heart attack.

Perceived Factors Affecting health

Both Travellers and health staff were asked if they were surprised about studies showing that Gypsy Travellers had poorer health than the majority population . Most health staff were not surprised.

One clinical staff member said

> *Well I think the things you were saying about poor health outcomes in Gypsy Travellers is not a surprise really, I think that we all are aware of that.*

Some of the non- clinical staff have known a lot of Travellers through growing up and going to school with them . One reacted by saying

> *I know they don't take care of it as much as you or I would. It's not their first priority.*

Some Travellers were surprised but not disbelieving . Most weren't surprised and gave various spontaneous explanations for why this was the case. Even those who were surprised could rationalise why Traveller health was poor and also gave likely explanations.

> *It's a true known fact that Travellers do have poorer health than the non-Travellers because they don't go and seek it, they genuinely don't go.*

> *Didn't surprise me. I think a lot of it, they listen to other people too much within their own community.* [A relative] *would eat fat with bread out of a frying pan, and because he had a cup of tea afterwards, he thought that swilled all the fat away and it would be fine.*

> *I knew that yeah and I wasn't surprised. They don't look after themselves.*

> *I think with Travellers they just carry on. They don't think really about their health. I think they're very busy people*

> *It shocked me on the statistics. There is a lot of 'what we don't know doesn't hurt us' so there's got to be. If you don't get it checked you don't know you've got poor health and sometimes you leave it too late.*

> *I'm shocked that its worse , but I'm not in a way; mental health is a massive taboo.*

The apparent acceptance of a degree of ill health was noticeable. One Traveller talking about health problems being mainly ‘bones’ and ‘nothing major’ put this down to *“I suppose wear and tear when you get to our age”* She was only in her early forties.

The perceived explanations given above by Travellers in this study , which can be summarised as lack of preventive care, poor health literacy, and not seeking timely health care, all resonate with findings from previous studies of Traveller health and attitudes and access to health care

Travellers expanded on these explanations when specifically asked what they thought were the important factors that affected their health . Several spoke of the importance of lifestyle factors such as a having a healthy diet, exercise and avoiding smoking and alcohol but there was also a strong belief that their stressful lives were a crucial factor.

> *Anxiety and depression is a big thing with Travellers- we’ve always had a lot of racism. I only went to school for a few weeks, and I got bullied, so we moved on.*
>
> *Hard work! Stress*
>
> *I think Travellers have a lot of worry and a lot of stress; they’ve got a lot of commitments. None of them’s employed, they’re all self-employed, majority of them, and especially the men. It’s tough for them, it’s a big responsibility*

Accessing health care on an urgent basis

The stress and hard work were not just cited as direct factors , for example lifting heavy loads in the family business as a child leading to mechanical health problems, or worry and commitments contributing to anxiety , but they were also seen as reasons for delayed access to health care .

> *Because his lifestyle was that demanding he didn’t have time to go to the Drs ; he didn’t have time to get himself sorted out . Unfortunately, it was too late.*

Racism towards Travellers was also seen by some not only as a direct factor leading to mental ill health but also as an explanation for not seeking medical care.

> *Depression and stuff like that, and they can't go to the Doctors because they feel a bit embarrassed, or sometimes I think non-Travellers don't really like Travellers, so they do push them out a bit. That wouldn't stop me, I would just ask to see another Doctor so it wouldn't matter to me , but it does to some people.*

Health staff were asked about Traveller's attendance, and most weren't aware of many Traveller patients because they saw them rarely , and they spoke of Travellers only seeking appointments on an urgent basis .

> *I think they leave it till the last minute to seek medical attention. We're sort of their last port of call…. The men when they come, they want an appointment, and they need it that afternoon- 'I need it, I need it now and I can't wait, that sort of thing…. They definitely leave things to the last minute.* (non- clinical staff member)

> *If they do book in advance they very rarely turn up for the appointments* (non-clinical staff member)

> *I feel they go to A&E more than they go to the Doctors* (community health staff)

> *You probably have more book on the day urgent stuff, I would say, rather than kind of your routine reviews. It's often kind of the sick child and doctor needs doing something now.*(GP)

Most staff were more used to seeing Traveller children being brought to the surgery on an urgent basis and this is certainly also a finding in other studies, that Traveller parents will always seek medical care for any health concerns about their children but much less for themselves. GPs in this study were aware that there was often a lack of health literacy that compounded the family's fears about the health of their children and led them to bring the child to the surgery on an urgent basis when the symptoms themselves didn't not necessarily warrant an urgent appointment.

> *I'm not sure they would have much of a concept of what would be urgent for their children, I think if they're worried about their children they would just want them to be seen* (GP)

> *I can't imagine how awful it must feel if you imagine that your child is seriously ill , and that happens 10 times a year because they get 10 colds a year. You must spend your whole time living on your nerves*.(GP)

Travellers themselves recognised this urgent need for them to have their children seen when unwell, as one explained

> *like Travellers , their kids are everything to them . They'd bring the child to the hospital for the least little thing they couldn't manage , just to get the reassurance from the doctor. They're not so protective about themselves.*

Health literacy

Reference has already been made about lack of health literacy, in relation both to factors affecting health and affecting attendance for health care, whether that was attending on an urgent basis for minor health problems in children, or adults not attending until too late when they had symptoms that could be indicative of a serious condition. The specific question was subsequently asked of Travellers about how they acquired their health knowledge. Knowledge, whether accurate or not, was often passed on by word of mouth from family members and friends

> *I think it's just what you hear through conversations we'll all have or what's happened to somebody and how they've found out*

> *stuff that pops up on Facebook, like things that other people have said that they've done or tried, someone talking about some things that's made them feel better, or something that's made them feel ill.*

Several Travellers did look things up on the internet by googling. Some knew to look for the *'NHS site'* or had been specifically told to use it by their health visitor if googling, but others said "*I'd just google and see what it comes up with"* or *"probably the first thing that comes up"*. Another Traveller was aware of the differing information from different sites and wouldn't use google saying "*I don't believe in Google because there's so many things"*.

Not all Travellers, particularly older people, have had good access to education and are not literate enough to access health information. There was also a concern that they didn't necessarily understand explanations about health

> *Travellers is not educated people. I think where it comes from , because obviously in our culture , like years ago, we couldn't see a doctor . So, it was like our granny would have a cure for you- 'do this , do that'. I think that's where it come from and it just carried out, making our own remedies .*

Health staff also noted that lack of understanding about the significance of symptoms was an issue

> *It's education as well. I think a lot of them won't realise they're not just feeling a bit crap and they have genuinely got symptoms that they need to just go and talk about* (non- clinical health staff)

There was little mention of acquiring information about preventative health care and the question was asked about whether they would watch TV programmes about health . Although a small minority did say they acquired knowledge from the TV one Traveller explained why this wasn't common.

> *I think if they were sat on their own in the room they would, but if there were a few of them it would be 'oh ladgful, ladgful*[3]*, switch over'. I would imagine each one of them in that room would want to watch it, but not in front of other people- deep down they'd want to watch but would want the others to think they don't, it's shameful.*

This cultural attitude towards certain health conditions, particularly mental health or health conditions affecting certain parts of the body, needing to be kept private and not discussed

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[3] Romani term meaning shameful

means not only that minimum knowledge might be acquired about them, but that they would be more likely to delay seeking health care .

> *the fact of not talking about certain illnesses – depression, cancer, anything to do with women's bits, men's bits, anything, they're just not spoken about. Everything's just painted over.* Do you mean ignored? *Yeah, its ignored, things are ignored.*

<u>Avoidance of use health care services due to cultural experience</u>

Lack of health literacy and its consequences are only one reason for avoiding seeing a doctor for as long as possible . Other reasons have been mentioned in relation to factors affecting health care- such as leading a busy lifestyle and perceived prejudice towards Travellers .

Current perceived prejudice in health care settings did feature in some accounts, although these weren't often given as reasons for not attending health care . Several Travellers were satisfied with the care they received at their surgery.

> *I've always found them absolutely brilliant*

> *I've got a really good relationship with my Doctor*

Like many non-Traveller patients there is dissatisfaction at the difficulty experienced in getting an appointment, but when discrimination and prejudice are everyday features of Traveller experience, they are understandably sensitive to prejudice even if prejudice towards Travellers genuinely isn't the reason, or if there is prejudice but it's not overt.

> *Well like ' you can't have an appointment until next week'; 'but I really need one now',' no you can't have one now'* (So you would think that was because you're a Traveller?) *Yes, you can tell the vibe* **;** *we've been used to it , we know the vibe* **.**

One account of such an experience reveals the difficulties, that are also highlighted in an earlier study about communication between Travellers and health staff,[xxii] where there was most likely a sense of urgency and fear about the need for an appointment and the possible difficulty a receptionist might have in dealing with the way that need is expressed, particularly if there weren't any appointments immediately available.

> *It's hard work to get an appointment; it takes a while. You need to persist to get one. One receptionist had me in tears and my daughter made a complaint.* (Did you think that had anything to do with you being a Traveller?) *Yes, I did. It wasn't her words; it was her attitude that showed it.* (What happened about the complaint?) *They were nice about it. It's good now.*

> *I think the receptionists could be a bit ignorant at times , but maybe they've had a bad day . But the Doctors I find ok .* (What way are they ignorant?) *The way they talk to you, not a very nice manner when they answer. Not all of them's like that though.*

One clinical health staff member spoke of the experience of prejudice towards Travellers in society generally and therefore was not so surprised that it was sometimes manifested among staff .

> *We live in a society that is incredibly unequal and I think it's one of those hidden forms of racism . I mean, if you asked my Mum what she thought of Travellers she wouldn't say a single positive word and then if you asked her if she'd actually met or had a conversation with a Traveller the answer would probably be no , or not knowingly . I think they're a bunch of people about whom not enough is said . It seems unfair that we challenge people with their perceptions or prejudices about people with lots of other particular characteristics, but this seems to still be acceptable, and I've seen that with the odd thing that even a receptionist or administrative staff might say that you think, oh you wouldn't be saying that if it was someone who had darker skin than you or lots of other things.*

Non-clinical staff also made this association between the negative experiences Travellers have in wider society and the expectation they have of prejudice towards them that it engenders .

> *I think some of the Travelling community in our area have had bad experiences where they get tarred with the same brush and they have very negative experiences out in the*

> *wider community……. it’s so sad that they feel that you know they would maybe get looked at in a clinic environment, or something like that, or stared at or talked at or whispered about.* (non-clinical staff member)

Historical experience of prejudice or outright racism towards Travellers by non -Travellers generally were quite likely to be associated factors in the lack of trust and also the stoicism and self- reliance which appear to be strong traits among of Travellers. These are also indicated as reasons for not attending for health care. So too are some experiences of poor care in the past, that are not necessarily due to racism or prejudice .

> *I mean my uncle was in the same GPs as mine and his wife rang up to say he was having a heart attack . She said he’s got chest pain , terrible . They said ’ tell him to take an aspirin ‘ and they didn’t come out to him and he died, and so you know, I’ve had some failures with doctors, total trust’s not there.*

This and other accounts of poor experiences of health care, in hospitals in particular, were recounted in interviews for this study, but these same experiences will also be well known and circulated among other Travellers and will reinforce mistrust in medical care and reluctance to attend for care unless considered urgent. It’s the case everywhere that stories of bad experiences do seem to be remembered and circulated much more than good ones. Although, that said, where there is a known empathic GP that is trusted by one or two Travellers, that positive experience is spread widely , and others will also seek out that GP. One GP’s name cropped up in interviews more than once in that context .

> *He’s one of the older ones that’s been there a while and he’s really, really, nice. Everybody likes Dr X ; he’s good at everything.*

Admin staff who book appointments were also aware of the extent to which this trusted GP is sought out

> *This particular doctor, they think he’s like God, he’s so much in demand*

Avoidance due to fear or stigma of specific conditions

- **Cancer**

Fear of poor treatment for whatever reasons is only one reason why Travellers spoke of their reluctance to attend the doctor's surgery.

Travellers were asked what they feared most in terms of health and the two conditions that most feared were heart disease and cancer.

> "*because heart attacks is the big problem in Travellers and sometimes at a very young age as well*"

> *Heart! Because obviously it runs in the family; my husband died of it. Probably that. That is one of the biggest killers among Travellers, and cancer.*

Even though heart disease was strongly feared and several Travellers had relatives who had died from it, it was cancer that was so feared that it's taboo to talk about it in the community, or if they do talk about it they use an euphemism for the word cancer.

> *Cancer is a taboo subject. They don't even say the word ' that unlucky thing' they say, or you've got that bad thing'*

> *Cancer is a big thing – you don't say the word*

> *You see in Travellers , when the word cancer is mentioned , we don't even speak of cancer , we don't even say the word , it's 'the worst complaint 'or 'the bad thing' , we don't even mention it .*

However, such fear of these conditions does not always lead to uptake of screening or attendance at signs of early symptoms. In part this may sometimes be due to lack of knowledge of the significance of some symptoms.

> *It was about 5 years ago, I looked and saw a red cherry there, I thought it was a red cherry ... from doing the flowers and caught myself , but my nose was getting bigger.*

> *and I went to the GP and he sent me to Preston hospital. He said to me that's not a red cherry, that's cancer . Once he said cancer I was frightened.*

For many though there are also indications of fear leading to inaction due to fatalism, in the belief that nothing can be done, or in the vain hope that 'it will go away' on its own.

> *If it was a pain in your chest, you'd go and see the Dr in case it was a heart attack but you wouldn't go if you thought you had cancer symptoms..... because you think that it's- not going to get better*

> *You tend to believe it's a death sentence*

In discussing fear as a reason for avoiding going to the Doctor if she developed symptoms, one younger Traveller explained denial as her reason :

> *Maybe finding out something I have that I didn't want to know..... when you don't know you just carry on don't you.*

Others also indicated that this was a common reason

> *I think a lot of them don't want to know what's wrong. They won't go until it strikes them down.*

Attitudes to attending for cervical screening or mammograms varied . Some Travellers reported that they did attend

> *I always went for cervical screening, and my family and friends do.*

> *Yes I go for smears. I think most Travellers go for smears now because they know people who've had calls and it's been cured.*

Travellers who had a close experience of cancer themselves were sometimes more inclined to encourage others to avail of it

> *I had a friend once who didn't go; she was an old-fashioned sort of Gypsy, and she caught cervical cancer and died. Before she died, she told others to go for screening so it wouldn't happen to them.*

> *Yes, I've always kept those appointments and my daughters will because they know what I've been through.*

Others though wouldn't go for screening , often for reasons already mentioned , or most often due to embarrassment

> *No, No. I'm embarrassed about them* (cervical screening). (Would you go for mammogram screening when you're old enough?) *Probably not.*

> *So yes, I would urge anybody to get it checked out. Because the embarrassment that you think you're going , they're very private people , So, when it comes to cervical smears , when it comes to breasts , to any of your private parts , they're very reluctant to report that because its embarrassment .*

Poor health literacy was also a noted factor, with evident lack of understanding about prevention, when one young Traveller didn't think there was any need for cervical screening because she didn't have any symptoms.

> *I don't need one. do I***?** (Then, after explanation about prevention) *Yeah, but you'd start getting pain wouldn't you*?

Health staff weren't aware of many Travellers attending for screening, but due to lack of ethnic coding , which is discussed later in the report, they weren't able to give any figures for uptake .

For the same reason, oncologists weren't aware of how many of their patients were from the Traveller community. However, they all sensed that they had seen less Travellers than they would expect to see over their collective long years as oncologists in this area. Two oncologists surmised that this is because cancer is predominantly a disease affecting older people and Travellers with poorer health may not be living to an age when they might expect to get cancer.

> *the reason we are seeing more cases of cancer on the whole is that people are generally healthier overall and that before we would see people die of a coronary in their 60s , and if you're healthier and on statins you live to get your cancer in your 70s and 80s . So, if it's true that health in the GRT community is generally poorer then its logical that they're not seeking advice about their blood pressure or their cholesterol either , and having a higher incidence of heart attacks , in which case you would see less cancer.*

This theory would be borne out by the number of reported deaths of relatively young relatives from heart attacks .

Another oncologist surmised that another reason that they saw relatively few Travellers was that if the cancer was so advanced when they eventually presented for health care, then their case may not be referred to a multi- disciplinary team meeting where oncologists and other meet to discuss treatment . This might particularly be the case where they have presented as an emergency in hospital.

However, late presentation was something that had been noticed by oncologists among the few Traveller patients that they had knowingly seen between them .

> *we do still see women present with very advanced breast cancers that they will undoubtedly have been aware of for months if not going into years, where the tumour is fungating.*

Late presentation for a cancer diagnosis , particularly if the delay was due to denial, can cause additional suffering for themselves and their families through also denying themselves a conversation about their wishes regarding terminal care , as one oncologist pointed out

> *The consequences of NOT having that type of conversation is that people are more likely to end up in hospital , and dying in hospital , which a lot of the time is not necessarily the best place to die. So, if someone is in denial then obviously they think*

> *something can be done , and then they end up being brought to hospital and you end up with the scenario of 15 to 20 relatives all saying 'why can't you fix it?'.*

Denial is also evident in the self-reliant attitude that the family can always sort things even when they are told that nothing more can be done . One non-clinical staff interviewee spoke about conversations she had with a Traveller in relation to a cancer diagnosis

> *we as a community sometimes just throw money at something and we'll fix it because that's what we can do, we can all get behind it and sort it*
>
> *somebody she knew who had a cancer diagnosis and was incredibly poorly, and the first thing they did was whip him over to Germany because they wanted to give him the best possible private care and that's where they had googled and found all these wonderful things that were going to happen, but sadly he never got there*

However, not all Travellers are in denial when they get a cancer diagnosis . Some of those interviewed, or those with family members have used either a hospice or Cancercare .

> *After the first treatment I went back to work, and I spoke to a customer and told her I was suffering with 'nerves' . She told me about Cancercare and the hydrotherapy pool and swimming there that she went to and suggested I go. So, I went for it and I enjoyed the swimming.*
>
> *Yes, the doctors told us about it . We didn't have carers as such . They offered it to us and there was a lot of help if we wanted it but we did all her personal care and looked after her ourselves . They just came in and gave her the morphine and stuff , they'd come all the time and monitor her so we knew.*

However, although willing and grateful to have hospice care for family members, there was less willingness to seek available support for themselves afterwards when bereaved

> *They offered i , they offered for us to go for some counselling . We didn't go for that because nothing can bring her back .*

One Traveller spoke of wanting to offer her children to be supported by bereavement counselling and betrayed the felt stigma of seeming weak, something that is covered later in the report.

> *I didn't want it for myself, I probably did want it for myself, but I didn't want to show weakness, I wanted them to see I was a stronger link , and I wanted to see if the kids wanted to talk to her .*

Some thought that many other Travellers wouldn't use CancerCare for themselves as cancer patients either and they would need encouragement to do so

> *I don't know; I'd say maybe 30% of people I know would* use cancer care]. What would stop the others? *I think you still have this stigma with a few of them when its 'oh well they know what we are and they know who we are' , especially the older generation.*

- **Mental Health**

Mental health is another taboo subject within the community, even though it is apparent from interviews that mental illness affects a lot of Travellers in this community, not just among respondents but also in their wider family and networks . We know from the Sheffield study on Health of Travellers in 2004 that anxiety and depression was the most significant aspect of health inequality experienced by Travellers and also that it was kept hidden as much as possible from others in the community, with medical help rarely sought.
Comments from the health visitors interviewed for this study suggest that many Travellers in Lancaster and |Morecambe will also keep any mental ill health hidden.

> *We do ask about their health. Physical health they answer the question. Mental health, they answer but I'm not sure it's entirely true, but I guess there's no way of knowing that. But a lot of the time, the difficulty is them having another person with them- the Grandma or the Auntie. I very rarely see them completely on their own. So, you ask the question with sort of delicacy – they're always 'Fine', never any problems.*

> *When we work with Travellers we don't get any information on mental health, there's still such a stigma with that, we defiantly get no information on domestic abuse, and I*

> *have worked with some Traveller's that have experienced domestic abuse and once they've fled they've been open about their experience, but they've had to move area and make sure there's nobody with any links to where they came from, because of the stigma of it really so I do feel like as much as they do engage with us it's very much on their terms and they only give us so much. But if it's for the children they're happy to share and to ask for health advice, but anything for themselves, no.*

However, there are indications that some Travellers do seek medical help for mental health issues , even though it may well be only a proportion of those who need to . One doctor said

> *I think the biggest thing I've come across more recently is perhaps, the very high degree of mental illness in the young women community, because they found it very hard to open up, there doesn't seem to be that much support within the community* (GP)

Some Travellers reported that they had received good support from going to the Doctor about anxiety and depression

> *It's been so bad I've had suicidal thoughts and my GP gave me a number to ring.* (Did you ever use it?) *Yes, I did, and she talked to me and reassured me. She really helped.*

However, all were aware of the stigma and taboo about discussing mental illness within their community and so often bear their anxiety or depression without wider community support.

> *they're scared of mental health.* **,** *they're terrified of it . Travellers call psychiatric hospitals the Divvy Tan (Divvy House) I've talked to some families and when they've opened up they've said ' well actually my uncle …. But we didn't tell anybody, we just shut him away'*

> *It's like they'll suffer inside themself . That comes from years ago- ' ah she's stone mental '*

> *Yeah ' She should be in the mental that one' Traveller women now will go out , wash their clothes etc but yet she's suffering inside. We can't see it and we can't speak about it.*
>
> *Anxiety and Depression is a big thing with Travellers, but they don't talk about it.*
>
> *The women talk more* [than men] *but you'd be worried that people might think you were mental, like mad.*

One Traveller spoke of the impact on the stigma about mental health from Tyson Furey[4] being open about it .

> *There was a lot of people saying whatever did you tell people that for? , you shouldn't have said nowt to them, they're going to pick on you for that, you're going to be judged for it. There was a lot of people said ' Don't' but then there was a lot of them said he was very brave for doing it .*

There are some Traveller women who do feel able to talk to certain close family members

> *I could explain to my mother-in-law what way I was feeling , she'd say a prayer , give you a cup of coffee , shed give you that love like a mother.*

However, even when Travellers are aware that one of their family or friends are suffering there is more often a reluctance to reach out because of fear that they wouldn't want people to know and would not welcome that recognition, or because they don't know what to say .

> (When you see a person, but they're not telling you , could you say anything to them?) *No, they're not letting you, no you couldn't . You'd love to , but you couldn't .*
>
> (Do you think people know though without them telling anyone?) *Yes, you can tell they're behaving different, but you can't talk about it.(* If one of your brothers was depressed, would you talk to him about it ?)*No, you couldn't talk to them.*

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[4] Tyson Furey is a Traveller celebrity, a world champion boxer, who lives with his family in Morecambe

Even those who have sought medical help for their anxiety or depression have often done it secretly and reluctantly or out of desperation and continue to experience the added burden of the associated stigma and labelling or denial.

> *I've got it myself ; I take medication. You wouldn't know , like I deal with it , and I know its medical , it's under the label. To be honest I don't like it , I don't like the label of mental health , but now I say yes, I've got mental health.*

> *I mean depression, anxiety, they brush it off and say oh she's just a bit down, go shopping and you'll fix it , let's go to the pub and you'll fix it, but it doesn't, and you know it doesn't.*

The inability to talk to friends or often even to close family intensifies the isolation and loneliness of dealing with depression

> *I mean, I suffer from depression but it's hard because everyone has their own …… everyone has their own problems . You walk in ' my heads not so good' , they don't be interested. You could be crying in your own bedroom, and you want someone to talk to , that can fill your whole day ,*

The 'suffer in silence' mentality is prevalent throughout the wider Travelling community as other studies have shown, with fear and shame often preventing people from seeking help . One Traveller spoke of this hidden burden of depression in relation to the risk of suicide , recognising, what we already know anecdotally, that suicide is very high among Travellers in the UK.

> *the biggest problem is suicide – because they can't talk to people, they've got no-one to talk to. They obviously can't talk to their own kind because they're not understood. You can't talk to your parents, can't talk to your children, can't talk to your brother and sisters.*

We know that men in wider society especially suffer from keeping their depression hidden from family and there are health campaigns to try and rectify this . The cultural barriers for

Traveller men who are expected, and who expect themselves, to be strong, and who might see airing such feelings as weakness, in addition to causal factors of depression that may arise from their social situation, all point to a higher incidence of suicide among Travellers. It is very likely that the incidence of suicide here is on a similar relative scale to the incidence in Ireland compared to the general population i.e., six times higher, and when focussed just on men , it is seven times higher, according to the All Ireland Traveller Health Study [xxiii]

- **Dementia**

The taboo and fear of mental illness also extends to dementia, and this too is something that is often hidden for as long as it can be, and again there is often ignorance or denial and consequent lack of support among the wider community .

> *sometimes Travellers are very uneducated to it . Like I knew my mother had it- she was tested and diagnosed but I knew it from her manner , and sometimes Travellers would be ' Oh there's nothing wrong with her , she's fine '. They've got this 'Oh she's fine, she's very clever', but as we know with dementia, you get episodes . Yes , they're very uneducated to dementia . They have to be at the last stages of dementia before they recognise it.*

There is also an intensified burden on the family due to the stigma associated with not looking after your own, and therefore a great reluctance and sense of shame to accept social care support even when it becomes near impossible for the family to manage at home

> *It's a bit taboo , yeah. My auntie has got it now and my Dad had it, but the one thing we were really against was , we were going to manage it and it was horrendous towards the end……. but we were determined he weren't going in a home.*

> *My grandfather had dementia and there came a stage when it got too much. He was getting up in the early hours of the morning and running around in his pyjamas – all sorts, going missing . He was like a danger to himself There came a stage when they had to do it, they didn't want to do it but they had to . He was a great grandfather and there probably people did say ' they're throwing him into a home', I don't know . He wasn't that long in it before he passed…. but at the end of the day it had to be about*

> *him. It's not what next door says. But Travellers will say 'Oh they left him in a home to die on his own, big family and they wouldn't look after him'.*

Avoidance due to feelings of inadequacy and lack of self confidence

In common with previous studies, lack of understanding about symptoms or their implications, and fear of diagnosis, were not the only cited factors in delaying seeing the doctor about them , for some was also the fear of feeling unable to articulate their health concerns and make themselves understood.

> *I think it's hard for Travellers to try to make themselves understood***,** *and I think they just don't* [go to the Doctor] *not because they don't want to.*

> *They're like oh, I'm not going to go , I'm not going to talk to her because she's not going to understand what I'm on about , but* [non -Traveller friend and neighbour] *is different because she knows us.*

> *I think maybe the way we talk sometimes ; they may not understand what we're saying I suppose they don't understand the way we are*

> *They* [other Traveller women] *wouldn't go to the Doctor's they probably wouldn't have the confidence*

Another example that perhaps indicates lack of self- confidence or the feeling that they are not important enough, is the notion that by going to the Doctor they may be seen to be wasting the Doctors time, although this might also be partly due to the lack of awareness about the significance of symptoms.

> *I'm not calling the doctor's ; I don't want to bother them 'oh it will go on its own'*

> *I'm still worried. I'm only being honest with you. You might think, but Why? but I genuinely can't tell you why. Because they'll start mixing my tablets up, or changing them, or I feel as though I'm wasting their time and I just think, oh do you know … I just think I'll do it tomorrow, that's what I'm like. I know I'm not the only one like that.*

Doctors recognise this lack of confidence and the felt sense that they will be judged as time wasters

> *the problem of feeling prejudged seems to be with all of the Traveller families I've met really.* Do they voice it ? *No, it's just that sense of having to prove yourself* (GP)

When Travellers with such lack of confidence in their ability to convey the seriousness of their concerns and inability to convince a doctor of their need to have attended, do then pluck up the courage to attend they will often bring another family member with them for support.

> *sometimes you might have a mother bringing the child , she might be quite young and feels quite intimidated and feels like she's not going to be listened to. So sometimes you might have a matriarch, a grandmother or something like that* .(GP)

In many cases this is welcomed by doctors when there is difficulty in eliciting the history or details from Traveller patients who are feeling intimidated or lack confidence in explaining

> *Sometimes, I've been wishing they'd brought another member of their family because it's been a lot harder to perhaps move things forwards , partly down to reticence in terms of explaining things, or such like, and sometimes I think, especially with the inability to read that I've come across from a few people, it's been harder to generate a plan for the future. So, it's perhaps more useful to have someone with that person.* (GP)

Poor literacy and the shame in this being made apparent to staff is also recognised by non-clinical staff and they will help discreetly

> *I think also a lot of them are just embarrassed because they can't read or write. That's another thing that sort of puts them off engaging. Normally we'd fill in the registration form for them because sometimes you can see they're embarrassed, so we sort of take them to one side and sort of fill it in for them.* (non-clinical staff)

Trust and Continuity

All the above reasons or factors involved in reticence, or avoidance of seeking health care, overlap with, perhaps the major factor for most, lack of trust .

Perceived or anticipated prejudice based on life experience has been mentioned as one of the reasons why Travellers are mistrustful of non-Travellers in general , but that is not the sole reason for the lack of trust. Lack of cultural understanding is also a factor. A couple of Travellers who live in Skerton, an area with a high population of Travellers, who attend the GP practice there, feel that there is greater cultural understanding among some staff there .

> *I think round here, pretty well* [Skerton] *because there's a lot of Travellers , we're a big community round here, but I do sometimes think that if you had to go to smaller towns , like Blackpool I do know they're not really understood . But I think we're lucky round here because they've got to know us.*

Travellers who are fortunate enough to know someone outside of the practice with a health care background or knowledge, and who they trust and who understands them, are more likely to be persuaded to attend when necessary . One Traveller interviewed was in that situation and it made a lot of difference to her.

> *I've had a few little problems that I've been worried about, and I've spoken to* [non - Traveller friend and neighbour] *, and she said, 'Go to see a Doctor' , and yet I haven't, and it's a case of, because I trust her and I know if she was really concerned she'd be like 'I've made you an appointment GO!' If I didn't have that trust in her, I wouldn't be going to a doctor's.*

However, even when there is better cultural understanding from staff there is still the issue of lack of continuity and the need to build a relationship with one doctor who they can then start to trust. Non -Traveller patients will also say they prefer to see the same doctor, but the lack of trust and confidence in a doctor is not usually such an issue

> *All Travellers would have to see the one doctor . You'd have more confidence in that one doctor . There was a doctor years ago in a surgery in Preston and if you went to*

> *the surgery you'd ask for him and he built up a relationship with Travellers and that's very important .*
>
> *you don't see the same Doctor twice. That not good because you build up confidence in a doctor*
>
> *I think a lot of Travellers they want to see the same doctor; they don't want to go and see a different doctor. They might have to repeat themselves again and ramming that into a 5-minute appointment as well as what they've come for*

Health staff also recognised that trust took time to develop among Traveller patients. Time however is not something that is often available unless Travellers can be persuaded to return for follow up when necessary. This is always going to be hard and there is need to build some trust in that first appointment . It is especially difficult for Travellers who find it difficult to make themselves understood, especially in a short appointment slot , and when they have left it longer than they should to attend and often only present at urgent appointments. They may also be especially fearful when they do attend, because they may have delayed until symptoms had seriously affected them .

> *I think just over time as well, it's building trust over time, I think that they seem to be very loyal people, if they decide that they trust you then they are very loyal. …. but I think it takes a bit of time to develop that trust.* (GP)
>
> *you get the impression in urgent care that they are quite mistrustful… and I think that you feel that it takes time to sort of win them over really and win the trust.*(GP)
>
> *I think there's a bit of a suspicion …. I suppose I guess sometimes I've felt that we're seen as figures of authority or part of the state as it were* (GP)

Trust is also harder to develop when there is a predetermined lack of confidence in a doctor's competence or lack of confidence that they will be taken seriously. Such lack of confidence, as has been referred to earlier, is often based on circulated stories of bad experiences of treatment.

> *You don't run to the Doctors and waste their time and waste your own time , just for them to say, 'it's a virus, it will go on its own'. What's the point?*

Doctors who were interviewed also recognised the imperative for Traveller patients to be confident about the diagnosis or that they will receive appropriate treatment, especially with regard to their children.

> *I think with parents with children it's mostly about distrust really . Distrust of what I'm going to say . There seems to be a feeling that they come in feeling prejudged as wasting your time already and that they, I don't think exaggerate is the right word , but feel they have to overemphasise the severity of the situation to be taken seriously* (GP).

Self -reliance and stoicism

For many of the reasons already mentioned Traveller are very stoical and self- reliant. There is a pride in stoicism as a cultural trait as well as a felt necessity to be self -reliant, born from decades of cultural experience of hardship in various forms, including ostracisation. Where there is mistrust in wider society there is a reinforced belief in the need for self- reliance and for mutual family support It is important to live up to the image of being a *'tough breed'* , among women as well as the men.

> *But there's some people who are hypochondriacs and they're there all the time; we're just a tough breed! . We don't believe in running to hospitals and doctors unless it's really necessary*.

> *I'm not one to go to the Doctors . I don't like to go, so when I do go I let myself that bad. You know, it's a family trait probably*

> *Like sometimes I'll have a bad back , my back gets very bad, I'll go to the Doctors to see what's going on and to up the painkillers that I've got , but if it's something simple, no, I'll just try and cure myself* .

> *They* [previous generations] *were a tougher breed and a bit of that culture is still in us*

> *I mean I should be at the Doctors now with my back , I mean yesterday I could hardly walk with it . I don't know what's happened , if I've slipped a disc or something , I was in agony , I don't sleep at night , I'm just taking painkillers . I should be at the Drs but I'm not going , because it will go . If it comes on its own it will go on its own .*

Apart from the consequences of delay in seeking medical care there is also a burden of bearing worrying symptoms alone , particularly depression, as referred to earlier, through not wanting to seem weak.

> *like non-Travellers might go and talk to their Mam or someone but they tend not to, they see it as sign of weakness of embarrassment. Well, it's like ' What's wrong with you, how can you be upset?'*

> *You can't talk to them* [adult children] *if you're feeling down or fed up, because you're not meant to be, you're not allowed to feel down or fed up. You've got to get on with it. You're showing your weakness if you're down and fed up and we're not meant to show that.*

Not seeming to be weak is not the only reason for not sharing the burden of worrying symptoms with family members, there is also the burden of felt responsibility to protect them by keeping worrying things secret .

> *Personally, I don't want to burden anyone with anything*

> *I wouldn't want to worry them* [adult children] .

> *My father he used never to go to the doctors. He thought he had piles and my mother saw some blood on the sheets . Then at last he went to the doctors, he had to go to the doctors, and it was tumours . He hid it from my mother , I didn't know, he hid it from all of us.*

> *I've seen* [daughter] *when she has been upset or been low or down and I've said 'talk to me' and sometimes she doesn't because she feels she's putting a lot of pressure on me , because, as you know, the pressure's on, big style, with men and with women.' I*

> *say talk to me, but they don't ; my children don't talk to me . They say ' Don't tell Mam because you'll worry her' .*

This forced secrecy all adds to the burden on the Travellers who do have worrying health symptoms, and particularly those who are suffering from depression or anxiety, who could be helped by sharing their feelings. Whereas non -Travellers might be more likely to have someone they felt that they could confide in and obtain encouragement or support for their relative or friend to see a doctor, this is less of a likelihood among Travellers who feel compelled to silence and don't feel that they have that sounding board to discuss any health worries and whether they should seek medical help.

These beliefs in stoicism and self-reliance, combined with mistrust, contribute to avoidance or delayed access to health care , often with the serious consequences of advanced disease before help is finally sought.

Pregnancy, antenatal care and health visiting service

There is limited information from this study about current engagement with maternity services and it wasn't possible to interview anyone from maternity services . However, from the few Travellers who responded on this subject it would appear that there is good uptake of maternity services in terms of attendances for antenatal appointments and scans , but only after 12 weeks of the pregnancy as they don't tell anyone before that time . This has implications for any Traveller women who may suffer an early miscarriage

> *Travelling girls throughout, they don't tell their families , or their Mum's and Dads till they're 3 months gone . No-one would ever know if that baby got lost. I think do know of a few occasions and I think it's heart wrenching , a young girl's not told her parents of the pregnancy because they don't till after the 3 months, where they've lost the babby in the meantime , and they can't tell the parents that the baby is lost. They'd be grieving but they can't tell the parents and they're having to hold everything in themselves*

However not all Traveller women are happy to attend antenatal appointments and a story was reported about the friend of one of those interviewed who stopped going to appointments because of the way she was given the health advice to stop smoking.

> *I had a friend, and she was a heavy smoker , smoked 20 a day , and when the Doctors were like telling her' Oh you shouldn't smoke, you shouldn't do this', she said to them ' you won't tell me what to do , if I can smoke or not' and they kept saying to her ' now you're going to have to come to more appointments' and so then she just ended up not going to any appointments after that because she thought they would trash her*

This illustrates the heightened sensitivity to being judged or criticised as mentioned earlier in the report.

Although attendance is apparently usually good once they have booked into maternity services, Traveller women do not seem inclined to go to antenatal classes in preparation for birth and parenthood nor to mother and baby groups afterwards.

> *None of them tell anyone till they're 12 weeks . They don't go to the breathing classes, the antenatal classes , but they do go for the check- ups and the scans. They don't join mother and baby groups afterwards*

The cultural attitudes to privacy and avoiding discussion of anything to do with women's reproduction also mean that as schoolgirls they didn't have the opportunity to learn about sexual health or motherhood at school either.

> *We got took out of classes at school about it and a lot of girls are still took out*

Coupled with non-uptake of antenatal classes or groups, suggests that Traveller women are less prepared for their first pregnancy and have less knowledge and awareness about what will happen before, during, or after the birth.

> *One thing I did think , till I was a good age, about 14 , 15 or 16 ; I actually thought that babies were poo'd out . It's a steep learning curve, let's say that.*

> *When I started feeling sick, I thought , oh I must be* [pregnant] . *What no one ever told me , and I had my baby, and it was the 3rd day and no one had told me about the breast milk and I woke up like Dolly Parton with these 2 rock hard melons , in agony. No one told me to take in breast pads .*

When the health visitors take over from the midwives after 10 to 14 days, they will see Traveller mothers and babies and be available for advice about the baby's health and development as well as the mother's health . As part of their initial health assessment health visitors ask sensitive questions, about mental health, domestic abuse etc, but there is negligible response or focus from Traveller mothers about their own health and wellbeing .

> *because our focus is on mums and babies that I work with, mums are quite reluctant to share information about themselves and their health but will happily contact us if they're concerned about their babies. They're quite engaging as long as it's about the babies, but not for themselves.*

> *we definitely get no information on domestic abuse, and I have worked with some Travellers that have experienced domestic abuse and once they've fled they've been open about their experience, but they've had to move area and make sure there's nobody with any links to where they came from, because of the stigma of it really, so I do feel like as much as they do engage with us it's very much on their terms and they only give us so much. But if it's for the children they're happy to share and to ask for health advice, but anything for themselves, no.*

This is consistent with earlier references to taboos, stoicism, fear, shame and of lack of trust. Health visitors now have very little time and continuity of contact with families that allows them time to build relationships . One health visitor explained this

> *Before I came here as a health visitor, I covered a few other areas but there was a health visitor who was a link Traveller health visitor and from discussions in the team, when she was a health visitor working on the site, she got to know them, they trusted her, and she was able to give the information. She was a consistent person going on the sites, whereas we've completely lost that and it's a shame. I think for the family and wellbeing service, the children's centres, they had a regular person going in, again building those relationships, and they trusted her , but again it's been lost. I don't know whether that's purely because there's been so much change- health visitors are now under Virgin care, and the implications from that and the links from that are slightly different to what they were under the NHS.*

This lack of continuity and regular contact has obvious implications for developing trusting relationships with Traveller families.

Immunisations and Vaccinations

Although the major study on uptake of immunisations among Travellers, (UNITING) [1xxiv] in 2016 found that *There was widespread acceptance of childhood and adult immunisation, with current parents perceived as more positive than their elders,* this does not seem to be the case among Travellers in Lancaster and Morecambe. While again it's not possible to verify this with any statistics there was a perception among health staff and Travellers who were interviewed that refusal of some, or all, offered immunisations is more the norm here .

> *They definitely don't have their kids immunised, because I used to book all the appts for postnatal checks.* (Non- clinical staff)

> *the majority will go for the 6-8 week check for the baby, but they won't go for the vaccinations.* (Health Visitor)

One of the few younger Travellers interviewed did say that she had her child fully immunised *" He's had them all , everything he should have "* but others were still anxious about MMR and continued to refuse it. Although this fear stems from a generation ago due to the long discredited 1998 study reportedly linking MMR with autism, the resistance to this vaccine continues to be passed on to younger Traveller parents today, as one Traveller explained after I checked that she knew that this study had been discredited

> *I know, yeah, but I think it's just the way I've been brought up "don't get the MMR" and that's just followed on from my oldest to my youngest. All 4 of them never got it*

Health visitors also said that they had discussed the fears about autism, and other fears about immunisations, with Traveller parents but had been unable to convince them.

> *They've said ' we don't know what's in it' ' we don't believe what's in it' , 'we don't believe its going to help'. I've had people say 'my uncle's cousin had a significant side effect'. One of them said a baby had had a heart attack from the immunisation*

> *and that had been passed from something like her auntie's cousin's next-door neighbour.*

Even when the younger Traveller parent might be engaged and ready to listen to explanations and reassurance about immunisation safety, family pressure often prevails

> *when we were talking about it* [immunisations] *she was very open to them, but I think because of the pressure of family and friends to not, it was difficult, and she hasn't gone through with the immunisations.*

It is not solely the current generation who need the reassurance and information, it is also their parents and grandparents. Trust is a significant factor, and one GP contextualised the issue by suggesting this unspoken thought process for Travellers in the context of immunisations *:*

> *'we've had such bad experiences* [generally] *we will not trust you with our most precious thing.'*

Covid vaccination uptake appeared to be more variable , with several Travellers reporting that they and family members had availed of it , but others being hesitant. There have been several cases of Travellers catching covid, and also dying from covid 19 , and these are well circulated among the community. The fear of catching covid 19 and dying from it could in some cases override the fear of the vaccination itself and might have a bearing on the level of uptake, as one Traveller explained that her relative who is at high risk did have the covid vaccination

> *Yes, and because she's around a lot of people , like children in school. She wouldn't survive covid ; she's got a lot of health problems . I know she's diabetic and she won't go for the test* [to diagnose diabetes] *; she's grossly overweight.*

<u>Ethnic identity and self -ascription</u>

As has been stated, the reason that we don't know about the health status of Travellers in Lancaster and Morecambe is because their ethnic identity as Traveller or Gypsy is not recorded . Although this is partly because they have rarely been given that choice of ethnic identification, there is also the problem of many of them being reluctant to reveal their GRT identity. Nevertheless, some said that they would 'tick the box' if there was the choice

> "*I'd say Romany Gypsy or Romany Traveller"*

> *Yes, I'm not ashamed , I'm not ashamed to hide my culture , my ethnic minority, I'm not ashamed, but if I'm going for an interview, I don't tell them.*

More Travellers though were less trusting and would only say they are 'White British'
A key factor in wanting to hide their identity and identify only as White British is the fear of being treated differently.

> *I always get scared you get looked at differently if I'm honest and I'd get scared they'd look into it further , and it's just, No, I'll put White British.*

> *The reason I put it* [Gypsy or Irish Traveller] *in school is because when we want to take them on the road we want them out of school , but in the Doctors I'd put White British. I'd be scared I'd get looked at or judged differently*

> *Even though they do know me I'd still put White British , and I bet that would go for 99% of the population*

When asked if it would make a difference if they were given an explanation and the reassurance that they wouldn't be treated less well , one Traveller replied

> *Yes, if I did it and then I was treated nicely, the same as if I wasn't a Traveller and then the word would get round that you get treated nicely even though they know you're a Traveller.*

Some Travellers recognised that health staff might know that they were Travellers without asking the question.

> *People know we're Travellers because we talk differently and that*

This was borne out by several health staff who picked up clues when talking to patients that they surmised were Travellers

> *you tend to recognise them by the addresses and the names really. I expect there's a lot that we don't know (GP)*

> *Experience – you can tell who's a Traveller and who isn't. Sometimes the accent gives it away and sometimes the mannerisms give it away* (GP)

> *You can usually guess, by a combination of their address and their accent, or terms of phrase I think sometimes.* (GP)

> *We know by the names. Local ones all have the same surnames* (non-clinical)

When it came to staff actually asking, some were reluctant to do this, particularly as they didn't want to be seen to stereotype people , or to seem to suggest that someone may be a Traveller who might not be

> *I suppose one is at risk of , uhm, prejudice if that's the right word, if I suspect someone might be from the GRT community and they might not be . I suppose it's hard to know*

In general practice it was largely felt that it was down to the receptionist to ask the question because doctors and nursing staff were more focussed on the presenting health issue

> *you're usually trying to think about their healthcare rather than their ethnicity. So, it's probably a low priority as a doctor to think about that if I'm being honest.*(GP)

> *the time to do it would probably not be with the doctor because then at that time the patient is probably not that interested in discussing ethnicity that much because they've got a sore throat or they've got whatever else they've come with. It would*

> *probably be more a question of the receptionist when they book them in, just saying we've got an ethnicity questionnaire, that would be the time to do it.* (GP)

> *I think patients would be a bit annoyed if you started asking about their ethnicity, well, when you're halfway through checking your blood pressure. it's more about finding out about how many Traveller community patients we do have, which will be about bribing the receptionists to dig into ethnicity a bit higher (GP)*

However, after becoming aware of the lack of information on Traveller health and the importance of acquiring this information , some staff, including doctors, felt more willingness to ask

> *I think this project has made me more aware of the fact I might just be better just asking them………….I think I probably would now* [feel able to ask them their ethnic identity], *It's not something I've really thought about before, but I think I probably would ask.* (GP)

> *Yeah, I probably would feel comfortable. I don't think it's something I'd completely avoid. I think we ask plenty of intrusive questions, so I wouldn't have a problem at all with that really, but I guess it's how they feel on the receiving end, which is why I tend to give options and then they give up that information and I can work with that rather than straight asking* (health visitor)

Other however seemed less aware of the importance in terms of gathering data to identify health inequalities

> *I've never really been fond of the whole idea in general practice in making sure we know the ethnic identity of every single person, because to me it's irrelevant, you know, that's not what we're here for, we've got to treat each person as a person in front of you, just the same as anyone else. As soon as you start labelling people you start judging people and things, and they start… and I think by labelling people they start feeling judged.* (GP)

In in general across all disciplines more education is indicated , in terms of understanding and in how to explain the reasons to patients while at the same time being able to reassure them that they won't be treated negatively . In reality it is likely that only a member of health staff who was already well trusted and was able to take the necessary time to explain and reassure, would be able to give that reassurance.

Secondary care

It is not possible to know the uptake of referrals to secondary care for Travellers , but it is suspected by some that, certainly in terms of referrals for further investigations, it might be lower.

> *I think that it's been hard, I mean again it's not happened that often that I've had to do referrals, but I think that there have been, you know, it's been harder to get people to make the appointments for the blood tests that they need or go for the testing they need* (GP).

However, there was also a point made that Traveller patients who are reluctant to attend primary care are more often in greater need for a secondary care referral by the time they do come

> *it might be a self-selecting route who are coming and who are being referred if that makes sense, so amongst those that I see I can't see it being a problem, it's probably the ones that I'm not seeing that aren't being referred who need to be referred.*(GP)

Travellers report being terrified of hospitals and one in this study spoke of how she refused to go to hospital when the GP told her she needed to even though she required oxygen . The family rallied round to get her the oxygen she required at home

> *they said we want you to come into hospital …. I said ' I'm not staying in' . I was terrified of going in and not coming out . I know I can't see anyone now but at least I'm in my own home But they said you need some oxygen to help with your breathing but I said ' Don't worry my family will sort it ' and they did.*

As mentioned earlier, the oncologists who were interviewed had seen relatively few Traveller patients compared to the numbers that they might expect. Then, even among those, there was sometimes a tendency not to return

> *If I'm looking at the people who I suspect may be from a Travelling background there is more of suspicion , in inverted commas , about conventional medical treatment , and more of a tendency to reject, in inverted commas, standard treatment approaches, and not have that treatment*

> *sometimes in a consultation* [oncology] *, you may only have a one- off consultation, in the sense they have a one-off consultation and then a follow up but then they don't come to the follow up appointment, so you don't see them again. Whether they're not interested in your treatment or that links into some other reason why they haven't come back, they're not quite so engaged as such. I'm not sure which of the two it is.*

Specific challenges for Travellers and for health staff

Many challenges have already been discussed in the context of other factors, such as stoicism and lack of trust, often combined with poor health literacy, leading to increased fear of the potential diagnosis and presenting at urgent appointments . These are challenges for the Travellers themselves but also for the health care staff and they take various forms .

The fear that has led to the sense of urgency can cause problems in reception and in the consultation

> *there's often a sense of urgency in that they're wanting things to be done, and I suppose they can seem to be a bit of pressure on reception, and you know in that respect, things aren't the speed that they're looking for and they can, you know, make it known I suppose* (GP)

> *I mean I think as far as when they're come with their children they've presented in quite an aggressive way that puts up a barrier at the very start of the consultation, and that's probably because they're worried, and that's why they're behaving like that* (GP)

Consultations often take longer, partly because of difficulty in eliciting a clear history of other relevant information, and partly due to presenting with a stored-up list of problems

> *I think mainly the issue is that because they tend to need a lot of reassurance perhaps, or they might come with a lot of different problems, quite often it's not been easy when you're having a consultation ; you get a lot of information in a very disjointed sort of way, it always makes those moments a lot longer because trying to actually coalesce everything, sort of unpick the 'whilst I'm here' sort of thing, that doesn't help* (GP)

Poor literacy, as well as being a source of embarrassment for those Travellers concerned, which they try and conceal, is also a challenge for the health staff

> *there's quite high rates of illiteracy within the Traveller community, so that can make an issue if you're trying to get them to explain something and you might want to give them a leaflet on shoulder pain or something and they can't read it.* (GP)

It can also be potentially dangerous for the Traveller who is on various medications and can't read the labels . One doctor recounted a story of a Traveller lady she visited at home and whose medication she needed to check. She asked to see the eye drops and after searching around a relative presented her with a superglue bottle.

Lacking understanding of what the doctor is trying to convey to the patients is something that many Travellers worry about and has already been mentioned , but doctors too are concerned about this

> *it's so important to make sure that they absolutely understand what we're dealing with before they leave, but I mean that's something we might just need to make doubly sure that they really understand, but again that sometimes breaks down because I suppose the length of the consultations that may occur makes it hard to really truly make sure it's really happened.*

One doctor summarised the key challenges they face as lack of understanding of Traveller culture

> *perhaps that we don't understand their culture, so we don't understand where they're coming from with certain things and that creates barriers.*

Travellers also referred to the lack of cultural understanding as a barrier and in some cases when poor communication in the past had also been an issue this led to counterproductive efforts at persuasion .

> *I was getting a lot of grief off the midwife, " Breast is best." Traveller women do not breastfeed, and it was a really stressful time for me, and I had to go on numerous occasions; the child was in the neonatal unit and I said 'Please stop mentioning breastfeeding because I can't do it!' . I couldn't take breast pumps home and bottles; I couldn't do it . To just try to get through to them' I cannot do it, it's hard for me to do it* – [they would ask] *' but why can't you do it? It's not in our culture to do it* [breastfeeding] *..... You say no and that should be it, but they couldn't understand why I weren't doing it. I've nowt against it at all but we can't do it. That's it! .*

One aspect of Traveller culture is their nomadic lifestyle, and this can result in other challenges such as continuity of care .

> *If they're going to Middlesbrough tomorrow, it's no good booking an appt they can't attend '*(non- clinical)

Difficulty in giving a clear history is a particular challenge , especially as many Travellers do travel and are seen in different places. Although in theory it is easier now to obtain previous medical records for new patients than in the past , this does depend on having accurate information.

> *things can be very vague, like a recent one I had was, this woman was coming as a temporary resident and needed all this medication, so I said well, you know, what dose of what are you on? And I couldn't be told, so I was given the previous GP in Ireland, and "oh yeah, yeah we have got that person but not as that date of birth", it*

> *was a different date of birth, and "no, no that it is me I just gave a different, I just gave the wrong number" he says, so they had two dates of birth* (GP)

> *Sometimes it's quite difficult to get information, like past address or previous GP, things like that, so half the time you're just second guessing or put unknown. Because they'd say like, 'I was here for 2 weeks, then I went somewhere else* (non- clinical staff)

Another challenge for hospital staff is the cultural tendency for large numbers of extended family to gather to support their relative who is seriously ill.

> *Travellers have very large extended family and they're very close , so if you had someone who was dying or was seriously ill you might see 12 or 15 relatives all on the ward, which is quite unusual , and if you present with your cancer by being admitted as an emergency to hospital we do see that….. there can be a tendency when you've got that number for people to get cross and sometimes if there's frustration about the situation, when one is upset about a situation its quite easy to get cross about it.*

Travellers also referred to the tendency of extended family coming in large numbers and understood the difficulty for health staff, but felt this problem was compounded by the way that some staff react to and deal with the issue and in doing so alienate the Travellers concerned .

> *because we come in hoards, and I do get it , I really do get it . I mean I've been there when my family's been in . I've come out of the room and sat in corridors waiting to be able to go in. I get it they're a hindrance , there's other sick people but at the time the only thing on our mind is our sick person. I know the nurses have a job to do but sometimes they're downright rude and treat you like scum.*

Frustration was also put down to lack of trust in the treatment and wanting something else to be done to ' fix it'. The same lack of trust or belief in the diagnosis or prescribed treatment also leads to seeking a second opinion or going to be seen privately , with no extra benefit to the Traveller patient.

> *if someone is in denial then obviously they think something can be done , and then they end up being brought to hospital and you end up with the scenario of 15 to 20 relatives all saying why can't you do something about this, and the reason you can't do anything about it is because the person is dying from cancer , so that can be a problem.* (oncologist)

> *I remember one Traveller, he had Parkinson's disease and he wanted to go for a second opinion and it was difficult to explain that I was more than happy to just refer him to another doctor rather than him going to London and spending, I knew money wasn't flush in this family and I was trying to explain, look I just want to try and save you some money here and so sometimes they might be making health decisions which probably might not be as beneficial for them as they might imagine* (GP).

> *There was a lady, I'm pretty sure she was a Traveller, she took herself off to Newcastle and then to Preston . That's fine, it's their prerogative and some people get on better with some people than others but it's the searching for different places for what effectively is likely to be pretty similar treatment.* (oncologist)

One doctor spontaneously suggested "*some sort of key worker that worked with the Traveller community"* as a way to meet some of these challenges . A question concerning their views on the suggestion was subsequently put to other health staff and to Travellers when interviewed.

Views on provision of a dedicated health worker for Gypsies and Travellers in Morecambe Bay CCG

There was enthusiastic support for a dedicated health worker for Travellers from health staff across the various disciplines.

> *I think it would be something that would be really good, yeah, I think the people definitely have poorer health outcomes and we have a number of them in our area so it would be a really good thing. (*GP)
>
> *we're always going to be pressured in general practice, it's always going to be hard to truly meet their needs* **;** *the only way I could truly see that people are not going to fall through nets or miss things is to have some form of link or liaison between the community and us* (GP)
>
> *I think it would be perfect, I think there just needs to be some health representative to work with this specific cliental to help build a relationship to get them to engage and understand, and so they've got somebody they can go to if they need service or guidance* (health visitor)
>
> *Definitely, if you've got a hard-to-reach community health- wise it can only help to have someone in there that they can learn to trust, and that can be an intermediary, that can see both sides.* (nurse)
>
> *Yes, a very good idea. Would be very helpful for cancer education and also as an advocate; accompanying patients to an appointment to help relay information (both ways). Would also be able to help the nurses to come up with solutions for identifying the profusion of medication that the patients needed.* (oncologist)
>
> *It would be useful to have a nurse background for raising awareness about cancer and picking up clues for early diagnostic referral. Could also be a patient navigator role- needs to be someone with initiative.* (oncologist)
>
> *Yeah, definitely. It would break down those barriers, I think. A lot of them there's a sort of a mistrust…… I think it would be beneficial if someone worked with them, engaged with them, and explained why we do certain things and why it's to their benefit* (non- clinical)

Travellers were also supportive of the idea, and some had already had experience of living in an area that had a health visitor for Travellers and had valued it. They explained how important it was to have someone who understood their culture and could advocate for them

> *she was very good, and it did help a lot , because she got to know our ways , know everything about us and she could step in* [intervene on her behalf to explain things].

Others without that previous experience also envisaged the benefits of having someone that could understand them and 'their ways' and that they could feel confident to approach .

> *I think it would be a good idea; someone who knew them a bit more, knew their ways, that they could speak to , that they'd know that person does know their ways, certain terms for different things .*

> *the word would get round like, there's this person for Traveller you could talk to, that could help you.*

> *Yeah, I think it would be easier, more comfortable* Why? *Because they're there for you , you could go to them.*

There was a feeling that Travellers would welcome someone that they felt they could talk to because a person in that role would accept them. It reinforces the lack of trust they hold in health staff generally and their sense that they are or will be judged for who they are or for wasting a doctor's time

> *They'd have to be wanting to work with Travellers , otherwise they wouldn't be doing that job.*

> *you'd go to her first wouldn't you- she could give you a letter to go to the doctors***.** *If you had a problem, or your son or daughter you'd go to her first. You could speak to her .*

There were some strong feelings about whether a Traveller should hold the role or not, with most being uncomfortable with the idea of a Traveller being in the role because of the fear of confiding in people who might know them or their families .

> *I'd prefer it not to be a Traveller – it's quite confidential what you speak about and you don't know if they're going to have a conversation at home .*

> *not a Traveller- people wouldn't want to talk to another Traveller about their health ; but a Traveller supporting a nurse would be good .*

> *I don't think anyone would be keen to share their information with another Traveller . Like I've only met you twice and I've talked to you about things, but I wouldn't share these stories with another Traveller*

There was more trust that a nurse for Travellers would keep confidentiality and that they would have the necessary qualifications and knowledge for Travellers to feel confident in talking to them about health matters.

> *but if you have a nurse she could talk to you, and she would keep it to herself . It wouldn't go all round the site*

> *I'd just want to make sure they'd done all the work and got the qualifications and that to be talking about your illnesses*

> *because if that person didn't have health knowledge they'd be passing everyone on to GPs , or if that person didn't have health knowledge and didn't pass someone on the GP and there was a genuine….*

Apart from the requirement of whoever was appointed to the role to be qualified , and to be knowledgeable about Traveller culture '*to know the community, their ways, and respect them,*' it was felt that person needs to be resilient as they could be overwhelmed with needs.

> *I'd love that* [a nurse for Travellers] *. Yes, I'd probably spill everything out to them, I'd tell them every problem I've got.*

> *I think the poor woman would be hounded . The poor woman would have to be highly resilient , because if someone knew there was a 'Traveller nurse' they'd follow her for everything. They wouldn't keep it to medical I don't think.*

The fact that someone in any role who understands and respects Travellers would be called on for advocacy, that is not necessarily related to their actual role, is borne out by accounts of an education worker being lauded for her intervention and advocacy on a health-related issue. This tendency to ask advice on any matter from a trusted practitioner is also recognised by health practitioners in such roles elsewhere, particularly when it comes to trying to understand letters or forms from authorities.

There were some positive views on the additional suggestion of having Travellers appointed to roles as health trainers or health champions and some interest in training for such a role, despite lack of self -confidence

> *Yes, that would be good- like explaining about what's good for your health*

> *Yeah that would be a good idea.*

> *I could do it myself, but I don't think I'd be that good at communicating*

Other suggestions for improving care and access to health provision for GRT

Some suggestions were made to aim for improved continuity within general practice. One such suggestion was for there to be a named GP for Travellers in each practice , or alternatively, several named GPs

> *maybe it might be worth having a few GP's, probably not one, but a few GP's and Gypsies and Travellers that could get some continuity with some of the families.* (GP)

Another suggestion was for each surgery to have a named GRT patient advocate

I would imagine that you're there and that you'd have like a 2-hour clinic and if they have the information that they could access someone to ring that that could help them – either understand their tablets, or something they could tell me and I could liaise with the doctors. (non-clinical)

Chapter 3 Additional Project Outcomes

Cultural awareness training

One of the outcomes of carrying out the interviews with health staff was that most reported that they knew little about Gypsy and Traveller culture and their beliefs.

One GP stated that their mandatory equality and diversity training was inadequate

> *You take each person as they come and you look after them the best you can; that's probably the sum total of my equality and diversity learning ; that we do teaching that puts people in boxes and then you get to the end of it and say probably we shouldn't put people in boxes .....I think a lot of racism is about putting people into groups and saying you're 'other'*

This understanding that such equality and diversity training doesn't necessarily result in cultural competency is important, as is the observation that racism, whether overt and intended or not, is sometimes present .

> *We have problems with discrimination , we have problems with inequality and they're not so easy to identify , but they're still there . Everybody knows you shouldn't use particular words and you should treat particular people in a particular way, but that still happens . It's a much subtler form of discrimination and abuse I think, and that's really about the way people feel about each other.*

As long ago as 1987, Hawes[xxv], in writing about inequality in his research on Gypsies and Travellers and the health service , advocated the type of training that must *'seek to overcome the barriers and hostilities and misunderstandings that persist in the delivery of health care'*, if appropriate services for excluded and marginalised communities are to be developed , i.e. cultural competency training .

This was developed further in research by Francis in 'Developing the cultural competence of health professionals working with Gypsy Travellers'[xxvi]. Whilst concluding that her project highlighted the need for staff to have improved understanding of Gypsy Traveller culture and the issues faced by the community, it also *'demonstrated the benefits of honest, non-judgemental, open discussion within professional forums about the existence and impact of bias and prejudice on practice.'*

Several staff expressed a desire and need to learn more about Gypsy and Traveller culture and how it affects their relationship with health staff.

> *I think a session on zoom with a couple of them* [Travellers] *actually telling us about their beliefs would be really helpful and them telling us how they would want to be treated when they come to the doctor, would be helpful.*

The need for Travellers to be involved in delivery of such training is important, and several Travellers in different areas of the country are engaged in delivering cultural awareness training that aims to improve cultural competency of health staff . Usually, they have developed the training model together within a Traveller forum and they deliver it as a half day or a full day workshop. One example is the Surrey Gypsy Travellers Community Forum; their training, delivered by a minimum of two Travellers , aimed at staff from any statutory bodies , health staff , local government etc stated the following objectives

- To provide a balanced, accurate explanation of Gypsy of Traveller history and culture
- Look at myths, stigma, conflict areas
- Provide potential resolutions
- Provide confidence to work with Gypsy and Traveller communities.

In Lancaster and Morecambe there have been no Travellers previously involved in delivering such training, but two Travellers , one from each Traveller ethnic group, were willing to deliver a training session to health staff with the action researcher and to answer questions that health staff would be encouraged to submit in advance .

Each PCN requested to have a cultural awareness session delivered at one of their hour- long clinical education events by zoom . To date only one has taken place , on the 25th of May 2021 at Lancaster Medical Practice PCN . One of the two Travellers was unable to participate on the day, so the session was delivered by one Traveller, with no prior experience of delivering such training, supported by the action researcher . Very few health staff responded to the invitation to send in questions in advance but questions that were asked included

> *why do Travellers they seem reluctant to have their children vaccinated ?*
>
> *what would they like us to do to make our services " more traveller friendly"?*

Twenty- two staff attended the session , which was well received according to the verbal feedback afterwards . Training sessions for Bay Medical Group PCN, and for Ash Trees surgery group are yet to be arranged at a time when two Travellers are available to be involved in the delivery. Ideally a longer session would allow time for addressing more questions that staff did not feel able to ask, and would need more encouragement to ask , and for delving further into barriers and solutions. There is also a need to reach more staff, including non- clinical staff, by providing additional sessions in each PCN .

Targeted Health promotion

The lead for population health transformation and change in the CCG approached the action researcher to see how the project might improve Traveller engagement with the National Diabetes Prevention Programme (NDPP)[xxvii]. Initially the wish was to explore barriers to engagement , but this was already being explored through the interviews. More specifically they worked together to produce a couple of paragraphs of information for the GRT communities about Diabetes Type 2 , the NDPP programme, and how to find out whether a person is at risk.

There were two ways in which this information was eventually disseminated. There is a magazine called Traveller Times that is specifically for news about, and for, Gypsies, Roma and Travellers nationwide . This free publication is distributed quarterly as a hard copy and is also available online . The action researcher contacted the editor and the short piece titled, *Type 2 Diabetes- 'Get With The Programme' Say The NHS* [xxviii] was published on the online version in April 2021, along with the link to the Diabetes UK risk tool . Traveller Times also added a link to a booklet titled *Don't Leave it too late,: Diabetes a Guide for Gypsies , Roma and Travellers* that could be downloaded or listened to as an audio file .

There is more limited space for articles in the hard copy magazine and the editor would also favour an article that has a Traveller voice talking about the story subject . At the time it wasn't possible to find a local Traveller who was available and willing to be a 'voice' in such an article.

The second method of dissemination, at a local level, was via the Facebook Group that the action researcher and a steering group member, Julieann Seaton, created in February 2021, called *Traveller Health & Wellbeing in Lancaster , Morecambe & South Cumbria.*

It was hoped that by creating a Facebook Group it would be possible to inform more Travellers about the project and to post messages with health -related information. Travellers from the steering group were requested to inform other members of the Facebook Group's existence and to encourage them, their family, and friends to join it. The Group was created as a private group so that potential members need to request to join . They are asked whether they live locally , what their interest is in the group and whether there is anything they would particularly like from the group . The main reason for making this a private group was to prevent any potential abusive posts towards Travellers from people who may join the group for that purpose.   In total there are 46 members of the group, but that number includes people working locally in the field of health promotion who also want to reach Travellers with their health messages .

Although some of the posts on the group, mainly from the action researcher, included videos featuring Travellers , with messages targeted at Travellers , the numbers who have 'seen' each post have usually been low, with the number of 'likes' even smaller . The various topics posted have included covid vaccination and up to date covid guidance, survey on barriers to cervical screening, prevention of and recognition of carbon monoxide poisoning , when to worry about a child's health , children's mental health (related to lockdown) , and posts about adult mental health (one featuring Tyson Furey, and one promoting a mental health telephone hotline for Travellers by Travellers) . The posts that had the most views (maximum number 33) were covid related or child health related .

There have been no new members since June 2021 , and in view of the disappointing lack of interest there have been no recent posts. It is likely that the sole health focus of the Group is one explanation for the lack of appeal . It is also possible to obtain health information targeted to the GRT communities and featuring Traveller voices from websites of national Traveller organisations or forums , such as The Traveller Movement (TM) , Traveller Times (TT) , and Friends, Families and Travellers (FFT) . Many Travellers do use social media , including Facebook and have their own Facebook accounts , but they are more likely to use social media for social matters and be less interested in specifically seeking out local health information from a dedicated Facebook group . There might be more interest in posts about health matters if there was a local Facebook group for the Traveller communities in Lancaster & Morecambe with a wider focus than health and that is created and moderated by Travellers themselves.

Vaccination and Immunisation

That this project took place during a pandemic and, once a vaccine was available , there was a concerted nationwide effort to encourage vaccination of eligible age groups, it was important to address vaccine hesitancy among groups were this was an issue .

In February 2021, FFT, a Traveller organisation , hosted an online workshop, in conjunction with Public Health England, on *Improving access to immunisations for Gypsy, Roma and Traveller people*. It was aimed at Health professionals, policymakers, members of the voluntary sector and members of Gypsy, Roma, and Traveller communities to share good practice. The action researcher attended the workshop on behalf of members of the steering group and shared the information at a future steering group meeting.

Various methods were suggested for improving uptake of vaccinations and immunisations and these included outreach by nurses and outreach workers or community health champion volunteers , flexible appointments and texts, and pertinent media to improve health literacy on the subject.

Prior to this, the UNITING study had emphasised the importance of trustful relationships with health professionals and continuity of care. It had recommended five top priority interventions to improve uptake of immunisations generally, which had been agreed among service providers and Travelling communities

1. *cultural competence training for health professionals and frontline staff*
2. *identification of Travellers in health records to tailor support and monitor uptake*
3. *provision of a named frontline person in general practitioner practices to provide respectful and supportive service*
4. *flexible and diverse systems for booking appointments, recall and reminders*
5. *protected funding for health visitors specialising in Traveller health, including immunisation.*

Regarding covid vaccination specifically, other Traveller organisations, have produced videos to encourage and inform Travellers of the need for covid vaccination. Two of these videos were posted on the Facebook Group .

Point of contact for Traveller health services

Although this has been a time- limited project and conducted during a pandemic , it has raised the profile of Traveller health inclusion, as it became known that there was a point of contact for different services and departments to try to find ways to improve their reach to Travellers. This could be a continuing value of the project if the steering group continues to meet in some form and if they are successful in bidding for funds for a practitioner dedicated to work with the Traveller communities.

Chapter 4 Conclusion and models of dedicated service provision

Conclusion

Although it must be acknowledged that the samples of Gypsies and Travellers in this study are small and not necessarily representative of their wider populations, many reported generalisations about their health , use of health care services, beliefs, and experiences related to health care very closely replicate findings from previous studies elsewhere .

Despite absence of hard data due to lack of ethnic coding there is strong indication of poorer health and higher mortality at younger ages than the wider population and poor timely uptake of health care service

Gypsies, Roma Travellers are not homogenous groups, and there is no suggestion that their culture is the sole explanation for the way in which they experience health and use health care services. There are many other factors besides individual experience, such as educational attainment, socio economic status and environmental factors that will influence health and attitudes to health services. However, their cultural identity and the wider context of their lives in light of their identity is one of these important factors and there was a strong overriding theme, from the interviews, as in other studies , that highlighted the cultural identity of Gypsy Travellers and its influence.

Helman [xxix] describes culture as *a set of guidelines that individuals inherit as members of a particular society and that tell how to view the world , how to experience it emotionally and how to behave in it in relation to other people…. It also provides them with way of transmitting these guidelines to the next generation.*

There is a risk of stereotyping Travellers by over generalising in explaining their health-related behaviours, as there are always differences among members of any culture in how they think or behave, as these interviews show. Many members of a group will also absorb some of the cultural attributes of the wider society. Nevertheless, there is overwhelming evidence from here , as elsewhere, that there is a major reluctance to access timely use of health care services, for a variety of reasons, and that mistrust, stemming from their position in society and how they sense that they are regarded, is a major factor.

Timely and effective use of health care services are important, but the social determinants of health, such as lifestyle factors, social networks, living and working conditions, socio-economic and environmental conditions, and crucially the health impact of racism and ostracisation, also need addressing if the health inequalities experienced by Travellers are to be tackled . A community practitioner in a public health role can play a role in helping to address these too, particularly if they work closely with other public sector bodies and agencies .

Models of dedicated service provision

There are various areas where workers are employed to work specifically with Gypsy and Traveller communities and there are various different service models provided . Broadly the different models are either a team consisting of a health professionals, or in some cases just one health professional , health trainers or community support workers , or trained voluntary health champions from the local Travelling communities.

Many health bodies have over the past decades employed a lone health practitioner, usually a health visitor, to work with all age groups in their local Gypsy and Traveller populations . Over time , these health professionals have been able to build trust and act as a bridge between Gypsy and Traveller communities and their local health services and thereby improve access.

One example which is being evaluated is in Leeds, where Leeds West CCG funded a specialist nurse to work with the Gypsy and Traveller community [xxx]. The key findings of the interim evaluation after one year were : there were several barriers to accessing services ; the nurse role is highly valued, accepted and working well but needed trust ; the health needs were very complex and outcomes include better access to health services (and services more widely), and improved self-reported health . Key to the success of building those trusted relationships has been working together with Leeds GATE, a community members' organisation for Gypsies and Travellers in Leeds and West Yorkshire. That post has now been funded for a further year and additional funding granted to appoint a community member to an Advocacy Post to complement the specialist nurse role.

Several areas, more usually those with large local Traveller communities, have employed Gypsy and Traveller health teams. Notable examples include Cambridge Public Health Gypsy Traveller health team, Leicester Partnership Travelling Families health service, the Gypsy Traveller health team in Surrey , and Durham Gypsy and Traveller Health team . The composition of several of these services change over time.

The Surrey outreach service for their Travelling community started as a 2- year programme in 2019 , commissioned by Surrey Heartlands Integrated Care System (ICS) with 2 health visitors, a part time school nurse and an admin support. The impact of the service was extreme success in improving access to healthcare , with many health issues picked up during visits . These included hypertension, domestic violence, sexual health, mental health, public health ,and environmental risks, safeguarding and poorly managed chronic illnesses. This service has also been extended for a further year , and now comprises one Band 8 clinical lead health visitor who also continues a wider strategic and liaison role, another band 7 health visitor, a health care assistant and an admin support.

These specialist roles can be isolating without peer support and in the 1990s a network of Health workers with Travellers (NAHWT) was established for postholders to gain such peer support This eventually disbanded as there was insufficient management support for them to continue to meet geographically in different parts of the country .

More recently a new network has been established of Queen's nurses[5] and others who work as specialist health practitioners with GRT communities . They meet bi-monthly by zoom. This video technology enables the specialist practitioners from all across the UK, and from Ireland to meet and also enables guest speakers to attend meetings more easily. The aim of this network is to support each other in their roles by sharing best practice and relevant information about new initiatives. Recently for example, practitioners have been notified by one of the NGOs working with and for Travellers about a project to understand rates of suicide and contributing factors among Gypsy and Traveller people so that they can ask the

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[5] A Queen's nurse is someone who fulfils the criteria and is committed to providing best care to their patients and work in any community-based role.

Government to do more to ensure Gypsies and Travellers have access to the support they need. The practitioners in the network have been asked to support the project by supplying anonymised data to inform it .

In certain areas health trainers or community support workers from the Travelling community are employed, although their roles differ and focus more on advocacy in general or in improving healthy living. Durham County Council employed two health trainers who worked closely with, and complemented the role of, the health visitor for Travellers (known as the Travellers health nurse) One of those health trainers was from the Travelling community and the other was not. This gave Travellers a choice as some preferred not to see someone from the community who would know them or their families .

The other model sometimes used, such as in Devon, and in East and West Sussex, is to train community health champions. In some areas these are trained but they work as volunteers .

In Devon a Gypsy/Traveller Healthy Living Project was funded by Devon County Council Public Health to take an asset- based approach to increasing health and wellbeing capacity of the Gypsy and Traveller communities living in, and in transit through, Devon over a 24 - month period. They recruited and trained six Health champions . Reported outcomes of the project were that individuals from the Gypsy and Traveller communities have the skills, motivation and knowledge to improve their own health and wellbeing and to act in the interests of community health and wellbeing; and that known members of Gypsy and Traveller communities in Devon have received or had opportunity to receive the health booklet that the health champions were helped to produce, and have been made aware of the health champions project which in turn will support informed decisions regarding their individual/ communities health. The 2016 report states that ongoing delivery beyond the project would require some funding to maintain the champions and cover the expenses attached to their work which would be a waged activity. It not clear if this ongoing funding was granted .

These and various models have different objectives and outcomes and there are advantages and disadvantages of each model. The ideal is to have a team incorporating the different models. The House of Commons committee report on tackling inequalities faced by Gypsy and Traveller communities recognised the importance of building trust to ensure engagement with health services and the length of time and commitment that this usually took.

We heard of good practice in healthcare in many local areas, which was often driven by passionate and committed individuals who were making great efforts to work with the Communities and build the trust that was needed, often over years.

However, the concern was also voiced that this could allow mainstream services to abdicate their responsibilities unless the effort was also invested in tackling some of the barriers that arise from within those mainstream services such as improving cultural competence and providing more flexibility in service delivery. .Where there are dedicated practitioners working with Travellers they are usually involved in working together with Travellers to provide cultural awareness training for health staff . It is important that mainstream services also become involved in tackling some of the barriers that Travellers face in using their services.

Summary

The overarching aims of this project were to work with members of the local GRT community with the aim of building trust with primary care services, increasing screening rates, improving prevention, effecting earlier diagnosis, and therefore more effective treatment, for Travellers with cancer , and all other conditions.

These were always ambitious aims for a year- long project and at best the project might have started to make progress towards achievement of these aims. However, the additional constraints of the project taking place in the middle of a pandemic and the imposed restrictions on face-to-face engagement, with consequent reliance on video technology, meant that only the first phases of the project i.e. engagement to form a project steering group and gathering baseline data through interviews were feasible .

The other major challenge, that was known from the outset, was the inability of obtaining hard health data due the virtual absence of use of the Gypsy and Irish Traveller ethnic coding on any health records. Many Travellers would also be loath to self- ascribe as Gypsy or Irish Traveller on health records if they were given the option because of the fear of being treated differently, despite the fact that many health staff recognised their Traveller identity by their names , accents or other clues. There needs to be work with Travellers and with health staff to explain the relevance and importance of capturing this information.

Although the number of interviews overall, with health staff and with Travellers, were small they reinforced the findings of previous studies elsewhere relating to GRT health and use of health services.

The self- reporting of health issues among Traveller interviewees and their families, and reports from health staff, suggests that their health overall is poor, with many experiencing ill health, and in particular anxiety and depression. There was also a strong indication of high mortality, often at a relatively young age, from heart disease .

Stress arising from their experiences related to being Travellers, including the impact of racism and prejudice towards them in wider society, was recognised by some Travellers as one of the causes of their poorer health, in addition to other more obvious explanatory lifestyle factors such as diet, smoking and exercise.

Use of health care services was predominately on an urgent basis, usually not until symptoms were more serious and affecting daily living . There were several reasons given for avoidance or delay in seeking health care, all in common with findings from other studies.

Mistrust was the overriding factor, associated with mistrust in all non- Travellers , arising from negative experiences that they have personally encountered or often from stories of poor experiences circulated within the wider family or community .

Cultural attitudes and beliefs in stoicism and self- reliance were also recognised as reasons for avoidance or delay in seeking medical care .

Other reasons included poor health literacy resulting in lack of awareness of the significance of some symptoms, fear of being judged, particularly as a time waster, and anxiety about communicating health concerns and about understanding what they might be told. Denial was also a factor

The exception to attendance only when symptoms became serious was in the case of Traveller children. As elsewhere, children here are promptly brought to the surgery with much slighter symptoms, by mothers who are usually very anxious about their child's health.

Attendance for screening , chronic health reviews or even follow -up appointments after an initial consultation, is poor.

Although some Travellers do seek medical help for mental ill health , many do not , and depression and anxiety were made worse by the associated stigma of talking about it with others and the felt need to 'get on with it' and not show weakness . There are similar attitudes of denial and stigma surrounding dementia , and the felt need by families to cope without outside support.

Cancer is strongly feared and talk of it avoided to the extent that if it is mentioned at all euphemisms used such as 'the worst thing' or ' that unlucky thing' are used instead of the word cancer. Many still see a diagnosis of cancer as a death sentence, not least because that has been their experience with many extended family members . This fear did not appear to lead to earlier presentation for diagnosis but rather, to the contrary.

There is uptake of maternity services and the health visiting service but with a focus on those services as they relate to the baby/ children . In particular the health visitors find difficulty in engaging about the mother's health particularly on sensitive subjects such as domestic abuse.

Resistance to uptake of immunisations appears to be a significant issue in Lancaster and Morecambe, more so than it would appear to be elsewhere.

Travellers and health staff alike recognised the need for greater awareness of Traveller culture among health staff and for them to understand the impact of any lack of cultural competence . Some work has started on this but needs to continue and to reach more staff. It is crucial that Travellers are involved in the delivery of training sessions.

All these factors that influence health and timely access to health services reinforced the case for employment of a practitioner or practitioners to provide a dedicated service to Travellers to help to tackle these health inequalities . Travellers and health staff made strong cases for such roles, in addition to some suggestions for improving service delivery in the GP practices.

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