# An Independent Evaluation

# **County Durham**

# **Gypsy & Traveller Health Project**

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#### **CHAPTER 1**

#### INTRODUCTION

#### **Contextual Background**

#### • National Policy Context

There has been a policy focus on tackling health inequalities in the UK since the publication of the Acheson report on an Independent Inquiry into Inequalities in Health in 1998<sup>1</sup>. Successive policies<sup>2,3,4</sup> since then have focussed on strategies, including target setting for reducing health inequalities. However, a study reviewing the impact of government policy initiatives aimed at poverty, inequality and exclusion<sup>5</sup> concluded that although there have been some overall improvements, for example in health and in educational achievement; there has not been a similar improvement in reducing inequalities. Ethnic inequalities were reported as remaining large in many dimensions, and some vulnerable groups, for example asylum seekers, were noted to be specifically excluded from the inclusion agenda. However, Gypsies and Travellers (GRT) <sup>6</sup> were not included in these examples, thus demonstrating the extent of their social exclusion.

It was not until after the publication of the 2004 Health status study of Gypsies and Travellers<sup>7</sup> which showed striking inequalities in their health, even when compared with people from other ethnic minorities or from socio-economically deprived white UK groups, that recognition of this disparity was reflected in any government policies. There was a requirement in the Local Government and Public Involvement in Health Act 2007 for Directors of Public Health to include under- represented groups, such as Gypsies

<sup>&</sup>lt;sup>1</sup> Acheson, D. (1998) Independent Inquiry into Inequalities in Health, London: The Stationery Office

<sup>&</sup>lt;sup>2</sup> DoH (1999) Saving lives: Our healthier nation, London: The Stationery Office.

<sup>&</sup>lt;sup>3</sup> DoH (2000) The NHS Plan, London: DoH.

<sup>&</sup>lt;sup>4</sup> Wanless, D. (2002) Securing our future health: Taking a long-term view: Final report, London: DoH.

<sup>&</sup>lt;sup>5</sup> Hills, John (2005) *Policies towards poverty, inequality and exclusion since 1997.* Joseph Rowntree Foundation <sup>6</sup> Gypsies and Travellers will often be referred to as GRT throughout the remainder of the report. It will usually refer to Gypsies and Travellers, who are largely English and Welsh Gypsies, Irish Travellers and Scottish Travellers. Very few Roma, who are Gypsies of Eastern European origin, are known to reside in housed accommodation in Co Durham and those few are unknown to GRT services.

<sup>&</sup>lt;sup>7</sup> Parry G, Van Cleemput P, Peters J, Moore J, Walters S, Thomas K, and Cooper C. Health Status of Gypsies and Travellers in England: A report of Department of Health Inequalities in Health Research Initiative Project 121/7500. 2004. University of Sheffield.

and Travellers, in the production of Joint Strategic Needs Assessments (JSNAs) to identify priorities for action on health inequalities.<sup>8</sup>

However it was not until 2010 that guidance on culturally responsive JSNAs <sup>9</sup> was produced, in recognition that until then there had been wide variation between areas in the quality of JSNAs produced and the responsiveness of JSNAs to cultural diversity. Even at this point there was no reference to Gypsies and Travellers. They were not officially referred to in terms of being identified as socially excluded groups until the publication of a guide 'Inclusion health - improving primary care for socially excluded people'<sup>10</sup> in the same year, even though a year previously one of several National Service Frameworks (NSFs) was produced specifically on Primary Care for Gypsy and Traveller communities.<sup>11</sup> NSFs were policies set by the NHS, mainly to define standards of care for major medical issues.

It was 2012 in the Health and Social Care Act<sup>12</sup> before there was a legal duty on Clinical Commissioning Groups (CCGs) to (a) reduce inequalities between patients with respect to their ability to access health services, and (b) reduce inequalities between patients with respect to the outcomes achieved for them by the provision of health services. This is in addition to The Equality Act 2010 which includes a public sector equality duty requiring councils and other public bodies to consider ways to:

- Eliminate unlawful discrimination, harassment and victimisation and other conduct prohibited by the Equality Act.
- Advance equality of opportunity between people who share a protected characteristic and those who do not.
- Foster good relations between people who share a protected characteristic and those who do not.

Finally, in the Inclusion Health programme between 2012 and 2015, Gypsies and Travellers were identified as one of four groups who had a significantly increased risk of ill health and

<sup>&</sup>lt;sup>8</sup> Local Government and Public Involvement in Health Act 2007

<sup>&</sup>lt;sup>9</sup> Race for health, (2010) Culturally responsive JSNAs: a review of race equality and Joint Strategic Needs Assessment (JSNA) practice

<sup>&</sup>lt;sup>10</sup> Department of Health (2010) Inclusion Health: Improving Primary Care for Socially Excluded People. London: Department of Health

<sup>&</sup>lt;sup>11</sup> NHS PCC (2009) Primary Care Service Framework: Gypsy and Traveller Communities. NHS Primary Care Contracting.

<sup>&</sup>lt;sup>12</sup> Health and Social Care Act 2012, c.7

premature death. An evidence-based commissioning guide for CCGs and Health and Wellbeing Boards<sup>13</sup> was produced jointly with the Royal College of General Practitioners as a source information and good practice to address this. At the same time, two other relevant guidance documents were produced to support commissioners and service providers: Standards for Commissioners by the Faculty for Homeless and Inclusion Health<sup>14</sup>, and Hidden Needs; Identifying Key Vulnerable Groups in Data Collections<sup>15</sup>.

However, despite heightened awareness of their specific health needs and inclusion of GRT in policy documents and guidance, little actual progress has been made. A Ministerial Working Group on tackling inequalities experienced by Gypsies and Travellers produced a Progress report in 2012<sup>16</sup> making 28 recommendations, of which five were for the Department of Health (see figure 1). These largely remain to be implemented.

7. We will work with the National Inclusion Health Board, the NHS, local government and others to identify what more must be done to include the needs of Gypsies and Travellers in the commissioning of health services.

**8.** We will explore how health and wellbeing boards can be supported to ensure that the Needs of Gypsies and Travellers with the worst health outcomes are better reflected in Joint Strategic Needs Assessments and joint health and wellbeing strategies.

**9.** We will work with the UCL Institute of Health Equity and the Inclusion Health working groups to identify gaps in data and research, and look to identity the specific interventions that produce positive health outcomes.

**10.** We will work with the Inclusion Health working groups to identify what more needs to be done to improve maternal health, reduce infant mortality and increase immunisation rates.

**11.** We will work with the Inclusion Health Board to embed the Inclusion Health programme in training for all health professionals with the aim of developing a strong, stable and capable workforce that can drive change and make a difference to the lives and health outcomes of the most vulnerable.

Figure 1 Ministerial Working Recommendations to Department of Health 2012

<sup>&</sup>lt;sup>13</sup> RCGP (2013)Improving access to healthcare for Gypsies and Travelers, homeless people and sex workers

<sup>&</sup>lt;sup>14</sup> Pathway, (2013) 'Standards for commissioners and providers: the Faculty for Inclusion & Homeless Health'

<sup>&</sup>lt;sup>15</sup> Aspinall PJ (2014) Identifying Key Vulnerable Groups in Data Collections: Vulnerable Migrants, Gypsies and Travellers, Homeless People, and Sex Workers, Inclusion Health

<sup>&</sup>lt;sup>16</sup> DCLG (2012) Progress report by the ministerial working group on tackling inequalities experienced by Gypsies and Travellers

#### • Local context and GRT population

County Durham is a socially, economically and physically diverse area, covering 862 square miles (2233 square km) and home to nearly half a million people in 12 main towns and more than 300 smaller settlements, many of which are former colliery villages. Gypsies and Travellers are the largest ethnic minority in the county with the majority living in or around the Bishop Auckland area, either on caravan sites or in housing (see figure 2).

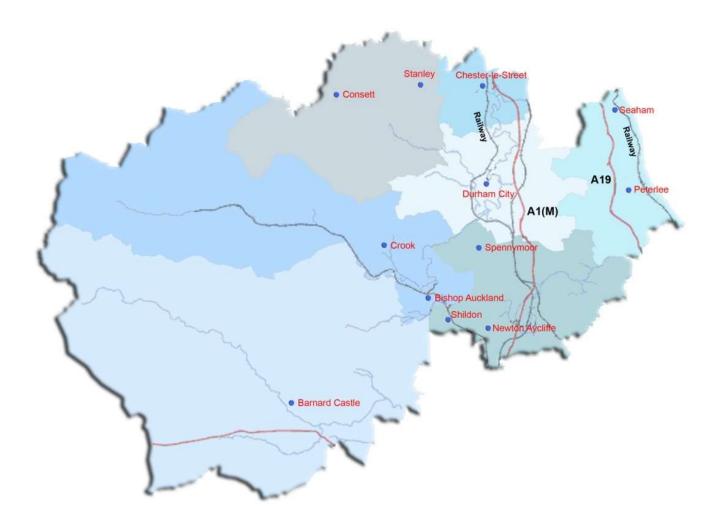


Figure 2 Map of County Durham and main towns

A separate Gypsy, Roma & Traveller Health Needs Assessment (HNA) for County Durham and Darlington<sup>17</sup> was commissioned and conducted in 2010 (published 2011) to ensure that this minority group were fully included in future health planning. The resident GRT population in County Durham, based on household survey and GRT Education records, is estimated in the HNA as being between 2,200 and 2,940 (0.59% of the total population). However, due to the reluctance of Gypsies and Travellers to self-ascribe, this is almost certain to be an underestimate. The last documented estimate of the national GRT population, also most certainly an underestimate, is over 300,000 (0.6% of the total population).

#### • Accommodation

There are six local authority owned and managed caravan sites in County Durham, now providing a total of 126 pitches.

Three sites are in the north of the County: Tower Rd site in Stanley; Drum Lane site in Chester le Street and Adventure lane site in West Rainton.

The other three are in the south of the county; St Phillips Park and Ash Green Way sites in and near Bishop Auckland, and East Howle site in Ferryhill.

In 2009 and 2011 two of the sites (St Phillips Park and East Howle) were refurbished. The remaining four sites were refurbished, in consultation with residents, over a 2-3 year period and completed in 2015. This refurbishment programme meant that at the start of the evaluation, as all four sites were closed at the same time, several families were living in temporary accommodation, either on other sites or in housing for several months to over a year, while others moved away. In addition, although the facilities on the new sites are vastly improved, the resulting rent increases, plus separate water rates, have become an extra financial burden for some families, especially for single and low income occupants. Durham County Council (DCC) previously included water usage within the rent. Generally across the country living on sites proves expensive for Gypsies and Travellers as the have to pay for their own trailers in addition to council rents for their pitch and utility building, and these rents vary considerably, between £40 and £200 per week<sup>18</sup>. Despite the increase, which took

<sup>&</sup>lt;sup>17</sup> Renaissance Research (2011) Gypsy, Roma and Traveller Health Needs assessment for County Durham and Darlington.

<sup>&</sup>lt;sup>18</sup> Richardson (2016) Managing and delivering Gypsy and Traveller sites: negotiating conflict Joseph Rowntree Foundation

place following considerable investment in site refurbishment and ongoing maintenance, the rates on the six DCC sites remain well below the mean average across the country, and the site facilities and management are cited as a good model example in the Joseph Rowntree Foundation study.

The majority of Gypsies and Travellers in Co. Durham live in 'bricks and mortar', and although some may be well integrated in their local community, we know from national studies<sup>7</sup> that their health is often worse than that of those living on sites. Many prefer to keep their Gypsy and Traveller identity hidden due to the fear of adverse consequences, and so are less easily reached for consultation. We therefore have limited knowledge of where housed Gypsies and Travellers are living, their circumstances, and the extent of their numbers. However, we did know, from conversations with housed Gypsies and Travellers in other areas, that many are likely to be feeling culturally isolated, separated from their wider extended families, and likely to be feeling excluded from, or unaware of, services and events targeted for Gypsies and Travellers. In the HNA, upwards of 570 GRT families were estimated to be living in housed accommodation in County Durham with the remainder living on smaller privately owned caravan sites.

There is still insufficient permanent or transit site provision nationally, and unauthorised encampments occur in the county throughout the year, but particularly in the summer months. However County Durham does have a policy of providing temporary stopover sites, and are planning for further ones. They also have a policy of provision of water, toilets and waste management services, which is a shining exception among most local authorities. There are a number of Gypsy Traveller fairs held in in the county, and also the large fair at Appleby in Cumbria in June, which result in large numbers of temporary encampments for several weeks at a time. There was no health related service with designated responsibility or authority to visit Gypsies and Travellers who are living in an unauthorised encampment on private land, with the result that they would be likely to have more difficulty in accessing health services.

## • HNA and recommendations

The HNA<sup>17</sup>, although it concluded that their findings appeared to paint a brighter picture of the GRT health in County Durham than that in the national study or other local studies,

acknowledged the difficulties of arriving at a truly representative sample and also that they had tapped into a seam of resilience and ability to cope. This resilience and pride in coping is undoubtedly an asset, but in terms of seeking timely access to care can also have adverse consequences.

They also found, health appears to deteriorate more rapidly in older age than the rest of the population, and through the family history strand of the assessment that Gypsies and Travellers in the area were more than four times likely to die between the ages of 55 and 74 than the population as a whole.

In all they made 20 recommendations (see appendix i) based on their conclusions. The various strands of the subsequent GRT health improvement programme are a response to these recommendations. Conclusion10.19 in the HNA in particular was taken into account: *Consistency and continuity are identified as necessary to gain trust, but many services are in fact offered by short term projects which are very vulnerable to changing priorities.* 

#### • Pre-existing initiatives supporting GRT Health in County Durham

Prior to the project there had been some interventions in County Durham aimed at directly improving health of Gypsies and Travellers.

The Health Improvement team had previously been commissioned by DCC to develop and deliver mental health improvement programmes with BME communities, including Gypsies and Travellers, following the 2011 Health Needs Assessment. The team worked with the DCC Traveller Liaison Service and the Gypsy and Traveller Support Service at DISC (Delivering Initiatives Supporting Communities), a voluntary sector organisation, to engage with communities on two of the sites. They were advised by partner organisations that they would experience the familiar problem of mistrust of external organisations going on to the sites and of being unable to consult and engage in typical ways.

Through consultation with key partners and informal community engagement with individual Gypsies and Travellers, they developed a community wellbeing action plan that focussed on improving access to social prescribing and reducing known risk factors by increasing access to many protective factors. They also aimed to improve awareness among those working with Gypsy and Traveller families.

Three separate interventions on the two sites took place: bespoke Zumba classes for Gypsy and Traveller women (attendance varied from zero to 8 women), a Samba drumming session (attended by 6 children and 2 adults), and a Cook 4 Life cooking session (attended by two

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women, plus DISC support workers). Although attendance was low for these sessions there was positive feedback via the partner agencies from those who attended. It was recognised that "*considerable handholding*" from support agencies was required for women to attend, and the extra initial time required for relationship building and for trust to be developed was crucial, although rarely factored in when services are commissioned. Despite initial interest in several other offers of activities from the team, no other activities were progressed. Similarly, there was very slow uptake of a pilot social prescribing initiative and mental health primary care support.

The capacity building element of the team was difficult due to the time required to build relationships, so it was decided to capacity build within those organisations already working with the community. They ensured that the GRT team in DISC was able to access all of the health improvement service training

This Health Improvement service has since been decommissioned and was replaced by a new model, the Wellbeing for Life service, utilising a Health Trainer model and delivered in the most deprived areas of Co. Durham and to the most vulnerable 'at risk' groups via outreach.

Mental Health Matters worked with the GRT team to produce a DVD to advertise services for Gypsies and Travellers in County Durham. Some Gypsies and Travellers were involved in the production of the DVD.

There had been no other direct health related work, although, health visitors who had GRT caravan sites in their areas attended ' play and stay' sessions for pre-school children and were able to use these sessions as extra baby clinics. The play and stay sessions were, and continue to be, delivered by the GRT Early Years workers from the Educational Support team for GRT (previously known as EMTAS).

#### • Existing Services supporting GRT in County Durham

The GRT education support team, the GRT site management service, the GRT service who meet the needs of GRT communities who pass through the county, and the DISC GRT team, all provide different aspects of support to Gypsies and Travellers, which, although not directly health related, have an impact on their health and wellbeing.

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The DISC GRT service was originally commissioned in 2009 and funded through 'Supporting People' to work with 10 GRT families across the county. The service has subsequently been funded by DCC and they now work with a caseload of 30 families at any one time, plus offer advice and assistance with up to three visits for anyone else in need. Their main focus of work is accommodation support; this includes:

- Maximising benefits
- Managing legal issues, planning permission requirements, grant applications
- Improving budgeting skills and reducing debt
- Improving literacy and numeracy skills
- Access to education and employment

In the absence of any dedicated health support to GRT families they also undertook some health related work, working with the Health Improvement Service to deliver their interventions, and also working to increase GP and dental registrations. In the course of their work they, along with other partners, have observed that mental ill health is a major issue and in particular are aware of at least 4 deaths by suicide in Durham GRT families within the last 10 years. They have also been working in partnership with EMTAS (Ethnic Minority and Traveller Achievement Service) to deliver literacy and numeracy sessions.

#### • Additional current challenges for GRT in County Durham

Aside from the lack of dedicated health service provision, there was a notable absence of any GRT self- organised groups or GRT support groups. In 2013, a GRT organisation called the UK Association of Gypsy Women (UKAGW), based in Darlington, was consulted by Public Health in the early stages of developing interventions to meet the HNA recommendations, specifically on the production of culturally relevant health information resources. UKAGW had also been involved in the Durham and Darlington HNA. However, none of the families consulted for the baseline evaluation in 2014, were aware of the members of this organisation and so they cannot be viewed as having represented the local GRT communities in county Durham. Members of UKAGW also delivered some cultural awareness training sessions to council and primary care staff, prior to 2014, but no details or evaluation of these sessions are available. The UKAGW ceased to function in 2014.

As was the case during the course of the HNA, the start of the health project and the evaluation period of 2014 to 2017 took place during a period of national austerity affecting all services.

Although the budget funding for the project had been protected, the general staffing reductions, resulting from the need for services to find additional savings each year, puts a strain on all service provision and staff concerned. This is partly from reduced capacity to deliver services to previous levels, and partly due to many staff reorganisations resulting in lack of continuity. Many staff consulted about their service and roles spoke of these changes resulting in lowered staff morale and in several cases voiced uncertainty about contract terminations in the near future.

During the evaluation period, since the start of the project in 2014, the following services with a role in Gypsies and Travellers health and wellbeing had undergone major reorganisation, staffing reductions or contractual changes:

- Public Health (moved from NHS to Local Authority)
- NHS affecting hospitals and urgent care centres
- Social Services
- Gypsy and Traveller team in DCC (split into two separate services ) GRT Services and GRT site management
- Gypsy and Traveller Site Management (Site Wardens became council employees with different role responsibilities )
- Public Health Improvement Services
- General Practice (primary health care)
- One Point Community bases for Children and Young People services (newly integrated services being disintegrated)
- Educational services, including Early years
- TEWV mental health Trust

This period of austerity also has direct impact on Gypsies and Travellers in terms of lowered work opportunities, particularly for young people, and in terms of poor pay and conditions for those who do find work. Most Gypsies and Travellers prefer to work for themselves in preference to being employees, but the austerity also has an impact on available work opportunities as people cut back on non-essential services. Government policy has had an additional impact on one common Gypsy and Traveller occupation with the introduction of a new law which requires anyone trading in scrap to apply for a separate license in every local authority in which they operate.<sup>19</sup> A collector who operates across different areas has to pay an indefinite number of fees for an indefinite number of licenses, and there are fears this will price many out of the trade entirely. Councils also have the power to decide who is, or is not, a suitable person to be working in the scrap metal trade.

## • Wider GRT strategy

Improving the health of Gypsies and Travellers is not being viewed in isolation by DCC but as part of a strategic vision of the overall needs of Gypsies, Roma and Traveller communities living in and visiting county Durham. The vision statement in the Strategic Action Plan 2014-2017<sup>20</sup> is:

We recognise that Gypsy, Roma, Traveller communities are one of the biggest ethnic minority groups in the County. Our vision is to provide a co-ordinated approach to the provision of services to Gypsy, Roma, Traveller communities in County Durham, tackle inequalities and ensure good community relations for all residents across County Durham.

The action plan was developed across a range of services within DCC in co-operation with key partners such as Durham Constabulary, with the aim of embedding a cohesive, partnership approach. A County Durham GRT Executive Group, made up of internal and external partners, was formed to provide a strategic lead for all activity and to ensure that a joined up approach is taken to address the needs of the GRT community.

A Health & Education subgroup was formed, with other subgroups also created; Policy & Strategy; Housing & Planning; Finance; and Operational Group. Lead officers in each group were appointed to ensure all objectives were actioned and that progress was regularly reported to the GRT Executive. This partnership approach and commitment is key to addressing the social determinants of health and therefore plays a wider role in improving the health and wellbeing of Gypsies and Travellers. Some of the many key actions in this respect

<sup>&</sup>lt;sup>19</sup> Scrap Metal Dealers Act 2013

<sup>&</sup>lt;sup>20</sup> DCC (2014) Gypsy, Roma Travelers in County Durham ; Strategic Action Plan 2014-2017

include site refurbishments, identifying temporary stopover areas (TSOAs), consideration of small scale proposals for private sites, work with welfare rights to ensure the most current benefits information is available for residents, and develop a hate crime action plan.

The Health and Education group met regularly to monitor and report on progress on their action plans. The key health objectives and actions were:

- Improving access to health services
  - Review and produce popular health leaflets in collaboration with members of the UK Women's Gypsy Association. These leaflets will provide key information about symptoms for specific conditions.
  - Provide cultural awareness training sessions to health and social care staff. The issue of lack of cultural awareness and sensitivity is a barrier that has been identified to health seeking behaviour. This is a contributory factor to late diagnosis and treatment
- > Tailoring health services to the needs of Gypsy, Roma, Traveller communities
  - Develop a dedicated team of health professionals and health trainers to raise awareness of health services and support healthier lifestyles. Linking with adult learning services. Key elements include;
  - Providing additional prevention work with mothers of young children. There will be a particular focus on increasing rates of breastfeeding and increasing immunisation rates.
  - Addressing the wider health promotion agenda, including timely presentation in primary care

These form the basis of the health project outlined below.

# **Evaluation**

# • Project Description

A consultant lead for Gypsy and Traveller Health was identified in the DCC Public Health team (formally part of the NHS). The consultant lead commissioned a GRT health improvement project based on the HNA recommendations to address the objectives in the strategic plan. The key components of the project were to be:

- Creation of a specialist Health Visitor post and a Support Worker post for Gypsies and Travellers across Co. Durham.
- Appointment of two health trainers for the Gypsy and Traveller communities and preferably to be recruited from the communities.
- Provision of cultural awareness training for local authority, health service and voluntary sector staff who may have contact with or provide services for Gypsy and Travellers in their work.
- Production of culturally relevant health promotion resources.

# • Evaluation Aims and Approach

In accordance with recommended good practice this independent evaluation was commissioned to assess the effectiveness of the programme from the start of the project. The aims and objectives of the evaluation, in accordance with the evaluation contract, were:

# **Evaluation** aims

- > To evaluate the effectiveness and economy of the interventions
- > To explore barriers and facilitators for adoption and development of the intervention.
- > To develop capacity building through the evaluation process
- To describe any added value of the intervention compared to pre-existing service delivery

# **Objectives**

- To work in partnership with a project steering group to determine desired short term and long term outcomes for the intervention.
- To work in partnership with the project steering group to develop appropriate indicators of success.
- To train and work with local community evaluators and meet regularly with the steering group to involve them in a collaborative evaluation process.
- To evaluate the process of the intervention delivery to assess whether it is delivered as designed, what elements of the intervention are effective/less effective, the extent of community participation and to determine any unexpected outcomes.
- > To produce a final report of the evaluation

However, as has been the case with the relatively few independent evaluations of service improvements to Gypsy and Traveller health, the evaluation approach is largely qualitative

rather than quantitative and more concerned with process and direction of travel than being able to quantify impact by comparing measurable baseline and outcome measures. The main sources of information for the evaluation have been

- Contextual material (reports, policy documents etc)
- Evaluations of cultural awareness and GRT health needs training sessions
- Activity data collected by staff
- Recorded disease prevalence using primary care data collection (QOF)
- Interviews with Gypsies and Travellers
- Stakeholder interviews

At the beginning of the evaluation, the Director of Primary Care Development & Engagement in DDES CCG was approached to explain the project and request support with data collection and ethnic monitoring. As a result of this meeting he nominated a CCG lead for GRT health. The CCG lead (HM) is a GP and she has remained an active key lead during the evaluation period. A lead was also identified in North Durham CCG but there has been less continuity, with 2 successive leads retiring. The current lead there is also a GP (DS) and has been in place since May 2015, but had taken an interest prior to that as CCG chair. An initial project steering group was convened comprising a wide range of key stakeholders, but subsequently, the working steering group, which met regularly, comprised each CCG lead for GRT health, the Public Health consultant lead for GRT, the Public Health lead for Capacity Building and Health Trainers, the GRT public health nurse, the line manager for the GRT health trainers and the independent evaluator.

#### • Outline of the Report

Chapter 2 reports on the training sessions on cultural awareness and health needs of GRT Chapter 3 reports on the development, role and impact of GRT Health Trainer element Chapter 4 reports on the development, role and impact of the GRT Public Health nurse Chapter 5 reports on the wider partnership and joint working of the GRT health team Chapter 6 reports on the progress of production of culturally relevant health information Chapter 7 reports on the comparative health data Chapter 8 provides the Gypsy and Traveller perspective Chapter 9 provides the wider Stakeholder perspective Chapter 10 summarises main findings and added value of the programme plus lessons learned and recommendations for future development.

# CHAPTER 2

# CULTURAL COMPETENCY TRAINING

## **Cultural competency - improving access to health care services**

Although addressing social determinants of health such as the living environment and educational attainment are of significant importance, there are many factors that are less easy to address at a local level and which are indicated in the poorer health of Gypsies and Travellers.

The GRT health status study 2004 demonstrated clearly that one of the key determinants of health for Gypsies and Travellers was their poor access to health care services.



Figure 3 Social Determinants of Health

One of several different reasons most often given, both in that study and in the Durham and Darlington HNA was the lack of cultural awareness or cultural competence of health staff: a common quote being *"need to know more about Gypsy ways and understand our culture."* 

Consequently, one of the recommendations in the County Durham and Darlington HNA was to provide cultural awareness training.

Objective H1 in the GRT Strategic Action Plan under the aim of improving access to health services was to:

Provide cultural awareness training sessions to health and social care staff. The issue of lack of cultural awareness and sensitivity is a barrier that has been identified to health seeking behaviour. This is a contributory factor to late diagnosis and treatment.

However, it is important to go further than cultural awareness as this is only a preliminary step in the development of cultural competency of all staff. This is acknowledged in the 'Standards for Commissioners and Service Providers'<sup>14</sup> with reference to 'DH guidelines on developing cultural competence of health professionals working with GRT communities'<sup>21</sup> Francis clarifies the purpose and definition of cultural competence, with reference to Hawes who championed the case for cultural competence training in 1997, by advocating that *training must address the misunderstanding, barriers and hostilities that persist in the delivery of health care, if appropriate services for excluded and marginalised communities are to be developed. (p12).* 

Much has been written about what cultural competency entails and the diagram in Figure 4 describes some accepted key features.

Richard O' Neill, a charismatic Gypsy with his family roots in the North East and highly rated for effective and engaging work in cultural awareness /competency training, was commissioned to deliver half day cultural competency workshops, on 'Health Needs of Gypsy, Roma and Traveller (GRT) Communities in County Durham.' These were held in different venues across county Durham for health and social care staff and the aims and objectives of the workshops contained several of the key features of cultural competency as described in Figure 4

<sup>&</sup>lt;sup>21</sup> Francis (2010) Developing the cultural competence of health professionals working with Gypsy Travellers



Fig 4. Key features of cultural competence (Saha 2008)

# Cultural competency workshops by Richard O'Neill

# • Aims and Objectives

Aims

- To equip health and social care staff with an awareness and understanding of issues related to Gypsy Traveller communities.
- To give participants an understanding of the cultural needs and legislative duties in relation to these communities.
- To provide participants with practical ideas to help to improve their services to these communities.

# **Objectives**

- > At the end of the workshop participants will be able to:
- Demonstrate an understanding of the cultural issues surrounding Gypsy Traveller communities.
- Explain and understand the difficulties encountered by Gypsy Traveller communities in accessing health and social care.
- Explore examples of good practice and what can work in relation to improving communication with Gypsy Traveller communities.

The workshops were advertised through DCC, and NHS services in county Durham for health and social care staff, Police staff and social housing providers to attend as in- service training. They were quickly oversubscribed. A total of 14 x 3hour sessions between May 2014 and January 2015 were delivered to health and social care staff and others with a role in service delivery to GRT community members. Two further 90 minute sessions were also delivered to 15 Elected Members.



Figure 5 Richard O'Neill delivering a cultural competency workshop

# • Initial Evaluation Findings

Evaluation forms (see appendix ii) were completed by 274 of the 289 workshop participants although some data is missing due to 4 sessions having incomplete forms with some questions inadvertently omitted.

#### • Services and Job roles represented

Just under two thirds of the participants were health and social care staff and staff from health related voluntary sector organisations (151), including health visitors, school nurses, maternity staff, hospital nurses, mental health staff, social workers, family support workers, health improvement practitioners, NHS chaplains, occupational therapists , ambulance service, Cruse bereavement organisation staff, health trainers and public health staff . Most of these services are under-represented however, and there is scope for further training to reach a wider number and range of staff, as the roles of all these staff disciplines will potentially involve service delivery to GRT patients / clients.

#### • Respondents' extent of direct work related contact with GRT

To understand how relevant this workshop was to participants we were interested in knowing the extent to which they had direct contact with GRT in their work. Approximately 25% had not knowingly had any direct contact, although for a few of these (e.g. public health staff) their work did not involve direct patient/ client contact. Others however may well have had some direct contact with GRT but because of GRT reluctance to disclose their identity they would be unaware. Others may potentially have GRT patients /clients but there may be reluctance on the part of GRT to access services as they might be seen as irrelevant (e.g. health improvement trainers) or they might only do so if absolutely necessary or in crisis e.g. social services, mental health services. Over half of respondents reported that they had 'Infrequent' direct contact, although in some cases this might be also due to the nature of their service as well as for the reasons previously stated. 39 respondents reported 'Frequent' direct contact but these included the GRT team and GRT health trainer.

• Respondents prior self-rated understanding of GRT cultural and health needs As might be expected, given that most respondents had infrequent prior direct work- related contact with GRT, roughly half (131) rated their prior understanding of GRT cultural and health needs as 'Very Limited.' 79 respondents rated their prior understanding as 'Fair', 37 as 'Good', and only 11 rated it as 'Very Good'.

#### • Workshop outcomes

Richard engaged the respondents extremely well and encouraged them to feel at ease from the beginning with a round to give each a chance to speak about their roles and state what

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they were hoping for from the course. Respondents were asked to rate the trainer in terms of knowledge, response to questions, encouragement of participation, enthusiasm and delivery. All but two rated him as 'Very Good' or 'Good' on each of these criteria. A range of questions on the evaluation forms were asked about the course with regard to how well the objectives were stated and extent to which they were met, pace, level, length and method of delivery of the workshop. With only two exceptions, respondents rated the workshop according to these criteria as 'Very Good' or 'Good'.

The range of positive comments are summed up in this collation of comments from the Elected Members

Very useful / more informative / excellent seminar - presenter was excellent / useful revision and consolidation of knowledge and experience / interesting and has enhanced my knowledge and interest in finding out more/found out what is right and what is wrong in law.

The main suggested improvements to the workshop were for it to be longer than a half day with specific suggestions for further time spent on exploring customs, religious needs, practical issues for delivery of services and to explore more 'issues' (not specified). The decision to limit the workshops to 3 hours was to ensure that a maximum number of a large pool of relevant staff could attend a workshop, but the following comment illustrates the feelings of many who felt that it was too short:

"scratching the surface in the time available and raises more questions than answers; I think this is a good thing because it fuels curiosity."

From these evaluation forms, completed at the end of the workshop, it certainly appears that the aims and objectives of the course were largely met. However the limitations of relying on an immediate evaluation at the end of the workshop is that we cannot know how this translates into work practice and whether services for GRT will be made more accessible, culturally acceptable, and relevant.

In the early sessions course participants were asked to get into small groups to think of ideas to improve service provision. This didn't continue in later groups and we only have two documented ideas:

- 1. A pictorial sign depicting half caravan and half house to indicate that the service applies to all, with contact details, phone numbers and photos of service providers
- 2. A practitioner group to share work practice and avoid overlap

One respondent's comment, under the heading of suggested improvements to the course, illustrates recognition of the need to go beyond cultural awareness and imparting of information if the aim of cultural competence is to be achieved:

"Something around challenging values, attitudes and beliefs as a starting point; knowledge is important and will influence views, attitudes and beliefs but I would argue this may not have the most immediate impact"

# • Follow up evaluation findings

In July 2015 (14 months after the first sessions and 6 months after the last ones) a follow up questionnaire with 10 short questions (see appendix iii) was sent to the 209 respondents who provided contact details with an email address.

Although several of these email addresses were no longer valid, 60 (28%) completed responses were received over a period of 3 months, which included a reminder after 6 weeks. Although this is only 21% of the total number who attended the training sessions, this is considered a good response rate, especially when the high turnover of staff is taken into account.

Nearly half of these respondents (45%) worked in health related roles; these included staff from community health, public health, hospital nurses, mental health nurses, occupational therapists, learning disabilities, hospital chaplains and health improvement practitioners. The remainder were mainly from social care or housing service providers.

• Level of work related contact with Gypsies and Travellers

Over 75% of those responding either had no known direct work related contact or their level of contact was less than monthly. However, some of these worked either in commissioning or managing services. Some of these services would not be aware of how many of their clients

were Gypsies and Travellers due to lack of ethnic monitoring or reluctance by Gypsies and Travellers to self- ascribe. Just 10% had at least weekly contact.

• Extent to which workshop benefitted work practice

The large majority of respondents (84%) reported that the workshop met their work related needs fully or to a large extent, with only 8% reporting to have learnt nothing new to help them in their work. Most of these gave examples that referred to increased understanding and awareness of culture and needs, and increased confidence:

*"it has made me more aware of their culture and helped me to support staff who are working on Gypsy Traveller sites"* Children's Centre leader

"increased my understanding of their culture and issues for the community and increased my confidence in addressing discrimination" Chaplain in Mental Health Services

*"increased awareness of specific cultural attitudes and awareness of specific health needs . It has helped with some myth busting"* GP

"I've not worked with any Gypsies and Travellers since the workshop but I feel more confident to do so" Occupational Therapist

"better understanding and confidence to discuss ethnicity" Think Family Practitioner

"changed my outlook" Social Work assistant

Just one respondent, a social worker, gave a negative comment about the relevance of the training and referred specifically to the financial situation faced by the council, questioning this training as a priority

"I feel due to the current financial crisis of the council that a workshop on Gypsies and Travellers is the least of its worries " Although only 284 people attended a training session, 82% of respondents had shared knowledge gained from the training with at least 2 colleagues, and in a high number of cases (38%) with their wider team.

• Implemented changes

Very few respondents reported any specific changes to their service provision and most explanations for this were on the lines of their service already being satisfactory.

No we did not feel that any changes were required because access and cultural acceptability were already satisfactory. Social Worker in Learning Disability team

However the Gypsy Sites Manager had implemented the suggested idea of a Practitioners group

Partnership Working (Practitioners Group set up as a result)<sup>\*22</sup> and Improved services for residents (Better joined up working) Gypsy Sites Manager

• Limitations and suggestions for improvement

Few suggested improvements were made that differed from those in the initial evaluation survey. There was a desire for handouts of the presentations and of contacts and links that could be made. Some also wanted examples of services that have worked well and of common pitfalls.

The earlier points that the workshop did not do more than raise awareness and had no specific health focus were repeated but with acknowledgement that to push boundaries on attitudes or to address health and social care in more depth would need more time or separate workshops.

In an attempt to see if there were any further or sustained changes to work practice after a 2 year interval a further short survey was sent to a random 20 people from the attendance lists with valid emails at the first follow up. There were just four questions:

<sup>&</sup>lt;sup>22</sup> see chapter 5 for further detail about the practitioners group

1. Approximately how much contact have you had with Gypsy and Traveller patients/ clients in your work since the training session?

2. Is there anything from the training that particularly helped or changed your work practice?

3. Have you been aware of the role of the Gypsy and Traveller health nurse (Bernie Crooks) and the health trainers?

4. Have you had a need or do you envisage a possible future need to refer to or liaise with the Gypsy and Traveller health nurse for advice or support for your patients/ clients?

Most of the emails bounced from the 20 that were randomly sampled, suggesting that further staff were no longer in post. Comments from the three people did respond were encouraging:

From the training I found understanding about the cultural aspects of having mental health issues invaluable. It has allowed me to adapt the language I use and approach to addressing and supporting mental health issues.

It was also important to understand about eye contact from male members of the community and about females requiring chaperoning.

Community Nurse Lead Child and Adolescent Mental Health Services (CAMHS)

I found the training very good, I gained a much clearer understanding of the culture of the travelling community. I remember many parts of it as the trainer was excellent. He asked us where we had previously gained our knowledge of Gypsies from; many of us said "my big fat Gypsy wedding" and he alerted us to the fact that Gypsies find out about our culture by watching Jeremy Kyle!!! I have repeated this many times. I am now also aware of accepting a cup of tea, I had previously refused.

**Community Psychiatric Nurse** 

Since [the workshop] I personally have had no contact with Gypsy and Traveller clients however we do have 3 Gypsy Traveller clients registered as lead tenants in our properties..... but our Community Co-ordinators who work with tenants in specific areas may in the future need to refer or seek advice.

Involvement & Inclusion Advisor for a Homes and Communities organisation

In addition, a few service providers were interviewed as part of the 2 year evaluation and two of these had attended the half day training sessions and spoke of the positive impact on their work practice

I wouldn't have had the insight on how to approach them, their culture you know, it is one of the better training courses I ever experienced and I do a lot of training in my line of work. I told the others you want to get on that, it is really good it is really useful. Most of my colleagues actually attended. One of my colleagues upstairs she attended the training and said she found it helpful. (Child protection social worker)

I have to say I have less phone calls from going in Darlington than elsewhere saying "we've got a Traveller, what do we do" kind of thing. So did you get a lot of that before? Well I got some of that ... What sort of things were they asking? Well sort of how to behave but I think the training was helpful to them and I found it helpful even though I knew quite a lot, it helped me to know that what I knew I knew so I felt more confident advising people about certain things. I think the gender rules of things we need to get most right because if you get those wrong at the beginning you are stuffed basically...But also I think people, staff that is, have anxiety because of what they see in the media and there's an unconscious bias about the Travelling community and because Richard was so not the stereotype, that in itself was helpful. Because if all you know is what you see on the TV and then all you meet is the people with mental health problems then they are not going to have a positive image of the community. We've put the training in our E bulletin and really encourage people to go. That is a very very good training. (Equality & Diversity lead TEWV)

#### **Training for Primary Care staff**

In June 2014, PVC (report author) arranged with the DDES CCG to hold an awarenessraising session at the forthcoming Time Out (Protected Learning Time) training half day. This 'Time Out' half day was open to practice managers, key office staff, GPs and nurse practitioners. The GRT awareness session was one of a choice of concurrent sessions, so the CCG lead (HM) encouraged a member of staff from each practice to attend. The awareness- raising session covered the background need for, and purpose of, the DCC GRT health improvement project and gave an opportunity for discussion and questions about

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practice involvement. A practice manager and/or a GP from 8 different DDES practices attended and each of the practices identified someone to be the lead contact. The contacts at these practices were subsequently visited by PVC. It had been envisaged at this time that the GRT public health nurse would shortly be recruited and staff were informed that she would then be an important link for the practices. The delay in this appointment coming to fruition meant a loss of momentum in keeping the practices engaged and involved.

As primary care staff experience the greatest difficulty in attending external training sessions, bespoke training with a primary care focus was offered to practices at one of their 'Time In' training sessions.

One practice took up this offer in September 2014, and the training was jointly delivered by Richard O'Neill and PVC, along with MC a trained nurse who is also a community member.

MC had attended one of Richard's training sessions, out of her interest both as a Gypsy from Darlington and as a hospital ward sister in the local hospital. As a result of attending the training session she was keen to become involved in further training as she found that she was often called upon by other hospital ward staff where she worked whenever they had any difficulties with Gypsy and Traveller patients.

17 nurses, reception and admin staff attended the 2 hour session but only 8 evaluation forms were received. These were completed a few days after the session and not all were fully completed. Of these only the practice manager, deputy practice manager, a practice nurse and an apprentice filled in their job titles. All four of these staff rated the session as very good or good, found it useful for their work practice, and would recommend it to others.

However only three practices, all in DDES, availed of the opportunity. The CCG lead in North Durham CCG explained the lack of uptake

Giving them the opportunity to access the training for instance is difficult for practices; it's a particularly a bad time to ask people to commit to time resources, to do anything other than get through their day to day work. It is a bit of a struggle even for practices who have not previously had a problem with recruiting staff, or doctors or nurses. It makes me slightly reticent about asking anything from them because I know in talking to some of my colleagues just how close to the edge some of them are.

To reach a greater number of primary care staff it was arranged through the DDES CCG for PVC and MC to deliver training sessions at each of the locality Time Out training half days that are open to all primary care staff in each locality.

Two hour sessions were delivered in each of the 3 locality Time Out half days in March, April and May 2015 At two of these Time Out days the GRT training session was one of a choice of concurrent sessions, but the session in May 2014 was a keynote session for all to attend and so reached a much larger audience.

There are no evaluations available for these sessions but each resulted in several questions and discussion, with some verbal positive feedback about the usefulness of the training.

At the final evaluation interviews with a sample of primary care staff, a few had attended the protected learning 'Time Out 'training sessions or had staff in their practice that had attended. One practice explained that they had acted on the knowledge that they'd gained

a couple of our staff went and fed back from that session and then we talked about having health checks done on that cohort of patients and recording them and we have been doing that. We are trying to do annual health checks and we have a register of patients coded to be G and T patients. So has there been a more deliberate effort to ask those that you knew but haven't previously been coded to ask them if they were happy to be coded as Gypsies or Irish Travellers. Practice Manager

However, for most practices, the selected staff interviewed had either not attended the training sessions or had not made any specific changes. They explained that the pressures and demands of general practice on their time meant that the topic of improving Gypsy and Traveller health and access to health care would not necessarily remain high on their agenda:

I am sure the clinical team did go at the time when Gypsies and Travellers were being raised as a priority. No, I can't remember (any feedback from the Time Out), but you've got to bear in mind we do get a lot of training that we have brought back and discussed at a clinical meeting. We have about 48 clinical meetings a year and there is a priority every week when something or some group is discussed so I will say it will be out there and there will be an awareness, but probably no greater awareness than the latest diabetes or foot care, paediatric. The big drive we have got is to try to keep elderly out of hospital. A lot of our Time In sessions are dedicated to that. Practice Manager

This is not to say that individual staff members who attended did not benefit even though they may not have felt a need to change anything in practice. Staff found it particularly useful to be able to ask questions of a community member about her experience.

it was good because we went over different things, and some services don't have as many different Travellers as we do but it was good, but it was what we were doing as well anyway... it was good that Michelle came and we obviously asked questions of her because obviously she is from the community, it was good to hear from her side of things. Practice Nurse

It was not possible to arrange to deliver similar training at any Time Out sessions in North Durham CCG but a training session was delivered by PVC to Practice Nurses at one of their Time Out meetings in November 2014. This was a short slot and made shorter with time being taken to try to fix the technology in order to use the slide projector. The meeting was well attended, and staff were encouraged to invite their practices to avail of the offer of lunch time practice- based training sessions but this offer was never taken up.

# In summary

- 289 staff from a wide range of disciplines attended 14 half day workshops
- 15 Elected Members attended two separate training sessions
- Most participants shared their increased knowledge and awareness with colleagues and their wider team.
- All training sessions evaluated very well in terms of learning about GRT culture, cultural issues and their culturally relevant health needs.
- Participants reported increased confidence in working with GRT communities or individuals.
- Participants reported and increased awareness of the impact of discrimination and prejudice experienced by GRT and felt more confident to addressing discrimination.
- Some staff and staff groups implemented changes to work practice as a result of the training
- The community member input was invaluable but a community member also needs the support to deliver training sessions if previously unused to doing so.
- More interactive input on service improvement and examples of good practice would be a beneficial component of training sessions, plus handouts that include further reading and useful contacts
- It would better to have separate training that focussed on culture and health needs provided for all primary health care staff in general practice and community health bases rather than trying to cover health issues more superficially in general sessions for wider staff disciplines.
- Many current staff did not have the opportunity to attend any training sessions so a rolling programme of training is required due to high staff turnover and number able to attend.
- Some prioritisation of attendees in the general sessions is required to ensure that the widest number of staff groups/ teams get the opportunity to attend and to reserve these sessions for non- primary health care staff
- Further training aimed at informing attitudes and beliefs to improve cultural competence would require longer time but may not necessarily attract the staff who most required it to attend those sessions.

#### **CHAPTER 3**

# DEVELOPMENT, ROLE AND IMPACT OF GRT HEALTH TRAINERS

# **Background to Health Trainer Service**

Health Trainer services were originally introduced nationally in 2004 .Its core goals included reaching out to the most deprived communities, supporting healthy lifestyle changes and ultimately, reducing avoidable illness and tackling health inequalities<sup>23</sup>. This has remained the core element of health trainer services but with variation and diversity according to local needs.

The Health Trainer service was delivered in County Durham by a leading third sector organisation, The Pioneering Care Partnership (PCP), with a focus on health improvement and reducing health inequalities through building capacity and life chances with disadvantaged communities.

PCP was commissioned by Durham County Council to integrate the Health Trainer model across the six Gypsy and Traveller sites across County Durham. The original aims were:

- To recruit and train two Health Trainers in County Durham, ideally, if possible, from the GRT community
- To recruit and train 15 Health Trainer Champions (volunteers) from the GRT community in County Durham
- To engage with 120 clients on a 1-2-1 basis by a Health Trainer over an 8-10 week intervention

Although the ideal is to recruit health trainers from within their own communities, the lack of prior community engagement and engendered trust meant that it was not feasible to recruit and then to train community members in time to work closely with the appointed project health visitor within the initial 2 year project timetable. It was therefore decided to stagger the two appointments and initially to appoint one Health Trainer, already undergoing training, but who would undertake additional cultural awareness training and orientation to the GRT communities.

<sup>&</sup>lt;sup>23</sup> DCRS (2015) Indicators of change The adaption of the health trainer service in England

## Health Trainer (CG) training, orientation and GRT engagement

The first Health Trainer (CG) was recruited in February 2014 as a trainee and she completed her training to achieve the City & Guilds Level 3 Health Trainer Award that summer.

As part of the evaluation she kept a reflective diary. Although she was keen to take up the post as a Health Trainer for Gypsies and Travellers, she admitted some initial apprehension. This is not at all atypical of those who are honest about their views and fears of the unknown arising from a limited stereotypical knowledge of Gypsies and Travellers, which is mostly via negative media portrayal. She reflected that her prior 'knowledge' of Gypsies and Travellers was mainly gained from watching the TV programme 'Big Fat Gypsy Wedding.'

However as part of her training specific to working with the GRT communities she diligently read and absorbed information from many resources which were given to her about GRT communities and their health. In May she and her then manager attended an external Cultural Awareness Training day delivered by Leeds GATE a GRT organisation. She found this very useful and it complemented much of what she had read from GRT literature given to her:

"It was excellent to hear first-hand about their experiences and life in a Travelling community. It also made me realise that the majority of the GRT community are not as bad as they are made out to be and are always subject to negative press because of the minority. It was also interesting to hear about the discrimination they were, and still are, subjected to and the inequalities that are still prevalent, simply because of lack of understanding and negative press and perceptions."

However it was 6 weeks later, on 20<sup>th</sup> June, when she attended the DCC half day workshop delivered by Richard O'Neill, before she was able to completely dispel lingering stereotypical views of the GRT population:

"We did not realise until about half way through the course when he started talking about his life and where he was born and grew up etc. I couldn't believe it! Here was a well dressed, obviously well- educated man with 2 daughters with a university education, who was passionate about his culture and in particular the health inequalities the people of his culture are suffering from. I surprised myself a little that I still had this perception of what a Gypsy/Traveller would be like i.e.-someone who was uneducated, intimidating and didn't want any help from services outside their community, even after the training I had received. I learnt from the course not to judge, and to go into sites with an open mind as not all Gypsies and Travellers are what you perceive them to be. Richard himself is an excellent example of that."

CG's orientation to the GRT communities was facilitated by AG, the GRT officer for the DCC owned GRT caravan sites, who accompanied CG and introduced her to residents on two of the six sites (Site A and Site B). The other four sites had been closed for refurbishment. She also accompanied ER, the GRT officer for unauthorised encampments, to some of the temporary sites.

Engagement with GRT residents on any of the sites would be expected to be slow in terms of uptake of services, particularly services being offered by staff previously unknown to them. It's common for apparent enthusiasm for services or activities, even when initially offered by known and trusted workers, to be followed by poor attendance when the activities or services are provided, particularly if being provided by unfamiliar and therefore untrusted staff. This is not unique to GRT residents on sites in County Durham. It is a familiar experience to those providing services to people in marginalised communities and was highlighted by the Health Improvement team in County Durham, who had previously been commissioned to develop and deliver programmes to GRT communities.

There were additional difficulties in the first months of the project, with sites being closed for refurbishment. As the sites re- opened residents had much to deal with in relation to moving in. There were also tensions which hindered engagement on one of the sites that had been refurbished much earlier, related to the sudden high increase in rent and some of the residents taking the council to court. Furthermore DISC had previously invited a generic health trainer to a couple of the sites to conduct health checks and so it would have appeared as if this was just another new person offering another temporary initiative.

Although CG was given reassurance that slow engagement and uptake of services was to be expected it was not easy for her in the early months, despite her positive attitude and perseverance. She reflected at the end of August:

"It is becoming apparent that it is going to be very difficult to engage with residents at [Site A], but we can't force anyone to engage. It is disappointing but I need to try to remain positive."

From the beginning the target, of engaging with 120 GRT clients on a one to one basis over an 8-10 week intervention, appeared highly unrealistic and placed undue pressure on the health trainers; the target was subsequently modified.

## **Recruitment of second GRT Health Trainer (MT)**

During the first six months in post CG worked part time with the GRT community and part time on wider health trainer projects with a generic health trainer colleague. During this time there had been a few changes of line manager and programme manager, and although one of them also attended the cultural awareness workshop, others had less understanding of the challenges faced by GRT and why it was hard for many to be motivated to engage in lifestyle change activity in response to someone unknown to them from outside of their community. CGs role in this respect was made harder by unrealistic target setting at this early stage. She reflected in December: *"have been coming under quite a lot of pressure recently as to why we haven't been hitting targets"*. She had been set a target of engaging with 60 residents in her first six months but had engaged with 20, which given the circumstances was a good achievement. She had carried out 10 health checks and was working one to one with one resident who wanted to increase her physical activity. Her subsequent manager accompanied her on a site visit and was shown round by the GRT officer. This opportunity gave a better understanding with consequent relaxation in expectations.

In November 2014 recruitment commenced for a second part time (16 hours per week) health trainer. The job was advertised as a trainee post with the successful applicant being required to achieve the City & Guilds Level 3 Health Trainer Award.

Although it was hoped that a member of the GRT community would apply and be successful, the essential requirements for the post did not specify any requirement for knowledge or experience of the GRT community. The advert (see appendix iv) was circulated by word of mouth on the GRT sites and one resident (MT) applied.

Of the nine applicants, MT was the only member of the GRT community. She already had her level 3 Health and Social care qualification and six years' experience working in the care sector, and, in addition, at interview she demonstrated enthusiasm and aptitude for the role as well as having excellent communication skills. These assets along with understanding the needs of her own community and why they have poor access to health care, equipped her well to work with CG as an effective team.

MT commenced her training on January 19th 2015 but started her Health Trainer course in March. Meanwhile she accompanied CG to her sessions on sites and also to meetings with other service providers, particularly those with specific services to the GRT community. She also undertook other short courses so that she was also qualified to carry out Check 4 Life checks. Between them, CG and MT became qualified as a Walk leader, a Cycle leader, a level 2 Stop Smoking instructor, a Practical Cookery instructor and an Exercise to Music leader.

### **GRT Health Trainer Activity**

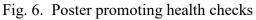
## **Check4 Life health checks**

In addition to engaging with clients to deliver health improvement interventions the Health Trainers had a remit to deliver Check4Life health tests (NHS health checks). In 2009 NHS health checks were introduced for eligible adults i.e. those without existing heart disease, diabetes or kidney disease, and who are between the ages of 40 and 74. They receive an invitation to attend every five years. The aim is to measure the risk of developing these health conditions and to offer preventative advice. Initially these checks were delivered mainly in GP practices across the country but in 2011-12 only 54% of eligible adults attended for a check.

Provision of the checks by GP practices varied widely in County Durham. With the aim of reaching those who wouldn't otherwise take up health checks, it was decided to complement the GP practice-based Health Check screening programme with a rebranded Check4 Life screening. The nationwide 'Change4Life' campaign was utilised and its logo was incorporated in promotional literature.

Check 4 Life is delivered in community settings by health trainers and targets specific areas and groups who are at high risk. The reports are sent automatically to the GP practice, with high risk patients flagged up. To complement this work Mini M.O.T checks are also offered to adults between the ages of 16 and 39 years. An important component of the Check 4 Life screening is the explanation of results and an opportunity to discuss relevant lifestyle changes. CG and MT are both trained to deliver these checks and mini MOTs and to offer tailored advice to all eligible adults on the GRT sites. Posters were displayed on the community buildings.





# Drop-in sessions and health promoting group activities

In the early weeks CG had built good relationships with the site wardens and also introduced herself by going door to door with the GRT officer, making enquiries about what activities they would like. By the end of the first six months she was holding regular Drop in sessions on two sites and was continuing to engage and build trust with residents on the other three sites that were open. CG also set up a Twitter account. Although this was not well used, she simultaneously she set up a Facebook page, with the added benefit of being able to post health tips, recipes and notifications of events to increasing numbers using social media. Use of her Facebook page was initially slow but when MT took up her post she linked her page to MTs and because of her higher number of Facebook contacts from within the community their page, tagged to MTs, is visited much more frequently.



Fig. 7. Facebook page

The Facebook pages also had the added benefit of reaching more housed community members. MT has had clients who have referred themselves for support for exercise as a result of the posts she has put on about her personal training classes.

Initially all those who attended the Drop Ins agreed to a health assessment using a detailed questionnaire. However the questionnaire included some questions about certain health issues that would be too sensitive to be answered and which would not be appropriate to discuss in a drop in setting. Use of this questionnaire was discontinued as its value was questioned. Those who did attend the drop in sessions took advantage of having Check 4 Life health checks and following consultation with residents who completed the questionnaires, the first group activities took place.

As Zumba was the most popular choice on site E this was first offered as a free course at a local community hall with an external instructor. This was fraught with poor attendance on most weeks but the few who did attend regularly felt they had benefitted.

Residents who had attended were then offered their second most popular choice of a boxercise class with a small cost to cover room hire. This activity, although requested, had even poorer attendance and the remainder of the classes were cancelled after no one turned up in the third week.



Fig 8. Poster promoting consultation on health related activities

No further activities were arranged until both health trainers were in post and when activities could be offered on site, as the benefits to the very few who were both motivated and able to attend regular external sessions were outweighed by the cost and time involved.

The Drop In sessions were later extended to all six sites when MT was in post and when the other sites were reopened. The demographics of the residents varied on the different sites and this corresponded with varied interest in the Drop in sessions. Site C Way is the site that MT lives on and may partly explain why this has been the most successful site to date for uptake of health related group activities, although this site also has the greatest numbers of younger residents and families with young children.

At the request of some residents who want to increase their exercise level, MT and CG started to run a weekly Walking group. Although they needed to knock on doors each week to remind them of the walk, there were several regular attenders.



Fig 9. Health Trainer Walking Group at site C Summer 2015

This activity was initially popular as they were able to bring the young children with them. By winter however the group were less inclined to continue and the walking group did not get re- established, although some individuals did continue to walk more without the support of the group. There are plans to start the group on site C again this summer and its expected that attendance will again be good.

Group dynamics among residents on the other sites meant that it was harder to engage residents in group activities at all; for example when it was suggested to the site manager on Tower Road site that they could put on a 'Feel Well Be Well' course for 6 weeks so that residents could do a taster session of all the activities they had expressed an interest in, they were dissuaded. The varied attendance and interest in group activities also correlated with the interest and support of the different site managers, who to some extent were seen as 'leaders.' The managers on three of the sites initially showed marked reluctance to engage with the health trainers and did not actively support their service. Over the course of the first couple of years two of these managers have become much more supportive and one of them has recently signed up to the service herself. The Drum Lane site in the north of the county remains a site where it is more difficult to engage. This illustrates the need to allow a long period to become known and visible, and to build relationships before any realistic expectation of achieving high targets.

Up until the summer of 2015, the first full year since the health trainer project commenced, the main focus of health trainer activity was on seeing residents on an individual basis at the weekly drop ins; conducting health checks and delivering health interventions over a 8- 12 week period. 22 clients from five of the sites had a health check but others were ineligible by virtue of age, existing conditions or having had a health check within 5 years. Of the 22 clients who did receive a health check and were found to have risk factors for heart disease or stroke, not all felt ready to accept offered health trainer support at that stage.

## Health trainer interventions to support health behaviour change

The recommended maximum period of contact with a health trainer to offer personalised support, including the initial assessment, is 8-12 weeks. In the first full year 22 clients from four of the sites engaged in a health intervention for part or all of an 8- 12 week period. Some of these sought support as a result of their health check but others self-referred for advice and support, usually specifically to lose weight or to start regular exercise to become fitter.

Although the numbers appear small, it must be taken into account that this was the first year with challenges to engagement, for most of that year there was only one health trainer, previously unknown to the communities, and only three sites were open initially. This was

therefore a promising start. The positive impact on the wider family of one person engaging, particularly a mother, must also be considered, as illustrated in Figure 10 case study, when other family members start to engage in healthy activity as a result.

CG reflected on her first year and how they had gradually began to get improved uptake of the service; she realised the difference it had made to have MT as a member of the GRT community in post:

I honestly do believe this is because of MT. She has the trust and the knowledge of the best ways of how to engage with the Traveller community, something I was never going to achieve overnight. And because of this, the community are starting to trust me more as well. I believe the only way is up from here and I am sure we can make this project a success.



Leanda with MT, health trainer

Leanda lives at site A near Bishop Auckland. She heard about the GRT Health Trainer Service through Sure Start, who hold a weekly playgroup session in the community building on the site, which Leanda attends with her son. She wanted support with weight loss.

Leanda's weight has been up and down over the years and she was not sure the best way to go about losing it. Since completing her Health Trainer intervention she is eating more healthily, including more fruit and vegetables. She has also started swimming once a week and makes the effort to go walking more.

She felt that the advice and support she received from the health trainers was the best part of the service and it has encouraged her to make the changes she has made permanent. She also feels that the service has benefitted her family, who come swimming and walking with her.

She believes the service could be improved if the Health Trainers were able to offer support for longer than 12 weeks. Leanda still attends the drop in every week to get weighed and to seek advice and support from the Health Trainers.

Fig 10. Case Study Leanda during a session with Health Trainer MT

MT concurs that being a member of the GRT community has made a big difference to engagement but that even when she first took up her post, the uptake of services was slow and gradual. New clients are now self- referring that hadn't done previously and MT puts this down to people *'waiting to see how it goes and if we'll stick around'*; such is the low expectation due to experience of short term projects and changing faces.

Georgia is a housed Traveller living in Bishop Auckland. She heard about the GRT Health Trainer Service though GRT Specialist Nurse, Bernie Crooks. She joined the service for advice and support with weight loss and healthy eating.

Georgia had put on a lot of weight during her pregnancy and was struggling to lose it. She was feeling very low about herself and her appearance and did not feel selfconfident. She also was not sure what she needed to do in order to lose weight.

Since engaging with the service, she feels a little more confident about herself. She also made significant changes to her eating habits, such as introducing more water and fruit into her diet, and making sure she eats breakfast every morning. She is also trying to walk as much as possible and was signposted to GRT Health Trainer, Michaela Tyers for 1:1 fitness sessions.



Georgia showcasing some of the changes she has made to her diet

Georgia thought the best thing about the Health Trainer service was the fact that the health trainers could come to her house and she could have sessions in the privacy of her own home. She felt it was more private and confidential, which was important to her considering how she was feeling at the start of the intervention. She said, "I found the health trainer service really beneficial, it showed me how to make important changes to my diet."

Georgia's family also benefitted from the service. Her sister, Savannah, heard about the service through Georgia and decided she would like support with weight loss. Subsequently she is now engaging with the service and is doing very well so far!

Fig 11 Case Study Georgia

It is an added benefit to have two health trainers, with one who is from the community working with one who isn't, as MT acknowledges that there are some people who know her personally that would always prefer to see CG for that reason. It is also the case that more trust has been afforded to CG through her close association with MT who was already trusted. MTs knowledge of the wider community and word of mouth from those who have used their service has now resulted in many more referrals / requests for healthy lifestyle advice and support from GRT living on private land (sites) and those in houses, as well as increasing numbers of new referrals from the council sites.

By the end of a further year, ie mid- March 2016, the health trainers had signed up 62 clients for interventions over an 8 - 12 week period. Thirty two were from the six council sites, fourteen were from houses and two were from private sites.

The main primary goal for those seeking support was Healthy Eating (28 of the 62), with a further nine citing it as their secondary goal, and with that the associated goal to lose weight. As we know that obesity, and consequently Type 2 Diabetes, are significant problems for the GRT community, it is encouraging that increasing numbers are being motivated to address the problem. A near equal number (39) sought support to achieve increased physical activity as their primary or secondary goal. Other goals were: improved general health and wellbeing (10), smoking cessation (5), connecting with new people / reducing isolation (3), monitor blood pressure (1) and reducing alcohol intake (1). Some additional benefits were achieved, as in the case study below, in helping people to understand the effects of high caffeine intake through high energy drinks, commonly used among younger GRT, and to help them to decrease and finally stop using them.

16 of the 62 fully completed their course with 14 having achieved their primary goals, six more having partly achieved them, and some are still in the process at the time of this report. Given the number of life events that so often interfere, and also the travelling that many take up in the summer, this is a good achievement. Word of mouth of the success from those who have achieved their goals is helping to increase uptake. By the beginning of March 2017 the health trainers had achieved their target of 30 new clients in the year April 2016 to end of March 2017 and they have more ready to sign up.

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X is a housed Traveller. She heard about the GRT Health Trainer Service through GRT Specialist Health Nurse, Bernie Crooks. She told Bernie how she wanted support with her diet and losing weight, at which point Bernie referred her to our service. Before engaging with the service, X did not eat breakfast and was eating one or more takeaways every week. She was drinking up to three Red Bulls a day and coke through the night if she woke up. The only exercise she did was walking as she did not have time to go to any exercise classes because of her children. In terms of portion sizes, she felt she was eating a lot, usually of the wrong foods.

X has made significant changes to her lifestyle since engaging with the service. She makes an effort to eat breakfast and drinks water through the night. She rarely drinks coke or Red Bull and now does stomach toning exercises every night in the comfort of her own home, which Cat, her Health Trainer, provided her with and showed her how to do. She has cut down on the amount of takeaways she eats and only orders them now and again. She has started eating healthier snacks and has taken control of her portions. Cat also provided her with some healthy Change4Life recipes to try with her family, with the pasta carbonara being a firm family favourite. During the intervention, despite making changes to her diet, she was finding it difficult to lose weight, which was made apparent through her weekly weigh ins. She discovered it was down to some medication she was taking, which she changed at the doctors. After changing her medication, she lost weight more easily and as a result from both the intervention and the medication change, she dropped a dress size, from a size 10 to size 8!

X thought the best thing about the GRT Health Trainer Service was meeting Cat, with whom she built a good relationship, and the support she received from her. She said, "Knowing that the Health Trainer (Cat) was coming to weigh me every week kept me motivated."

X also felt her family benefitted from the service as they eat what she eats, so found the Change4Life recipes that Cat provided her with particularly useful.

Fig 12. Case study X

Most of those who have used the service would not attend public exercise facilities or groups to increase their fitness or to lose weight, partly through lack of confidence or cost but crucially for many of them because of fear of embarrassment and their culture of privacy. Being given the confidence and motivation to begin classes and to realise the benefits on a 1:1 basis has encouraged some clients to continue exercising in their home surroundings after their course finished, as in the case of Victoria below.

Victoria is a Traveller living on a private site in Bishop Auckland. She heard about the GRT Health Trainer service through friends on Ash Green Way. She wanted support with weight loss and increasing physical activity.

Victoria was particularly keen to increase her physical activity in order to in aid her weight loss, but did not want to go to a gym or exercise class. GRT Health Trainer, Michaela Tyers was able to offer her 1:1 fitness sessions in the community building on Ash Green Way, which she really enjoyed. As a result of the fitness sessions, Victoria lost weight and increased her physical activity. She also feels a lot better in herself and has more energy.



Victoria (left), GRT Health Trainer Michaela Tyers and friend Lois Mitchell after a fitness session

Victoria thought the best thing about the Health Trainer service was having the support of the health trainer on 1:1 basis. She also liked the fact that Michaela could come to her and that she could do the fitness sessions in her own surroundings. She also believes that her family are also eating more healthily as a result of the intervention. She said, "I thought the service was fantastic, but I wish I could have more than 12 sessions."

Victoria still sees Cat and Michaela on a regular basis and comes to the drop in on Ash Green Way to get weighed. She is also keeping up her fitness sessions.

Fig 13 Case study - Victoria

# Health campaigns

One of the targets for the health trainers for the past year was to promote 8 public health campaigns over the year. PCP have funded the provision of notice boards in each community building on the six council sites so that health promotion posters can be displayed. The campaigns are chosen on a monthly basis from the calendar of national campaigns organised by Public Health England and the aim is to make them as interactive as possible. For example in January 2017, the chosen campaign was 'Dry January', and the health trainers made 'mocktails' to raise awareness and promote non- alcoholic drinks.

Mental ill-health is both a disproportionate cause of ill health among GRT communities but also a subject that is kept secret by many. In February the health trainers used the national Time to Talk Day campaign, aimed at breaking the silence about mental health, to hold coffee mornings on the sites for this purpose. In March, there were two campaigns. One was to mark National Stop Smoking day and the health trainers gave smokers the opportunity to use carbon monoxide monitors as research as shown that this is a useful aid to measure their progress.

The second campaign was much on a much more sensitive subject for GRT; cancer .Cancer is a much feared condition that many GRT are averse to discussing on any level. However for the past 3 years the Macmillan charity has raised awareness by having a presence with their mobile van at Appleby Fair. Numbers visiting the van and seeking advice or support have risen each year.

Some of those interviewed for this evaluation, still see cancer as an inevitable death sentence, usually based on their experience within the community; for example:

"If you've got it, you've got it, not a lot they can do with it" (M13 age 71)

*Everyone is frightened of cancer, terrified of the word ". Some people keep it in and won't tell anyone* (F24 age 38).

However more GRT are becoming aware of the benefits of early detection, for example

I mean if anything happens like cancer, you'd want to get it treated sooner than later (F4 age 47). in recent years there's been a lot of women died of those things, that's the C word. You think "wow we got to wake up and we got to go and get it [cervical smear] done." (F16 age 24).

The health trainers put up displays on cancer awareness, highlighting prevention and focussing on two specific cancers (Fig 14)

It is hard to measure the impact of such campaigns in a short time frame, but over time it is increasingly likely that awareness raising of previously taboo health subjects will encourage people to address such health issues in their own and their families lives and with the increased possibility of earlier presentation when they are affected by those issues.



Fig.14 - Cancer awareness display

The health trainers have also taken their service to Appleby Fair to raise awareness there and generated a lot of interest, particularly with the free fruit that was given out as an alternative to the less healthy food that is generally on offer. Many showed an interest in the service and in what they aimed to achieve. They have also held stalls at local events in County Durham. Such events are an opportunity to raise awareness of their service.



Fig 15. Health campaigns at Appleby Fair and local shows

# **Health Champions**

When the GRT health trainer service began in 2014 one of the original aims was also to recruit 15 Health Champions from the GRT community as volunteers to support the health trainers through awareness - raising and to support them to work with individuals in the community. This was an unrealistic aim in the early years of such a project in a community that had no prior self- organised groups and poor history of engagement with health services.

One of major barriers to recruitment was the was the formality of the role and the expectation that health champions would undertake the 2 day free training to achieve the Royal Society of Public Health (RSPH) level 2 Understanding Health Improvement Award.

One health campion, Linda, the site warden on site C, was recruited in the second year. She took on responsibility for organising healthy snacks for the homework club, as an alternative to the fizzy pop, sweets and crisps that had previously been consumed. However, she had no interest in in accessing the offered training or widening her role beyond promoting the health trainer service

The target was drastically reduced downwards after the first 2 years to recruiting just two health champions. It was no longer a requirement or expectation to undertake the training although it is still offered.

In the past year two more health champions were recruited. One, Lois, is from site C where the most engagement with health trainers has taken place. She promotes the Service and helps to organise events on the site. The third health champion, Sharon, decided to become a health champion after having benefitted from the health trainer service, as described in Fig 16.

Sharon told her story at the GRT health conference in March 2017 and felt empowered by her experience. She now wants to promote the health trainer service on East Howle site where she once lived and where there is still low uptake of the service.

Neither Lois nor Linda wish to do the offered training but are enthusiastic in the level of the role of Health Champion that they are undertaking. Sharon was recruited more recently and had not yet had the opportunity to undertake the training.

From the summer of 2015, when the health trainer service was becoming more established and accepted, the GRT public health nurse was also in post and after her induction period began to work closely with them as a team. This partnership working resulted in added benefit for Gypsies and Travellers from both services, and increasing referrals for those in houses and private sites, as well as on the council owned sites. The development and impact of the partnership work will be outlined further in chapter five.



Sharon is a housed Traveller living in Fishburn. She was referred to the service by Livin, a social housing provider Sharon wanted support with racial issues so she did not feel so isolated in the "mainstream" community. She was feeling very low and depressed and the situation was exasperated by her limited mobility. She also felt very emotional because she had bottled up how she was feeling for so long and did not talk to anyone about how she was feeling.

Since engaging with the service, Sharon feels that she is now realised that she does not need anyone's permission to fit in to her community. She is more confident and is happy to let

people think that she is thick skinned, even if she does not feel it. She feels the service has given her the confidence to go out and explore her community. She has visited and plans to join the Trimdon Legacy Gym and also plans to go back to college next year to study a patisserie course, all of which her health trainer supported her to do.

Sharon thought the best thing about the Health Trainer service was the 1:1 support from someone who specialises in working with the GRT community and has an understanding of the community. Having someone to talk to was also important to her. She said, "*The health trainer service have been a massive support and help to me. I couldn't recommend it enough. It has helped my mental health, people don't appreciate how debilitating depression can be*".

Sharon's daughter and friend have also noticed a change in her and say she is more like her old self again. There are less tears and more of her old personality back!

Fig 16 Case study- Sharon

# **CHAPTER 4**

# DEVELOPMENT, ROLE AND IMPACT OF THE GRT PUBLIC HEALTH NURSE

## **Recruitment and appointment**

Public Health in DCC initiated contractual arrangements for the specialist health visitor and support posts with CDDFT, the Trust responsible for health visiting at that time, in March 2014. There were protracted negotiations over aspects of financial costs for extra cover for potential sick leave, maternity leave etc and over the detail of the job description, grading and person specification. The job description and person specification was negotiated at length as the proposed job purpose that DCC wished to commission differed in its focus from the job purpose of the specialist health visitor for Gypsies and Travellers already employed for the past 20 years by CDDFT to cover Darlington.

In February 2015 the job description and person specification were finally agreed between DCC commissioners and CDDFT, with the following Job purpose:

The aim of the specialist HV for GRT is to provide an enhanced health visiting service to the wider GRT population over and above the generic HV service.

- To deliver a proactive outreach service for members of the GRT communities ensuring equality of access to preventative health services.
- To be a source of specialist advice and best practice to support services to achieve equity of services for Gypsy Travellers and their children.
- To ensure that children and families from the GRT community achieve their full potential and life opportunities.

Population Served:- All Gypsies, Roma and Travellers who are permanently or temporarily residing in County Durham, whether on authorised or unauthorised sites, in bricks and mortar or in institutions.

The crucial difference in focus between the County Durham post and the pre-existing post for Darlington is that the Darlington health visitor offers a core health visiting service to all Gypsies and Travellers in Darlington, whereas in County Durham Gypsies and Travellers would continue to receive the core health visiting service from their generic health visitor, so the specialist health visitor will have the capacity to deliver the enhanced service to all age groups across the county who are not covered by the generic service.

The specialist health visitor post was initially to be advertised externally but the time delay in agreeing the contractual arrangements deemed it necessary to expedite the recruitment by only advertising internally, as the project was already compromised by the health trainers working in isolation for what would be the first year of the project before the appointed health visitor came into post.

In conjunction with the specialist health visitor post it was originally intended to commission a support worker to work closely with her and under her supervision. This post was to have been a family support worker or health visiting assistant, ideally with a community development role. However, in the contractual negotiations over the extra required finance for the health visitor post, there was less funding available for this post and it was therefore to be funded as administrative support only. No extra administration support was in fact ever provided above the support that was already in place for generic health visitors.

Two members of the Gypsy and Traveller communities were supported to be on the interview panel; one was MC, the nursing ward sister who had become involved with the project and the other was one of the GRT site wardens (all the site wardens are members of the Gypsy and Traveller communities).

#### **Induction period**

BC, the appointed candidate, already had considerable experience of working with Gypsies and Travellers on her previous generic caseload, had forged good working relationships with those at St Phillips Park site and in houses, and was knowledgeable about their health needs and barriers to accessing health care. She had also made links with other agencies working with GRT and was attending the GRT practitioner forum prior to commencing her post in May 2015. During her induction period she met with more key staff in agencies working with GRT across county Durham.

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BC along with NS, Public health lead and commissioner for the project, travelled to Cambridgeshire to meet SL, their Lead Nurse for Gypsy & Traveller Health, and their GRT team who are funded by Public health in Cambridgeshire County Council. SLs role is similar to that for the Health Visitor post commissioned for County Durham and it was useful to share her experience of several years. Gypsies and Travellers are the largest ethnic minority in Cambridgeshire, as they are in County Durham, although the size of Cambridgeshire's GRT population is larger (2-5% of the total population). In addition to the lead nurse role (a qualified health visitor by background) their team also comprises an advocacy worker, an adult education worker, community development worker and a worker from the racial equality diversity service who facilitates access to school education.

Following this visit it was agreed that BC would be known as the specialist public health nurse for GRT rather than as the GRT health visitor, as this would be both less confusing (as some GRT would already have a health visitor) and more readily understood. It was also agreed that BC and SL would meet on a quarterly basis for peer supervision as it would be of most benefit to BC to have supervision from someone who was experienced in a very similar role. FC, the GRT health visitor from Darlington also attended the first subsequent peer supervision meeting, although her role focus differs markedly.

#### **GRT Public Health Nurse activity**

### Data management and ethnic monitoring

One of the early requirements for BC was to have a means to identify her own caseload on the System 1 database to be able to manage her record keeping and data collection. Although many of the clients she sees are already on System 1 as registered patients with a GP, some practices use a different system such as EMIS. BC worked closely with IT staff to secure a comprehensive way of gathering measurable data to ensure that any reduction of health inequalities could be captured. By October 2015 she was finally able to move from having to record all her contacts and data on paper to having a page on System 1 for her own caseload records.

An important focus of BC's work is to encourage staff and families to be aware of the importance of recording and consenting to recording of their GRT ethnicity. The Commission for Racial Equality (CRE) make a very clear analogy to explain why this is an

essential component of BC's work: *To have an equality policy without ethnic monitoring is like aiming for good financial management without keeping financial records.* 

Most GRT are recorded as White British because the NHS is still using the 2001 ethnic codes in the NHS data dictionary. Although Gypsy and Irish Traveller codes are in a drop down list under White Other, this option is not known to many practitioners, and as it is also hidden, it is rarely used. An additional issue is the reluctance of many GRT to self- ascribe as such, out of fear of discrimination or prejudice, which they all too readily experience in many other spheres.

As BC became trusted over time by more GRT clients, and was able to explain the importance of ethnic identification, she gradually gained consent from them to have their ethnic coding changed on their central record on System 1 or EMIS. This was not a subject that was raised in her initial contacts with anyone as it was a subject that needed careful explanation and it was important to address presenting health issues first. However, by February 2017 she had raised the issue with 48 GRT people. 45 of these agreed to have their GRT ethnicity recorded as such on System 1, with only 3 refusals.

# Work with temporary GRT residents on Unauthorised encampments and Temporary Stopover Sites (TSOs)

In the first summer months after BC took up her post much of her work focused on reaching GRT on unauthorised encampments, and on temporary stopover sites. No health staff previously had any remit to visit these sites and any health needs were not previously identified, although the GRT team does carry out welfare checks on their arrival. BC made contact with each family to identify any health needs and to signpost them to appropriate medical care as required.

She carried out a mapping exercise to identify the areas where unauthorised encampments in County Durham are most used by the GRT and then to identify the local GP surgeries so that she could direct them and liaise with those practices accordingly. She gives out information to the families regarding the nearest GP service and when necessary assists them to complete temporary registrations. In addition, links with maternity services were made to ensure they have access to antenatal care.

#### GRT public health nurse role awareness raising

BC also spent necessary valuable time in raising awareness of her role among other primary health care staff and with staff in other agencies who work with the Gypsy and Traveller communities, particularly in Education, DISC and the GRT teams for site management and unauthorised encampments. She devised a referral form (see appendix v) for use by other agencies but also learnt about the services they offered and how she could refer to them. She particularly ensured that she introduced herself and explained her role via a generic email to all the health visitors and school nurses in the county. This was followed by positive liaison with several health visitors in the south of the county with whom she held further meetings.

The health visiting manager organised to have the same generic health visitor responsible for families on the two sites in Bishop Auckland so that there could be continuity and close working. The meeting also resulted in some joint group work with one of the health visitors to plan a short course on one of the sites on 'managing minor ailments in children'. This had been an identified need for mothers who frequently sought health care for minor ailments at A&E or Urgent Care Centres.

Another challenge in the short term was for BC to identify and to reach Gypsies and Travellers living on private sites and those in housed accommodation. We knew from meetings with various housing providers during the baseline evaluation that anecdotally they are aware of significant numbers of Gypsy and Traveller tenants but that very few identify as such. In the early months, until knowledge of her role became more widely known through word of mouth by GRT living on the sites, she relied other agencies such as DISC and the GRT Education team to make any necessary referrals to her.

## Engagement and work with GRT on council sites

It took time, as to be expected, for BC to build trusting relationships with so many Gypsies and Travellers across six widely spread sites in County Durham, particularly given the priority in the early months on developing a data management system, raising awareness of her role amongst other service providers and on identifying and meeting the health needs of the many Gypsies and Travellers passing through the county for short stays. It was important for her to become known and to be visible on the sites. She introduced herself and explained her role to the site wardens and the health trainers and did some joint visits with the GRT team and also the GRT education staff to make herself known via an already trusted staff member.

During that first summer she concentrated on working with the Health Trainers, and DISC on organising summer holiday activities on site C. This site has the highest number of children of all the DCC sites and was therefore chosen as the site to focus on in the first summer. They organised a youth group to run over the six weeks holidays. Activities included a sports day and a healthy eating session, and as the mothers also got involved it was a good way for her to start to get to know some of the families.





Fig 17 Sports day on site C





Fig 18. BC with children and healthy eating sessions on site C

# Role development and key performance indicators (KPIs)

After allowing the first 4 months in post for induction and orientation to the community and other service providers, a meeting was held with BC and key performance indicators were agreed in September 2015 ( see appendix vi )

One of the key indicators concerned the enormous challenge of promoting action to address the significant issue of mental ill health among GRT. BC arranged a meeting with Tees, Esk and Wear Valley NHS Trust (TEWV) who provide mental health services in County Durham and surrounding areas. As a result a Band 6 mental health worker was allocated to do outreach work with her, initially in the north of the county. Unfortunately this worker had only been able to make two site visits with BC before her allocated GRT role was ended. TEWV were not able to provide further dedicated GRT support due to increasing financial restraints and an increasing workload.

There were simultaneous plans for BC, in conjunction with DISC GRT service, to address the significant health and health related needs of GRT prisoner families and newly released prisoners. They aimed to do this by working with a local charity, NEPACS<sup>24</sup>, whose purpose

<sup>&</sup>lt;sup>24</sup> www.nepacs.co.uk

is to provide practical and emotional support to prisoners and their families. There is much documented evidence of the scale of mental ill health among all prisoners and the consequent impact also on their families. A 2014 report by the HM Inspectorate of Prisons<sup>25</sup> found that:

27% of GRT prisoners reported feeling depressed or suicidal on arrival (15% of other prisoners),

GRT prisoners were less likely to report receiving information about what support was available for their mental or emotional health needs (35% GRT compared to 44% other prisoners).

*GRT prisoners were also more likely to report having a range of other problems on arrival in prison:* 

mental health problems – 27% compared with 13% problems contacting family – 30% compared with 23% money worries – 23% compared with 16% problems with drugs, diverted medication or alcohol

A study of Travellers in prison, Voices Unheard<sup>26</sup> identified multiple extra difficulties faced by Travellers in prison and on release. For example it found instances where prison resettlement professionals stated .prisoners due for release on licence were unlikely to be permitted to live on authorised Traveller sites and that Traveller prisoners due for release would not be eligible or suitable for support services. The difficulties faced by GRT prisoners are also compounded by the impact on their families.

BC and the GRT worker from DISC arranged a presentation to NEPACS staff to highlight their roles and the support that they are able to offer to GRT prisoner families. This meeting was cancelled due to staff sickness but subsequently the CT, the health trainer, and her manager met with NEPACS to promote the GRT health services. This has not yet generated the involvement that they had hoped for.

<sup>&</sup>lt;sup>25</sup> HM inspectorate (2014) People in prison: Gypsies, Romany and Travellers

<sup>&</sup>lt;sup>26</sup> MacGabhann (2011) Voices Unheard, A Study of Travellers in Prison Irish Chaplaincy in Britain

Contact was also made with the Roman Catholic Prison Chaplain who runs a monthly group for GRT prisoners at the Deerbolt Young Offenders Institution. There were plans for BC to have input into this group on oral health, followed by signs and symptoms of diabetes, but plans stalled due to the protracted negotiations required via the Bishop for her to be involved. Since then contact has been made recently with the community probation service and discussions are now taking place on how BC can offer health related support to offenders through this service.

#### Home visit referrals and health assessments

As BC became more widely known and trusted, and as she made links with other services the numbers of referrals grew. Many of these were vague in nature, for example *'Tell Bernie I need to see her'*, and it would take time for the real concern to be revealed when she did visit. Many requests for visits were inappropriate, for example requests for assistance with official letters and forms or financial difficulties requiring assistance with welfare rights entitlement. Whenever appropriate BC referred on to the DISC service, but on occasions when there was urgency causing distress and when DISC was unable to respond quickly, BC found a need to act as an advocate. However, whatever the presenting reason for the visit would be, health concerns were often subsequently revealed.

It was not always possible to carry out a full needs assessment when the presenting health issue was urgent in nature and when there was great reluctance and wariness in answering questions that didn't appear relevant. Each referral therefore could and often does involve several visits over a period of time. It was important to proceed at the right pace for the individual concerned and to allow sufficient time for relationships to be developed and for trust to be engendered.

Many of those using her service would be seeking her advice or support for something that they had not previously sought help for but had kept to themselves. By allowing time and demonstrating understanding of cultural needs, by responding to presenting problems and by being consistently reliable in following up requests for contact by telephone or face to face visits, BC was able to build trust and confidence in her ability to advise on health matters. Whereas previously a niggling concern might have resulted in either increased anxiety or delayed presentation, as seen in Chapter Eight, BC was able, over time, to either reassure and advise on appropriate self- management or make relevant referrals to be seen by a GP.

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In 2015 the role commissioning of health visiting services was moved from the NHS to local authourties . In BC's second year in post Harrogate and District NHS Trust succesfully tendered to take over the management of the Health Visting service and the School nursing service in County Durham. BC successfully re-applied for her post and it was subsequently mainstreamed as a specialist post in the wider health visting service.

One of the new developments in the Trust was the introduction of improved electronic record keeping, and provision of laptops to aid this, in conjunction with the new core health visting service and in depth health assessment. New templates were developed to facilitate comprehensive data collection of health assessments on System 1 database.

BC was able to liaise to include two specific templates for all adult GRT and another one for all GRT children. These templates would be used not only by BC but also by the generic health vistors who had GRT families on their caseloads, thus enabling more comprehensive capture of GRT health needs.

The templates include checklists for type of accomodation, discussion of ethnicity, literacy, general mental state, screening for specific health conditions, immunisation status and advice given on immunisations (adult and child), and in the case of the child template, education status ie whether the child is educated in school, is home educated or is not receiving education.

There were currently 82 children known to GRT education service who are being home educated incounty Durham, with an unknown number who have never been on the school role. No-one except BC has an official remit to assess their health needs. BC has advised families of such children when she sees them to attend the GP for immunisations that they are eligible for at school age.

Many referrals to BC are complex in nature, requiring liaison with other services

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## Role development in the 2<sup>nd</sup> year

Much of BC's work in her 2<sup>nd</sup> year has been in responding to the increasing rise in numbers of referrals, including self referrals. Partnership work, discussed in chapter five, has helped to increase awareness of and appropriate use of her service. The amount of her time involved in one to one visits has limited the time available for raising awareness of her role with all the GP practices but where she has been able to do this, there have been appropriate referrals to assist in reducing non- attendance for hospital appointments. BC has been succesful in increasing attendance for appointments , in some cases by accompanying a client who for different reasons would not otherwise have done so. Her aim is to gradually increase their independence and confidence for them to attend with another family or community member. The increasing workload was recognised by BC's management and in early 2017 a part time early years practitioner was appointed to work with her and with the generic health vistor allocated to work on the Bishop Auckland site. There are also now plans to appoint a staff nurse to work with BC , particularly to assist her in her role with school age children, many of whom are not able to access the school health service

By February 2017, eighteeen months following the completion of her induction and orientation period, BC had worked with 240 GRT clients who were registered on her database. Of these 61 were children under 5 years of age. Although the generic health visitors mostly undertake the core health visiting for GRT children under 5 years , there were some GRT mothers who refused to be seen by a generic health visitor, and more children over the age of two years who would not routinely be seen by them and whose parents consult with BC with a number of varied concerns when she is on the site.

BC saw 34 children between ages 5 and 16 years. Many parents of young children account for the 47 adults seen between the ages of 17 to 45 years, but this number also included 10 men who don't typically access health services except when they consider it to be urgent. Only seven GRT on her caseload were aged 46 years and above, although this number is expected to rise as word of mouth is increasing the number of self-referrals.

Most of the GRT clients have been referred by other staff groups or agencies (see Fig 20)

Referrals by generic health visitors	- 14
Referrals from DISC	- 10
Referrals from GRT health trainers	- 10
Referrals from GP	- 3
Referrals from GRT Education	- 15
Referrals from DCC site managers	- 10
Self referral	- 8

Fig 20. Referrals to the GRT public health nurse

In turn BC has also made appropriate referrals to most of these staff groups , including 13 referrals to GPs . Many of referrals , both to and from her have involved joint working. In addition there has been a high level of joint working with Social Services and GRT education with five families where there have been child protection concerns.

As might be expected, given the poor health status of GRT there are a range of health conditions that she has identified on health needs assessment of these clients:

•	Anxiety/depression	11
•	Other mental health / psychosis	2
•	Dementia	2
•	Alcohol abuse	3
•	Substance misuse (prescription drugs)	) 5
•	Domestic abuse	7
•	Asthma	6
•	COPD	1
•	Type 2 diabetes	3
•	Heart disease	3
•	Stroke	1
•	Arthritis	5
•	Injury	1
•	Cancer	5
•	Polymorbidity	4

This list only includes conditions that have been identified or previously diagnosed, but one BCs challenges is to improve early detection, identification and presentation for treatment of more hidden conditions or those conditions where early symptoms are often ignored, such as anxiety and depression, cancer and diabetes. Another important challenge is to work with other agencies and staff groups to improve management of existing conditions such as diabetes and asthma and to work with health trainers to reduce the risk factors associated with heart disease, stroke and renal disease. Partnership work has been a key element of the GRT health project and will be discussed further in chapter five.

One of the features of her work with some clients is the complexity of the families health needs and the need to act as an intermediary between services

#### **CHAPTER 5**

## **GRT HEALTH PROJECT - WIDER PARTNERSHIP AND JOINT WORKING**

## **GRT** health team

From the beginning when BC was in post she and the health trainers worked closely together as the GRT health team. At the beginning while BC was making herself and her role known to residents on the sites she attended the health trainer drop in sessions and joined with the health trainers and DISC in organising health related events on the sites.

In the summer they have worked together to hold sports days on site C and on site E and have involved the parents. There are plans to try to extend this to the other sites where there is sufficient interest, although these two sites have the highest number of children.

Through this joint working they have also organised a summer youth group on site C with various activities which have included a nature walk, a litter pick around the site with Tidy Ted , First aid session and a quiz to guess how much sugar in various foods and drinks . They ended the summer holidays with a family barbeque but incorporating healthy food such as vegetable kebabs and smoothie drinks and involving the parents as much as possible. A family orientated approach to health and wellbeing has proved successful in getting residents interested in engaging with and getting to know the GRT health staff and also to try new activities, new foods etc . So far this has been most successful on one site but there has also been interest from some housed Travellers who know residents on the site and they are freely invited to come and participate.

In addition to the youth group, BC, the health trainers and DISC also collaborate to organise other events during school holiday and half term breaks, for example Chsitmas parties, Halloween events and a half term roller skating trip. In the second year when they repeated the sports day on site C they were able to include a 'Mam's race' as well as the children's sports events. This was followed by a BBQ that was cooked by GRT Health Team champion Linda and another resident.

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Fig 21 Youth Group and family activities

The team also used this event to invite DCC's Senior Partnership Officer, to consult with residents to help inform the Children, Young People and Families Plan and the Health and Wellbeing Strategy to ensure GRT inclusion

The GRT team approach was particularly beneficial in increasing awareness of each others services and in generating appropriate referrals (see Fig 22).

Mrs A is an 80 year old lady, originally from the cultural Showmen group of Travellers, those that travel the country with fairground attractions. She now lives alone and is very isolated, only having contact with one member of her family, her brother. Mrs A, was referred to BC by a social worker involved in her care. She was diagnosed with Dawson's disease; a progressive neurological disorder caused by a complication of the measles virus and is partially sighted with resulting difficulties in mobilising around her home. She is unable to attend to her hygiene needs and she has carers coming in daily. She also has meals delivered three times a week and her brother does some food shopping for her weekly.

Mrs A was a very frequent caller to 111 and 999 and rings for different things such "she is hot" or she, "can't adjust her pants." BC did a joint introductory visit with the social worker who wanted her to become involved in a supportive role to assist in maintaining Mrs A's independence.

BC also involved the GRT Health Trainer as part of the support package, and between them they initially carried out regular weekly support visits to assess her further needs and to see what gaps in provision still needed filling.

It was proposed that she attend a day centre that had animals as she had requested this and the health trainer liaised with an organisation called the B Network (Cornforth Partnership), who looked at what was available suited to Mrs A needs.

Regular team meetings were held between the social worker, a member from her GP practice, her home carer, BC and the GRT health trainer, to review and discuss any further care required. The GRT health team ensured coordination to meet her personalised care and culturally relevant needs.

## Fig 22 Case study Case study – Mrs A

On Drum Lane site where engagement was always most difficult, a breakthrough was made when BC offered to see a new mother at a weekly drop- in to weigh her baby and the health trainers were also there . Previously the health trainers had reduced the frequency of their weekly drop in to fortnightly due to lack of interest from the residents. That mother sought advice on healthy eating during her weekly visits to have her baby weighed. It was not unusual to have the the excuse of wanting the baby weighed as a pretext for seeking health advice, but once this mother had sought health advice for herself, another resident subsequently came to seek advice about the effects of energy drinks and fizzy drinks, and asked to be weighed. It is more likely that word of mouth will therefore increase the uptake of services on this site as with the others over time

BC and the health trainers formalised their joint working by promoting themselves as the GRT health team. They produced a Meet Your GRT Team poster to put up on each DCC site community building and they also submitted an article (see appendix vii) to the Travellers Times about Michaela and her role as a Health Trainer in her community. This was published on their website as well with an excellent response online. The health trainers also promoted the article on their Facebook pages and it was shared over 80 times!

They also produced the first GRT health team quarterly, A4 size short newsletter that is distributed among GRT residents on the sites and in houses but is also circulated to other service providers electronically. In the first newsletter they produced a Meet the Team front page to promote their roles (see Fig 23 below)



Fig 23 GRT team newsletter no 1

The newsletters have a dual purpose in not only publicising their activities and events but also giving health advice, recipes and tips in an informal newsy format. They also give an opportunity to celebrate and demontrate pride in GRT culture by including atticles on GRT histroy month. (see Fig 24)





Fig 24 - pages from GRT health team newsletters

BC recently arranged for the GRT health team to attend some intervention training with the drug and alcohol team, called 'Have a Word'. This will equip BC and the health trainers to raise the issue when unsafe levels of alcohol intake are identified at health needs assessments and to offer appropriate advice and support .

# **Practitioners Group**

Prior to, and at the start of, the GRT health improvement project, most of the staff who carried out work with GRT clients were working in isolation and often lacked awareness of other services or agencies working with the same client group. It was in this context, when various staff came together from different agencies and disciplines at the cultural competency training workshops, and there was realisation of the range of people with input, that a suggestion was made to set up regular practitioner group meetings to enable information sharing and ensure coordination of services for the GRT Community.

The DCC GRT site team manager took on the role of developing the meetings, and, by email, invited approximately 100 staff who had attended the workshops to the inaugural practitioner meeting in November 2014. They were invited to attend if they worked *"closely and deliver services/training or support to the GRT community on a regular basis to discuss the possibility of setting up this Forum"*. Of those invited, the staff and services represented at

the first meeting were DCCs GRT teams, DISC GRT project, GRT health trainer service, School nurses, Health visitors, CAMHS (Child and Adolescent mental health), GRT education, Infant feeding Coordinator, hospital ward sister (MC), Healthwatch, and a family worker.

At this first meeting the respective GRT teams in DCC explained their services and presented an overview of the GRT Strategic Action Plan. They were then asked, in mixed groups, to consider:

- the benefits for them as staff in having a regular practitioner forum,
- who should be involved,
- the benefits to the GRT community
- what should be included in the terms of reference

# The main perceived benefits to staff were:

to know the services out there for GRT, prevent duplication, partnership working, to share information, find out what families want, learn from each other.

The main perceived benefits to the GRT community were:

Raise awareness, achieve targets/own agenda, Share knowledge/tips/advice, understand other service's remits, Improve liaison, Networking/Ability to sign post clients, overlapping/joint working/joint events, safeguarding, Share resources/knowledge/ideas, Keeping services up to date.

The final agreed terms of reference were:

# <u>Remit</u>

The Forum is for all practitioners working with Gypsies, Roma and Traveller Communities in Durham

# Purpose

- 1. An opportunity to share and disseminate information about services
- 2. An opportunity to work together on specific issues

- 3. A forum to discuss any information that may have an impact on GRT or the way practitioners engage and work with them
- 4. Sharing skills and expertise to the benefit of GRT Communities
- 5. To enrich the practice of agencies attending by sharing different views and perspectives
- 6. How we can work together and identify barriers that get in the way
- 7. The organisation of the forum is a shared responsibility of all the agencies involved.
- 8. To facilitate a 2 way communication between the Strategic GRT Groups currently in operation and frontline practitioners.

The practitioners group has continued to meet for two hours on a quarterly basis with regular updates from the different dedicated GRT services (GRT sites, GRT education, DISC GRT team , and the GRT health team) being standing items on the agenda. After the initial meetings most of the generic staff rarely attended as they could not be released from their work to attend, but the services whose core work was with GRT attended regularly. In addition to the useful information sharing about service developments and the beneficial networking opportunities, the meetings soon became a forum for speakers from other services and agencies who wanted to improve inclusion by bringing their services to the attention of GRT communities.

Speakers from the following services have given presentations at the meetings and discussed ways of including members of Gypsy and Traveller communities in their service provision:

- School nursing service information about the forthcoming school nursing review
- Fire service- explaining and including GRT in their Safer Homes Scheme
- Witham Community Arts Centre promoting activities and workshops that are open to local residents, including GRT, in the summer holidays
- Dementia Advisor Service information and offer of training to become Dementia Friends
- Stroke Association promoting awareness of signs of stroke and available support.

An extra benefit of these various services seeking advice on how to engage with GRT communities to ensure their inclusion via GRT services is that the GRT site managers subsequently invited some of them, for example the Dementia Advisor service, to the monthly Site manager meetings. The GRT health team also attended these sessions to jointly deliver the training so that site managers could benefit directly and use the knowledge gained in their roles to raise awareness among GRT residents.

#### GRT team working in partnership with DISC and GRT education

Initially the DISC GRT team helped the CG as a new health trainer by introducing her to GRT families but it took a little time for them to start making referrals to the GRT team and to relinquish the health advocacy aspects of the role that they had taken on prior to the inception of a GRT health team service. This early difficulty in working together was overcome through communication and clarification of roles and they now increasingly make referrals to each other's services and work together as described earlier on delivering activities on sites. Having a service such as DISC is extremely beneficial to BC in her role as without it the need for support with forms, benefits and housing provision would inevitably fall to her and decrease the time available for meeting other specific health needs. Equally there are GRT clients who the DISC team see where health needs are identified that they refer on to BC.

There are a number of ways in which partnership working with GRT education has evolved and by which both services have further benefitted GRT families. The GRT education team have benefitted from being able to refer two families of home schooled children to BC for support with their children's behavioural/ health issues.

BC has had access to many families that she wouldn't have otherwise known of through referral from GRT education and they have carried out many joint visits concerning the children's health needs. This has also enabled BC to carry out health needs assessments on adult family members on occasions and make appropriate referrals where required. Many of these families would otherwise have been unknown to and unaware of the GRT health team.

The GRT home schooled children (82 in 2016) are to be referred to BC so that she can carry out health needs assessment. She is also liaising with the newly formed immunisation team in the Harrogate Health Trust to enhance the uptake of immunisations in home schooled teenagers, and those who are no longer in school, by conducting immunisation clinics on the sites.

Where there have been families who have come to the attention of social services child protection team, BC and GRT education have been able to work closely together with the

social worker and family members and provided culturally sensitive support to facilitate engagement.

The GRT education team have also been involved in collaborative initiatives on the GRT sites. In addition to provision of healthy snacks at the homework clubs by the health trainer service, referred to earlier in the report, they have worked with the GRT health team to set up a gardening project with the children on Adventure lane site. They have helped the children to grow herbs and this has been tied in to the healthy cooking sessions that the health trainers have been doing with the residents.

#### **<u>GRT team collaborations with other services</u>**

Durham Community Action is a local charity that has worked with North Durham CCG to deliver part of the CCGs patient engagement activity on local health service issues. To enable engagement with GRT communities they liaised with the GRT health team to attend some of the Drop In sessions to consult with those who attended.

TEWV, the mental health trust is another team with whom the GRT public health nurse in particular has close liaison and partnership working. The case study of Mr A on page 64 highlighted the need for a referral care pathway and, with support from the Equality and Diversity lead for TEWV, a key worker, EH, has been identified who would be the first and consistent point of contact following a referral from BC via a GP.

In late 2016 EH was appointed as the team leader of the newly commissioned practice aligned mental health service, to improve access to and to streamline appropriate mental health services for patients with mild to moderate conditions. They work with and receive referrals from twelve GP practices in DDES CCG and they also work closely with practice counsellors and with the IAPT service.

BC is able to liaise with EH and EH has also agreed to run a Health and Wellbeing session in a short parenting course that BC will be running on each of the six sites in 2017.

As a result of the emphasis in the cultural awareness training sessions on recording GRT ethnicity, TEWV, through the Equality and Diversity lead, have been proactive in adapting their data collection system (PARIS) to include English Gypsies and Irish Travellers in their main ethnic categories. Since they have done this they have noted that the number of GRT patients have increased although it's not known whether this is a genuine increase in referrals and attendances or improved reporting.

Collaborative work with other services has been referred to earlier, for example NEPACS, the Prison service, and Social Services. It is of great benefit to GRT families and an important aspect of their roles that the GRT health team work closely with all other agencies, as ultimately access to and engagement with these services is much improved as a result.

# CHAPTER 6 PRODUCTION OF CULTURALLY RELEVANT HEALTH PROMOTION RESOURCES

# Background

The original aim in the DCC GRT strategy was:

to review and produce popular health leaflets in collaboration with members of the UK Women's Gypsy Association (UKWGA). These leaflets will provide key information about symptoms for specific conditions.

This work was suspended after the UKWGA ceased to function and meanwhile, as part of the baseline evaluation, consultations with members of GRT communities in Durham revealed that leaflets were not thought to be useful. The Public health consultant GRT lead therefore convened a Health Information Group to meet to plan the development of more culturally relevant resources and the group decided on the approach of producing short films, about 10 to 15 minutes in length, on health topics that could be viewed as DVDs or as You Tube clips.

In addition to the GRT health team, DISC, GRT site management services and PVC as external evaluator and critical friend, MC the nursing ward sister from the Gypsy community was also a core member of the group.

#### **Going into Hospital film**

The group agreed that a useful topic for the first film would be about 'Going into Hospital.' This was considered to be a less sensitive topic for a first film than some that were considered such as mental health and it was also deemed a very useful first topic as there is so much evident anxiety amongst GRT about going into hospital. MC has had a lot of experience as a ward sister not only in reassuring and responding to anxieties amongst GRT patients and their relatives but also in being called upon by other hospital staff who encounter difficulties with their GRT patients and relatives. It was agreed that the film would be aimed both at the GRT community and at hospital staff, but that the GRT community would be involved as far as possible in the production. To this end a young Gypsy youth was recruited to do the filming and another Gypsy woman agreed to play the part of a prospective hospital patient with MC also on film in her role as a ward sister. The group considered the aspects of the topic that needed to be covered, informed by MC's and PVCs experience and devised a topic guide for the film. They agreed that the best format would be for the prospective patient to ask about

the questions that raise anxiety and for those questions to be answered by a nurse from the hospital.

As the filming was to take place in the hospital it was first necessary to obtain permission from the Chief Executive of Darlington Memorial Hospital. The Chief Executive granted permission and was very supportive of the project.

It was difficult to find suitable dates to bring all the key players together to plan and to finally conduct the filming but the filming did finally take place in December 2015. The unedited film has been shown to the group and well received. Since then there have been a series of logistical problems that have delayed the editing, but it is anticipated that this will take place in Spring 2017.

During the intervening time the group considered the next topic for filming. The group viewed films that had been made in Nottingham, also with and for Gypsies and Travellers on the topics of Heart disease, Depression and Diabetes and which are available on You Tube and also on Traveller Times online website. Each of these films had their merits and particularly the first two that included Gypsy patients affected by those conditions speaking on the films. The film on cardiovascular disease was considered by the group to be excellent and they felt therefore that it was unnecessary to make a further film on this subject but to promote the Nottingham film. Contact was made with Nottingham County Councils Gypsy Liaison Officer who chairs their County Gypsy and Traveller Partnership, comprising representatives from different service providers, akin to the Practitioners Group in county Durham, to enquire whether any evaluation had taken place on the use and impact of the films in Nottingham. The DVDs of the films were distributed to service providers and to some community members in Nottinghamshire. No formal evaluation had been undertaken as no resources were available for this and it was considered to be "*in the too difficult box.*"

## **Diabetes films**

Diabetes is a priority in County Durham and it was considered to be the next most important topic to be covered, based on the prevalence of the condition among GRT families and on the lack of knowledge about its prevention, detection and also its management. The Nottingham film covered signs and symptoms but not how to manage the condition or how to reduce the risk of complications. It was therefore decided to make a pair of films on Diabetes; one on prevention and recognition of the condition and the accompanying film on how to manage Type 2 diabetes. It was felt essential to include a Gypsy with Type 2 diabetes who was

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willing to be filmed in both of them and also via the provider of diabetes services in county Durham, to make links with the National Diabetes Prevention Programme aimed at people with a high risk of developing diabetes. For the first film there are plans to film a community member undergoing a health check. For the second film BC has identified a Gypsy lady with Type 2 diabetes who is willing to be talk and be interviewed on the films and MC is also willing again to be the nurse who talks to her. Topic guides for the draft scripts are to be finalised before asking the same Gypsy youth if he would like to undertake the filming again.

Although the process of producing both of these first two films has been protracted, they should both be available in 2017.

Consultation has taken place with both Gypsies and Travellers during the two year evaluation interviews and they were asked to consider how well the first two films would be, how they would prefer to view them and what other topics they felt it would be beneficial to cover. Most of the younger GRTs felt that the films would be useful either on You tube or as DVDs.

Yes I think it would be good to educate them cos lot of Travellers aren't sure about health problems and that and they just get on with things and they just get on with things and they have something wrong with them and they don't realise what's going on, so Yes I think it's a good idea. (F10 age 23)

<u>Going into Hospital</u> - like a lot of people avoid going so I think it would be useful. I think YouTube would be most accessible cos a lot more uses I pads and stuff. <u>Diabetes</u>- There's probably a lot of Travellers out there with Diabetes who don't know they've got it, cos they don't know about it and the symptoms and signs.

(F16 age 24)

<u>Going into Hospital.</u> – thinks that would be good. <u>Diabetes films</u>. Brilliant, definitely, especially for the young ones; I'd make them watch it. Me even (parents have diabetes) I don't understand it. (F18 age 38)

More of the older GRTs were less sure about whether they or whether other older GRTs would watch them and the younger ones also felt this to be the case.

Probably; maybe those with a sick person in the family, but I think maybe young ones who'd look at it on You Tube kind of thing; we don't do You tube, but yeah, maybe. . (F14 age 47)

Yeah because I know a lot of people go on the Traveller's Time website and look at stuff because there is a lot of news on there that interest us, it is about us and stuff. But the golden oldies like granny, they like to see in black and white and read it in their hands. I think that is what they need; they need reassurance they are going to be alright when they go into hospital. Because nine times out of ten the women have never had a night away, away from their mum and dad or their husband...... ....Diabetes is a big thing in our family, a lot of them have it. Oh they all know or they all go on about how they know. They all have these little machines and they all keep insulin with them. They all say it. It is something you can't muck around with your diabetes. Yes, the film is a good thing because I don't think you can be too educated and how to deal with it. (F38 age 24)

#### Other film topics

There were several suggestions about other topics; these included cancer, asthma and COPD postnatal depression and stress.

I think cancer and stuff. Because people don't like the sound of it they don't know a lot about it, like screening and stuff. My sister found a lump and we went and got her checked but because a lot of people don't know about things, how to check and things, or don't like talking about it, because families don't like talking to each other about breast cancers and stuff, it would benefit. For men as well cos I don't think any of them really know. Would that be better on YouTube or DVD? More DVD so you could give it out, because I don't think people would look it up on You Tube.

(F16 age 24)

a lot of the new Traveller mums get a lot of post-natal depression because they don't get the help off their husbands. So I think that would be good yeah because nobody recognises it. (F38 age24) Prompted for stress/ mental health Yes that would be quite good because there's a few people that I know who suffer from mental health issues and stress. I think if they knew more about it in the first place and it was more explained then other people would have a better understanding of what they're like. So I think it would benefit from other people knowing what it's like for them as well. (F16 age 24)

Consultations also took place in interviews with service providers on how they would use them and what other topics primary care service providers would like to see covered. There was a general positive view on the role of the films and the availability for staff to give them out to patients when relevant. Two suggestions were made for other topics to be covered; one on stress/ mental health and the other on asthma.

I think it is much needed the education, I mean I think we found a way in with this group in Middlesbrough through the fitness class. They have never been given the opportunity to talk about mental health, somebody will be talking to them and it is like unleashing floodgates, they didn't know there was mental health. I do not know how this gets done but there is some sort of educational role. I don't know how that happens because it's obviously much easier to talk about diabetes. (H15 Equalities &Diversity lead TEWV)

Yes. I mean anything really, any health needs that you think they should attend and might not attend for because every time they attend we go over and reiterate correct use of inhalers but I think anything that is visual that they can see about use of these devices is always going to be useful (H12 Practice Nurse)

# **CHAPTER 7**

# **COMPARATIVE HEALTH DATA**

One of the reasons for the lack of awareness of the health status of Gypsies and Travellers among primary care staff is their hidden identity and virtual absence of ethnic coding.

Unless there is a determined effort to sample Gypsies and Travellers and compare them by matching to another population by age and sex, as in the case of the 2004 Health Status Study<sup>7</sup>, the only other means of comparing their health status, in the absence of recorded GRT ethnicity, is to identify GRT using postcodes where everyone living in a specific postcode area are of GRT ethnicity. In county Durham each DCC caravan site has a unique postcode and in certain areas most of the residents on a site will register at the same GP practice.

## **GRT health status in one GP practice**

HM, the DDES CCG lead for GRT, undertook in her practice to examine the patient records and QOF data for the 50 GRT patients living on a caravan site and therefore identified by postcode.

QOF (Quality and Outcomes Framework), is an annual reward and incentive programme introduced as part of the GP contract in 2004, and details GP practice achievement results. It rewards practices for the provision of quality care and helps standardise improvement in the delivery of primary medical services.

The indicators for the QOF change annually. For 2015/16, the QOF indicators for which data is recorded includes:

- managing some of the most common chronic diseases, e.g. diabetes , mental health COPD (chronic obstructive pulmonary disease) , CHD (cardiovascular diseases)
- managing major public health concerns, e.g. smoking, obesity
- implementing preventative measures, e.g. regular blood pressure checks

Although 50 is a small number to determine any significance in results, there were some startling findings that highlighted the value of recording GRT ethnicity to alert practices to the problems identified in their GRT practice population.

For example, although 69% of the adults in her practice were recorded as either overweight, obese or morbidly obese 28% were current smokers and 33% were ex- smokers, none of them were on the COPD or CHD registers. This indicates that symptoms of COPD or heart disease have not come to the doctor's attention and fits with the knowledge that GRT are often loathe visiting the doctor before they consider their symptoms to be serious.

Another important finding was that 16 (41%) of the 39 adults were recorded as having a mental health problem. Although mental health issues often have an inherited element to them, and this population is made up of several members of a number of families, which may affect the statistics, these high levels of mental health problems are particularly alarming considering that these are only those GRT who have felt their symptoms to be severe enough to visit their GP. The mental health problems recorded include:

Anxiety	4 (10%)
Depression	9 (23%)
Drug dependance	3 (8%)
Overdose	2 (5%)
Psychosis	2 (5%)
Autism/special needs	1 (2.5%)

One commented that an inability to read and write affected mood, and, as we know from other studies, other social determinants associated with being a Gypsy and Traveller will also be relevant.

These results from one practice have alerted the GPs to the levels of existing morbidity and high levels of risks factors that increase the likelihood of undetected conditions.

## **Improving recording of GRT ethnicity**

This practice survey took place in October 2014 and the GP concerned took time to ask other patients who she saw and who she knew to be GRT but who were then living in houses if they would consent to their Gypsy or Irish Traveller ethnicity being recorded. As CCG lead for GRT she felt this to be important but was also aware of the pressures on GP practices that would make it unlikely that others would have the capacity to do the same.

Instead she focussed on improving the recording of GRT ethnicity and sent a request to GRT leads in all DDES practices via the practice managers. It is not feasible to change how the ethnicity codes appear on the ethnicity tabs on the electronic systems as an application has to be made to the Department of Health. It is possible to add the codes to the new patient templates but each practice uses their own slightly different new patient templates. She suggested therefore that the Gypsy and Irish Traveller codes be added to their paper new patient questionnaires and that from there the codes could be added to the patient record on System One or EMIS (whichever system the practice was using). She pointed out that the codes were available in a drop down list under White Others and requested that nurses and Doctors coded opportunistically whenever possible. This would only identify new patients though and there would still be a reliance on BC the GRT public health nurse, and practice staff, to approach existing patients for consent to add their GRT ethnicity.

At the same time the GRT lead in North Durham CCG contacted the relevant system manager for a group of practices in the CCG and arranged for the change to be made to their electronic new patient template (see screen shot in Fig 25 below )

🏋 New Patie	ent Check				x
Page 1 Fa	mily History Social		Ethnicity		
Core Data	i Entry		Date ⊽	Selection	
Ethnicity	<ul> <li>White British - ethnic category 2001</li> <li>White Irish - ethnic category 2001 ce</li> <li>Irish Traveller - ethnic category 2001</li> <li>Gypsy/Romany - ethnic category 2001</li> <li>Other White background - ethnic cate</li> <li>White and Black Caribbean - ethnic cate</li> <li>White and Black African - ethnic cate</li> <li>White and Asian - ethnic category 20</li> <li>Other Mixed background - ethnic cate</li> <li>White and Asian - ethnic category 20</li> <li>Other Mixed background - ethnic cate</li> <li>White and Asian - ethnic category 20</li> <li>Other Mixed background - ethnic catego</li> <li>Pakistani or British Indian - ethnic catego</li> <li>Pakistani or British Bangladeshi</li> <li>Caribbean - ethnic category 2001 ce</li> <li>African - ethnic category 2001 cers</li> <li>Other Black background - ethnic cate</li> <li>Chinese - ethnic category 2001 cers</li> <li>Any other group - ethnic category 20</li> <li>Ethnic group not given - patient refus</li> </ul>	Main spoken language English 🔲 🌌 Main spoken langu R 🗙		No previous values	
Record A	llergy or Sensitivity				
Current health	problems				

Fig 25. GRT comparative health survey in DDES

Following the findings from her own practice survey HM contacted NECS primary care data quality team to request a wider survey across DDES CCG using extracts from GP practice primary care systems for four other DDES practices with recorded GRT patients.

Overall there were 46 patients sampled by postcode, and an additional 7 sampled by ethnicity. There is a stark difference in the number, and the prevalence, of GRT people sampled in each practice. The data was extracted in July 2015 and overall there were 46 patients sampled by postcode, and an additional 7 sampled by ethnicity. There was a stark difference in the number, and the prevalence, of GRT people sampled in each practice.

With a small sample size of 53 patients and the measures looked at tending to have a low numerical incidence; it was surprising that the statistical test returned any significant results. Yet, a third of all GRT (aged 18+) in the sample were recorded as having depression.

In addition to QOF results a number of other primary care measures were looked at by the investigation. Due to QOF prevalence being reported nationally, and having related payments for reporting, it is likely that the standards of data quality for these are higher than in other areas.

Teenage pregnancy, teenage breastfeeding, teenage obesity and teenage perinatal mental health were all looked at. However as there were no GRT people recorded in the 15-19 age bracket there was no meaningful result for these measures in that they all showed zero incidence.

There were zero reported GRT people with a record on childhood immunisations. This could be due to the immunisations having been done at another location without a good transfer of records.

It was clear that to show meaningful results on GRT health status measures it was necessary to include larger numbers, therefore a request was made to include and aggregate the data from HMs practice.

A further report of data from the five practices was produced in December 2015 Overall there were 103 patients sampled by postcode, and an additional 9 sampled by ethnicity.

The addition of data from the original practice gave the sample enough power to produce significant results on diabetes mellitus and hypertension prevalence. This does not mean that the original practice was the cause of that result, just that the sample became large enough. Both of these QOF prevalence are lower than would be expected from the overall practice population. This suggests that there is under diagnosis of these conditions in this sample.

#### 2016 GRT comparative health survey in DDES and ND CCGs combined

In March 2016 data was also extracted from five practices in North Durham CCG. Overall there were 119 patients sampled by postcode, and an additional 11 sampled by ethnicity. The findings mirrored those in the DDES report.

To increase the statistical strength of the data it was decided to combine the two populations from DDES and ND CCGs despite them being snapshots at different points (July 2015 and March 2016). There was a very slight risk of double counting, if for instance a patient had moved to another practice within those periods. The different times of data extraction are therefore a potential source of error for this report. It was necessary first to obtain permission from the practices due to Information Governance and data agreements.

The following findings are from the combined data from these 10 practices with recorded GRT patients across county Durham. Overall there were 220 patients sampled by postcode, and an additional 20 sampled by ethnicity.

The investigation examined the QOF prevalence measures for the postcode sample only. This was compared in the table (see Fig 26) to the published QOF registers of the practices combined. Some QOF measures are age dependant, and the population used was adjusted accordingly.

The sample was reported in age bands, one of which is 15-19 years, so all the age dependant measures (marked with a \* in the table) have the same population. This could be a potential source of error in these indicators which could underrepresent prevalence.

QOF prevalence is highlighted in the table if it is significantly different in the GRT sample compared to the practice prevalence.

220 sampled patients (of which 152 are adults over 18 years) is still a small sample size and it remains noteworthy that the statistical tests returned any significant results. The same conditions showed statistically significant results in the combined data:

- 24.3% of all GRT (aged 15+) in the sample were recorded as having depression.
- Significantly low prevalence of atrial fibrillation, cancer, chronic kidney disease and hypertension were also observed.

Although the sample is still too small for statistical significance on other comparative data it can be seen that there is also an increased prevalence of other mental health conditions and obesity and a lower than expected prevalence of diabetes accordingly.

		2013-14 Q	OF Result	s	Practices Results	2013-14 Q	OF	GRT Pri	mary Care	Extract	Diffe	rence
QOF Disease Register	NHS England	Durham, DarlinGRTo n & Tees Area Team	DDES CCG	North Durha m 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

Fig 26. 2016 Comparative data from QOF disease registers

In addition to QOF results a number of other primary care measures were looked at by the investigation. Attendances for cervical screening, mammography screening and for flu, pneumococcal and shingles vaccinations for eligible adults were also lower than the practice populations (see Fig 27).

Number of GRT with:	Number in	Total GRT Age Band	% GRT	National Indicator:	NHS Englan	DD&T Area	DDES	North Durha
age 65+ Flu Influenza Vaccination (65+ y.o.)	9	14	64.3%	Influenza vaccinations given from 1 September 2014 to 31 January	72.7%	73.6%	72.4%	73.4%
age 65+ Pneumococcal Vaccination (65+ y.o.)	4	14		Vaccination coverage for patients who received PPV anytime up to 31 March 2015	69.8%	69.5%	65.3%	69.0%
age 70 Shingles Vaccination (70-74 y.o.)	0	3	0.0%	% of age cohort vaccinated to end November, routine 70 years	52.8%	53.8%	55.4%	55.4%

### Fig 27. Comparative adult vaccination data

## 2017 GRT comparative health survey in DDES and ND CCGs combined

Although there would not be expected to be any significant change in individual data in one year, the total GRT population was expected to have increased. In February 2017 data was again extracted Overall there were 255 patients sampled by postcode (increase from 220), and an additional 52 sampled by ethnicity (increase from 20). The main increase in the 2017 sample was for patients aged 0-4 years

A further comparison was made with QOF data but as in 2016 it was only the population sampled by postcode that was included for comparison.

As would be expected with a relatively small increase in adult population numbers and insufficient time interval in which to expect change in disease prevalence, there was minimal significant change in the comparative differences neither in QOF data nor in adult screening and vaccination data.

As previously, for most disease registers the prevalence rate in the GRT sample was lower than the combined GP practice prevalence. This is most likely to be due to under diagnosis of these conditions in a group that is usually slow to present to the GP until symptoms are considered too serious to be ignored.

The most marked differences both between GRT populations and others and/ or between 2016 and 2017 were seen in the following conditions, although with small numbers some of the changes can just be due to fluctuation.

• Asthma:

11% prevalence in GRT sample compared to 6.4% in GP practices.

The comparison with the 2016 sample shows an increase in both males and females, with a decrease in ages 0-19 years, but increases in 20+ years.

• Depression (18+yrs):

25.9% prevalence in GRT sample compared to 9.4% in GP practices.

The comparison with the 2016 sample shows an increase in both males and females, with a higher number of females compared to males, and a decrease in ages 20-39 years, but increase in 40+ years.

• Hypertension:

8.6% prevalence in GRT sample compared to 16.6% in GP practices.

The comparison with 2016 sample shows an increase in both males and females, and across all ages (45+ years).

• Obesity (18+yrs):

13.6% prevalence in GRT sample compared to 13.7% in GP practices.The comparison with 2016 sample shows a decrease in females, a decrease in ages 18-59 years, but an increase in 60+ years.

A further report is due in May /June 2017 that compares the total 307 recorded GRT population. This will also be a baseline for future comparisons which, over sufficient time, will be give an indication of progress in improving timely diagnosis of health conditions such as diabetes, cancer, hypertension, and also in progress on health promotion and health interventions , for example in reducing obesity and improving functional mental health.

# CHAPTER 8 GYPSY AND TRAVELLER PERSPECTIVE

## **Baseline evaluation of Gypsy and Traveller experience and perception**

## Methodology for baseline evaluation

It is unsurprising that contact with Gypsies and Travellers to discuss health needs and service provision is, of necessity, made initially through other trusted gatekeepers who work with the GRT communities. Time needs to be taken to build trust before attempting to launch into discussions about health, particularly without any seeming advantage to such discussion, and with an observed reactive approach to health being more widespread than the concept of prevention.

Where there are local Gypsy and Traveller groups or key community members who are engaged in voluntary or paid work in service provision, the task of consultation is made easier, but this is not the case currently in Co. Durham. The proposed plan to recruit GRT and to train them as community evaluators was therefore delayed until after the initial baseline interviews.

Building on the knowledge gained from the HNA four years previously, the aim of the baseline interviews was to gain the current perspective of a sample of GRT from different age groups, gender and living in different types of accommodation. The interviews were informal semi- unstructured consultations with no attempt to record them. Twenty- one consultations were conducted (see Figure 28)

#### Identified health issues

There was a reluctance to talk about health issues except in general terms or unless prompted by specific reference to more sensitive health topics. The identified health issues and concerns from the twenty-one individuals interviewed mirror many of the key health issues affecting the majority population, but of particular significance is that there is less access to support or knowledge of management of many of these conditions. Also significant is the apparent high prevalence of mental ill health and of suicides. In a relatively small percentage of the population, the numbers of individuals in this random sample with a close relative who had committed suicide highlights the health burden that is hidden by lack of ethnic monitoring. In addition to the articulated concerns there was evident need for patient education on chronic disease management and prevention, especially for diabetes and for stress management. There was also the more hidden need for support for carers, particularly those caring for a relative with dementia as there is still a stigma to admitting to stress, or in seeking outside support, for caring for a family member. Gypsies and Travellers expect to care for family members and are willing to do so. They would rarely identify themselves as 'carers' Dementia itself is likely to be hidden for as long as possible.

One Gypsy emphasised the need to avoid the term 'mental health' at all costs, as this feeds into the stigma and perception that to be diagnosed or referred to mental health services is a sign of 'madness.' This was a crucial point in regard to discussion about support or referral.

	16- 21yrs	22-39yrs	40- 59yrs	60- 75yrs	75yrs+	Total
Gender						
Female	4	7	4	2	1	18
Male	1		1		1	3
Accommodation						
DCC site	3	3	2	1	2	11
Private Site	1	1				2
Unauthorised site		4	3			7
Housed	1					1
Marital Status						
Single / Separated with < 16s		1				1
Single no children	2	1				3
Separated/widowed				1	2	3
Married	3	5	4	2		14
Total	5	7	5	2	2	21

Fig 28. Initial GRT consultations (March 2014- June 2014)

## Access to health care

The Gypsies and Travellers interviewed reported satisfaction with the care they receive from their GP practices, but, in common with the majority population, many were unhappy about being unable to get an appointment when they felt they needed it. They would therefore resort to attending A&E on such occasions. The site warden at St Philipps site was concerned about the lack of public transport and cost of travel to the GP surgery for elderly people especially for some who needed to attend regularly and who needed to get a taxi there.

There was a general reluctance to attend to see a GP unless or until really necessary, especially amongst men. This is in keeping with previous research findings of delayed access and late presentation of symptoms for a variety of reasons.

#### Views on the proposed GRT Health Project

There was scant consideration from many of those interviewed of what the proposed health project, in terms of the dedicated Health Visitor, could offer. However, some offered that the Health Visitor could help people to talk, rather than keep fears and burdens to themselves. This was particularly with regard to mental health and stress. A couple of respondents felt that support could be given to build self- esteem and to help women to seek support for domestic abuse.

It was suggested that the Health Visitor could improve awareness and understanding about alcohol and other addictions and on both prevention and management of health conditions such as diabetes, heart disease etc.

Women with young children voiced their wish not to lose their existing Health Visitors in whom trust has been developed, but there was also a suggestion that a specialist Health Visitor could give more time to explaining about immunisations, health screening etc. It was felt that by imparting more information to younger women, they would in turn reach older women about the importance of screening.

#### Two year evaluation

#### Methodology

During the intervening two year period since the baseline interviews there were attempts to recruit community evaluators with the aid of trusted staff from GRT services. Three different community members did express an interest and were initially keen during this period but each of them failed to pursue their interest due to different life events that occurred for them. It never became possible to recruit others who were interested in this role. Although there had been some success in capacity building in the second year with three health champions recruited, none of them had wished to extend their volunteering and embark on any training. The external evaluator, PVC, therefore conducted all the stakeholder interviews.

The evaluation steering group continued to meet regularly throughout the project period to this point and were consulted on the methodology and on the topic guide (see appendix viii).

To gain wide GRTs views and perceptions of the benefit and reach of the project it was important that the interviews were carried out with a random sample of Gypsies and Travellers and not chosen by members of the GRT health team. Therefore, with help from the GRT site team a random sample of GRTs of different age groups from the six DCC sites were selected for interview. Housed GRTs were also randomly selected by BC the GRT public health nurse. GRTs on unauthorised sites were opportunistically sampled and those on private sites were intentionally sampled. (see Fig 29 )

Inevitably there were some refusals for an interview but 38 GRTs were interviewed, most as individuals but some were interviewed in groups of two or three. There were 28 separate interviews in total. Consent was obtained verbally for all interviews and for recording of the interviews. Only three people requested that notes were taken instead of recording. Those who declined to be recorded were happy for notes to be taken. A good range of age groups was achieved and included six men (see Fig 29).

	16- 25yrs	26-45yrs	46- 59yrs	60- 75yrs	76yrs+	Total
Gender						
Female	6	14	6	5	1	32
Male		2	1	2	1	6
Accommodation						
DCC site	3	4	5	6	2	20
Private Site		2	1			3
Unauthorised site	1	2	1	1		5
Housed	2	6	2			10
Total	6	16	7	7	2	38

#### Fig 29. Table of interviews at 2 years

Interviews took place on all six DCC sites. Most of those interviewed were English Gypsies except for two Irish Travellers and three Scottish Travellers. The majority of Gypsies and Travellers living in County Durham are English Gypsies so this is not an unrepresentative sample by ethnic group. As well as avoiding selective bias by randomisation, it was also important to include Gypsies and Travellers who might not be using the GRT health team services or might not have yet encountered them.

Although the interviews took place 2 years after the baseline evaluation, the earliest ones were only conducted in September 2016, a year after BCs induction and orientation period. It is not therefore surprising that some of those interviewed were as yet unfamiliar with the service.

## 2 year evaluation findings

#### Reported health status and health conditions identified.

The self- reported health of those interviewed was broadly what would be expected considering the findings in the comparative data from GP practices, but as also expected their reported overall health was considerably worse than that of the general population. Only 17 of the 38 (44%) GRT interviewed reported that their health was 'Good' or that they had no significant health problems. Although it must be born in mind that these are very small numbers, this compares to 81.2 per cent of people in England and Wales who reported their general health as either 'Very good' or 'Good' in 2011.

The 21 remaining Gypsies and Travellers reported suffering from a variety of long term or chronic health conditions but there were four conditions that featured more frequently:

- 8 (21%) reported significant Mental ill health
- 5 (13%) reported Heart or Chest conditions
- 3 (8%) reported Diabetes
- 3 (8%) reported Arthritis

Three of those interviewed were also caring for a relative at home with a chronic health condition (one with enduring anxiety and depression, one with dementia, and one with severe COPD). Two of these were living in a caravan on the roadside and one was living in a DCC caravan site.

#### Reported factors affecting health and health promoting behaviour

It was important to understand the GRT perception of the factors that affected their health and to what extent therefore they felt that causative factors could be addressed or whether they took a more fatalistic view.

Nearly half of all those interviewed when asked what they thought might affect their health, spontaneously mentioned lifestyle factors ; particularly diet, but also including smoking, lack of exercise, alcohol and drugs ( including caffeine in energy drinks and coffee). Another lifestyle factor frequently mentioned by older Gypsies and Travellers was their '*hard lives working in all weathers*'.

Although most people knew about and mentioned eating healthily and taking exercise as ways to keep healthy, not all of them necessarily followed this or gave it much thought in their daily lives

Don't know. I could be more active I suppose. It's too easy to get in the car & drive, could maybe do a bit more exercise (F4 age 38 years)

Me, everything you're not supposed to do, I've done it (F12 age 71)

There was a markedly different viewpoint between older and younger GRT about the role of diet. Most older GRTs considered that they ate healthily compared to the younger generation who they felt lived on takeaways

Well the first one you think of is diet, but it isn't, they eat very well, the older generation; my age group and above will always cook. You tend to find a lot of

Traveller youngsters that are in McDonald. I have noticed it because it is always a social area where they can. (F 23 age 60)

our grandchildren, they'll send for a Chinese about 9pm or if not kebabs or a big box of pizza each. My grandsons they drink that much coca cola, Red Bull, first thing in the morning. (F12 age 71)

However the younger generation did not always agree that the older ones ate more healthily and pointed to unhealthy practices.

I mean my granny she uses a block of lard every time she cooks with anything. They are unhealthy, they don't like salad and stuff. Yes they do cook meals but with the stuff they cook it with they would be better off getting a takeaway. (F38 age 24)

Caffeine addiction emerged as factor, mainly amongst the younger generation who take it in the form of energy drinks. Some older people also mentioned it as a factor though

They are on Red Bull, he [husband] is on it too ... they're all on it. But I don't, coffee that's all I drink. ... I just got to have it. So if I have no coffee and drink tea for a day ohhhhhh I crave for coffee........ They said at the doctors it was migraine but I know it wasn't migraine cos I don't suffer with it. I think it is the strong coffee (F25 age 47)

Many referred to stress or 'worries' as a health factor. Financial worries, bereavement, worries about the health of family members, 'family problems', being moved on (when they were travelling), racial abuse and racism from housed neighbours were each specifically mentioned by at least one respondent in this context

I've had nearly 18 months of "dirty gypsy" which brings stress. ... they [neighbours] tried to get me out, tried to get the house off me. It can be very challenging and can have a very detrimental effect on your health (F 23 age 60)

Worrying about the health of other family members was paramount however.

Biggest stress? "if you're children's ill or anything wrong with the family. If your family's alright, you're alright" (F19 age 90)

Keeping busy and taking exercise were spoken of most frequently in relation to managing stress rather than as a means to keeping physically healthy.

Well, exercise can help, it's a good thing. It's just like doing things, keeping yourself occupied. If you just sit around & dwell on it it gets no better does it. I used to take myself for walks, things like that, keep busy, occupy my mind more, (F4 age 38)

...go to the gym 4 nights a week, walk the dog. Better if you keep busy, stops you feeling depressed and that (F1 age 38)

Is there anything else you consciously do? *Cleaning* (F7 age 47)

However there were several examples given of those who suffered stress and anxiety or depression in silence and 'bottled up' their feelings and fears with serious consequences

This man eventually went to the doctor after being ill quite a long time, fretting and worrying and losing weight – big strapping healthy man and there was a possibility, and maybe it shouldn't have been discussed in the Doctor surgery, of pancreatic cancer and they were sending him for tests. Well, he went and had the tests but he didn't wait for the results. He hung himself, cos he thought he was terminally ill with cancer. It's the ignorance, it's knowing so much and not knowing enough, that even if it was, and if it turned out he was misdiagnosed or mis-suggested (F17 age 60)

*I know men who've bottled things up and have hung themselves.* (M11 age approximately mid 60s)

I mean it's hard for a man to sit down and tell someone you feel suicidal but it does help to tell. So would you talk to other Traveller men and advise them to talk? Well a couple of friends, I've told them what happened and they said' Oh behave man, it's all in your head and all that', but they don't understand. If they ever had it themselves they would understand, but they don't realise. A friend of mine last year, he hung himself. I know x, he did it a long time ago and on a cause of him, his relation did it.There's been a few(M22 Age 40)

It really annoys me they'd rather try to kill themselves than trying to talk to the people that surround them and loves them, they are there to help them but they 'd rather go off and kill themselves and just leave them. And then people thinking look I could have help them, I could have done something. There's a young lad about a year ago he did it, he was only about my age. I grew up with him all my life. He killed himself in his mum's house, he had two kids. .....Half of them don't even show they are depressed, they act so normal it is uncanny. I think it is just depression (F38 age 24)

Several referred to types of accommodation issues as stress factors, particularly in relation to proximity to extended family and in relation to travelling lifestyle and being moved on.

*Miss the travelling life, loved it ...the mind set was better.* (F28 age 59)

To be honest I was fifty times better before I came on here. I have been worse since then. Whether it's the central heating in the shed, I haven't been used to it. To be honest with you, I'd rather be on the side of the road. You can't get away from what you were being brought up can you! I am getting on now; I was 62 the other day. I don't look it but I feel it. (F31 age 62)

When the question about factors affecting health was put in the context of how they felt about the HNA findings on GRT health, few expressed surprise and they gave different explanations for potential causes. Avoiding medical care, for various reasons, was given as an explanation by many, although each respondent invariably spoke in the third person ie. *they don't* ..., rather than saying *'we don't* ....

The varied reasons for delaying or avoiding medical attention include fear (especially of a cancer diagnosis), fear of being judged, lack of trust, embarrassment, shame, and lack of knowledge and understanding.

GRT don't neglect their kids but they neglect themselves. 90% of GRT won't go to the Drs with it (stress and anxiety) and 90% won't admit to it. Why? Probably feel embarrassed; Travellers don't socialise outside the site; don't go for help. If it was offered they'd probably accept it. (F29 age 32)

They'd conceal serious illnesses...from my understanding it is the fear of being opened up. .... they would say I don't want them opening me up, 'so and so' was opened up and died 2 months later. It just gets passed down, that inherent fear. "Ah no, I am not going to the doctors!" they'll find a lump and they'll suffer in silence. That lump could be there for years and by the time they are actually seriously ill and a daughter or a sister or a niece drags them to a GP it is too late. (F23 age 60)

.....Cos actually you don't talk about medical issues, you just don't in our community. (F34 age 29)

It's all hush hush when someone's sick-first you know about it is if someone's dying. We're (GRT) very secretive. (F28 age 59)

I suppose they just get on with it. I think it would have to be something quite serious before ....., because I think sometimes they don't like people to think that they're moaning or that they're exaggerating something. (F10 age 23)

they don't realise the dangers, like diabetes. They don't look after themselves. (F24 age 38)

lot of Travellers aren't sure about health problems and that and they just get on with things and they just get on with things and they have something wrong with them and they don't realise what's going on (F6 age 27)

These explanations are familiar ones to those who have worked with GRTs and they pose a particular challenge for the GRT health team to help people to overcome some of these fears and to gain a better understanding of common conditions that could be either prevented or detected and treated at an early stage.

In addition to attitudinal explanations for delayed attention to poor health the other frequent explanation given was that poor health was a consequence of the stressful lives that GRTs experience.

The stoical trait of 'just getting on with it' was mentioned frequently in relation to all aspects of health, whether it was in delayed help seeking or not making a fuss when they were receiving treatment.

he was in hospital in absolute agony but he wouldn't press that buzzer because he didn't like to ask for medication coz he didn't want to put anybody out. (F34 age 29)

In a way with Travellers we'll push on. We won't say' I'm bad and this that and the other.' We're all working away on it (M18 age77)

However there was pride in this stoical trait among GRTs and it can be a positive trait in regards to recovery or coping with a chronic painful condition

They're delighted with me how I got over my operation. They said women half my agewouldn't do the things I do. Just pity themselves half of them don't they. They don'tknow what hard work is half of them today.(F19 age 90)

I said "well I will just manage best I can, thank you very much but there's somebody always worse than you "Yeah I am in a lot of pain (with fibromyalgia) but I can normally get away with paracetamol and ibuprofen" (F37 age30)

Another positive trait is the level of family support available to a family member with illhealth, although this can sometimes to the detriment of all family members concerned

Family (sons and daughters/ daughters in law) are supportive and are always there tohelp but they don't discuss L's condition (diagnosis of dementia); their way of copingis not to discuss it.(M11 age approximately early 60s)

## Attitudes to screening and prevention

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Several people did believe in the value of cancer screening and said they either did attend or would attend for screening when called. Those that held this view felt able to use the word cancer and referred to wanting to get it treated sooner rather than later. However, the widely held extreme fear due to experience of deaths from cancer among family members still prevails. This fear, and the fatalistic view that nothing can be done to prevent it, deters many from believing in the benefits of screening.

NO. If you've got it, you've got it, not a lot they can do with it. .... because one of the biggest fears of a Traveller's life is the Big C. (M13 age 71)

I believe if you're going to get it, you're going to get it. You'd get the signs that would be enough for me... I'd go straight to the Dr. (F30 age 70)

Attitudes to vaccination also varied but those who did not attend for flu vaccinations were more concerned about perceived side effects. These fears still persists in relation to the childhood MMR vaccination and other newer vaccines which many parents still declined even if they were willing for their children to receive rest of the more longstanding elements of the childhood immunisation programme.

No we don't get the flu injections because we are warned we may get an allergic reaction to it, we are a bit scared of that. (F38 age 24)

Children all had baby injections except MMR- "still don't think there's enough research in it" (F24 age 38)

It was evident from these interviews that another challenge for BC is to be able to dedicate the extra time required for education to improve understanding about vaccinations.

## Views on health services and access to health services

Many GRTs talked of reluctance to attend the GP surgery for reasons other than those earlier described; mainly due to the perceived lack of empathy and understanding displayed towards them. Continuity with a trusted doctor, and a bond therefore with someone who knows and understands them, is an extremely important factor in whether they will attend a doctor or not.

I try not to go up there because I don't really like it up there [Drs]; it's not really brilliant. They don't listen to you anyway. From when I was at my own Drs at [place she lived before marrying and moving] I just don't think these Drs are as good. Like the Drs themselves don't really care that much. (F16 age 24)

My Dr [in Scotland] is very good. He's there when I need him. I've been there for years, don't think I could change. So if you needed a Dr again while you were here where would you go? We'd go to the Walk In Centre cos its open 8-8 A. You just want to be in and out; see what they give you .B I don't trust anyone apart from my own Dr; A we're very comfortable with our Drs ; they know who we are. (F7 age 47 and F8 age 25)

When it does feel necessary for GRTs to attend a Doctor who they don't trust or with whom they don't feel comfortable then communication is compromised and they are less likely to receive the level of care that they require.

We only say what we want to say, we keep the rest to ourselves. (F31 age 62)

Travellers don't check up enough and that gets the wrong side of the Doctors because he likes to see you up to date with your checks, everything going to according how it should be done. In x surgery you could just walk in and you could talk to them better. (M13 age 71)

Those who are travelling are particularly unwilling to attend a doctor as a temporary resident and are more inclined to attend urgent care centres or hospital accident and emergency departments for anything that they consider serious enough to require medical attention

*Every Traveller wherever they are go and find out where the nearest hospital or Walk In Centre is; they ask the neighbours.* (F29 age 32)

If you go to the Drs they ask you to fill out forms & it's all fuss and bother, but you can just walk into the Walk In Centre; no forms they just ask your name. When you want to be seen you just want to be seen don't you (F7 age 47)

Conversely, those who do have a doctor that they trust are much more willing to attend when necessary

X Surgery are really really good Drs. They're caring people, talk to you (F3 age 27)

if I've got a problem I go to the doctors. I mean I have been going to him for 20 odd years and we've got a really good bond. He was a family doctor, just him and his sister, but now there's other doctors but I always ask for him, I wait for him because I think he understands us. (F34 age 29)

There were additional concerns about hospitals and an even greater reluctance to attend unless absolutely necessary or to discharge themselves as soon as possible. Aside from fear, there were several concerns about hygiene

As soon as I can get out I get out. They are not just as comfortable at all, they are just not, and they stink because they are not clean hospital....If I had to go back into hospital it would have to be something very serious that I couldn't be treated at home for. (F38 age 24)

I did go to hospital there (London) and in my opinion it was terrible. I had gallstones and had bad migraines so I went one night and the state of it was disgusting. I had her (toddler) with me because I had no family to leave her with, and it was so disgusting that I had to have my husband sit in the car with her; there was blood on the floor. (F10 age 23)

Other frequently raised concerns about the NHS in general and hospital services in particular were about poor treatment they felt they had received, either due to poor communication and lack of cultural understanding or empathy or because they experienced poor medical care.

The midwives were really good in Darlington but not so good here. There was nothing wrong with them but they didn't understand Travellers: Like I had to go for a smear and she asked how many partners have you had in the past year? I said 'what? what do you mean, I've got a baby'? Have you really just asked me that? It's offensive. and

When [child] was younger I took him to the Drs cos he was heavy breathing and its one of the reasons he was in SCBU but they had it down along the lines that I was paranoid; I seen it "baby brought in for making noises". It wasn't like that at all; they never wrote down that he was in SCBU. If I hadn't took him in and there was something wrong it would have been my fault. (F6 age 27)

Fear and past associations of family bereavement were still the major factor for many GRTs when it came to hospitals

As soon as he goes in you can see it, he goes really red and he starts sweating and stuff. He likes panics in them....I think it's just the experience that he's had with family members being in hospital and being poorly. His grandad died in hospital, who he was close to as well, and he had to go and visit him a lot. Now he just tries not to go in if he can help it. (F16 age 24)

These accounts of health issues and health care experience highlight the many and varied challenges for the GRT health team in trying to improve knowledge and understanding and in improving timely access to appropriate health care. They also demonstrate the need for further training sessions on cultural competency for health staff in all disciplines.

#### Awareness and views of the GRT health team

Most people interviewed on the DCC sites were aware of the team but some were unaware or unsure about their roles. This was particularly the case for those who worked and were out in the daytime. Some knew about their existence but were not sufficiently motivated or confident to find out more and to access their service

"I don't really know what they do. I've seen them coming around but I've never been in to see what they do or what they don't do". (F1 age 38)

One of the respondents, who had benefitted from the GRT health team services and has since volunteered as a health champion, explained in clear detail how she realised that it will take time for many GRTs to build trust and confidence in the service, particularly in being able to approach them for support for sensitive health issues

Yes it's confidence. It's awareness that this service is there and that service being there. If you are going to be there- be there! I don't know it is softly softly catch your monkey...and especially with the kids. The last thing you want to do is go amongst that community to try and build that confidence and educate not just the kids but draw parents in as well...You are going to be like one of those child's psychologist that sneaks information out of the kids. It takes time. It takes not being there today then not there for weeks on time because you might sow the seeds today but you don't know when somebody is going to need you. Because for someone to have a need and be desperate, desperate to make that contact, they have got to know you. But it is the confidence that it won't go any further either. That they can break down, pull a skeleton out of the cupboard and not being afraid that they are not going to be paraded down when they get back. (F23 age 60)

Some, especially those on the unauthorised sites or temporary stopover sites (TSOs) were confused about the people they saw, thinking they were all 'from the council.' Since feeding this information back to BC she now visits TSOs with another member of health staff instead of with a GRT sites officer and is able to spend more time explaining her role.

#### Use and views of the Health Trainer service

Several people had used the health trainer service, either for a health check or for lifestyle advice and intervention, or both. Many had accessed the service opportunistically but some had been referred by BC. If they hadn't used the service themselves they usually knew of others who had used it and who had valued it. Some of those using the service mentioned that they wouldn't have accessed other sources of support to achieve their goals. This is important for the many GRT women who are very private, would not go to a facility where there were men and who lack the confidence as well as the motivation or finances to join public fitness facilities or classes.

*My friend on BA site goes to them and she's lost quite a bit of weight. It's good because you can do it on the site; not like you have to go anywhere.* (F3 age 27)

Yes they do that health stuff, and that gym stuff, I talked to Michaela about it because I was going to do it but then I changed my mind. Well I know few lasses that have been to their classes, the exercise classes and healthy lifestyle. I think they are giving the right advice out. They get listened to ...... (F24 age 38)

Good to know to see if your health's alright". good to have more information and not to have to do it on your own... We've always done everything on our own but some people don't. (F1 age 38)

*Met Cat (CG), she was really nice. I met her through Bernie (BC) for the weight; she came out. She wasn't judgmental or anything, she just wanted to help.* (F6 age 27)

One of my daughter's overweight and the other isn't. I think it's good, really good. Without it would they have gone anywhere else? No. She (her daughter) doesn't mind them coming to her but she wouldn't go somewhere. I think it's good in the comfort of your own home. (F21 age 39)

Some of those who hadn't uses the service explained that they worked or otherwise had busy lives. Others perceived the service as being there more for the younger generation but this is possibly because up until recently they have only seen younger people going to the sessions.

only seen them once or twice usually out at work.	(F1 age 39)

*it's good for those who've got the time to use them* (F37 age 30)

They put out leaflets about what's happening but the young ones with children usethem more(F28 age 59)

It is likely that over time older people will use the service more as they are encouraged by their younger relatives to do so and the perception of the service evolves.

Well I think it is great for them to be aware that the service is there or if they need it, I think that's amazing. It's just a shame that the older generation, they won't accept that there is that help for them. (F34 age 29)

It was acknowledged that the Health Trainers had been able to run more activities on the sites with most young people and that there had been initial constraints on offering the same level of services across all sites . GRTs from houses and from other sites are invited to attend the sessions, but over time it is likely that more activities and events will be available on each of the sites

I've been going over there; they were going to do healthy eating, and going to make things, and that started and then they were told that they couldn't do it because they weren't allowed to cook or anything in there and because of food hygiene and all that crap. So it was doing good because there were about half a dozen people or more who wanted to learn stuff. I think we did only one thing before they said we couldn't do it anymore. Because there's no permanent warden here it's harder to do stuff over here compared to Bishop; I think they do a lot more over there. (F16 age 24)

Some commented on the other activities concerning health topics. The positive use of incentives for attending was also mentioned.

There was a cancer thing; came and explained about breast cancer & type of things. Yes I go every Thursday. It was like for the children, the sun and certain times of day when it was worse and how to check lumps. They brought in these breasts with 5 lumps for you to find. We found them all. Has that made you check yourself? Oh yes, it makes you aware. Every week it was something different. The cancer one ran over 4 weeks & if you went to every one you got a free spray tan. I got one. (F4 age 38)

In addition to the topics themselves they were also seen as an excuse to go and engage in activities associated with lifestyle improvement. It appeared that these interviews were also an opportunity to promote or reawaken interest and to educate interviewees about the project where there was less awareness

I will start and go over there though because they do activities over there as well I think on the same day. .... It's just there so I may as well use it. (F16 age 24)

# Use and views of the GRT public health nurse service

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There was some misunderstanding about BC's role, particularly from those who knew her as a health visitor in her previous generic role. Despite BCs attempts explain the new service some of them still continued to contact her as if she was still in her generic role, and others felt that they couldn't contact her because their child had outgrown the usual age for receiving the health visiting service.

Bernie was our HV so we used to see her all the time at the health clinic. Since this role? Carried on the same. If we need anything we just ring Bernie, she deals with all Travellers now. (F4 age 38)

I just thought she was a health visitor. I met Bernie on the Bishop site when this site was being done up; she weighed J when he was a baby. Seen her a few times on there. Seen her twice here at the play session. I know she goes to my sister in law; she's got a baby, but Js at that age he doesn't get weighed no. (F3 age 27)

Most of those interviewed did know of BC and understood in vague terms what her role was. There was a strong emphasis on the importance of trust and continuity. Some interviewees referred to experience of other roles such as GRT officers where they'd experienced staff changes and were clearly wary that BC's role might also not be permanent. If this were to be the case it was their view that it could be detrimental to invest trust in her, despite feeling that they could talk to her.

With Travellers they send one person in, an outsider and then you get to know them and trust them and then they move them on. Worse thing they can do is move them. We don't like change! Takes a long time to know and trust someone. (F28 age 59)

Yes yeah [a good thing] because if it is the same person, it is not so much the younger but with the older ones it's that stigma about do you want to talk about what the problem is? ...You do not want a different one coming a fortnight later to them...do I trust you enough to tell her? but if it is the same one all the time you do, you build up like a friendship almost. (F36 age 32)

She helps everyone and that's what you need. It's hard to get into a Travelling family cos they're v close knit, v tight, conversations and such. They don't like to discuss

their business. If there's anything wrong with them they don't like to discuss it, but I think Bernie's getting there. (F17 age 75)

Those who had met BC did feel that they could trust her and this was highly valued. In particular it was her degree of cultural understanding and empathy that enabled her to be trusted, but also the fact that she was reliable; if she was contacted there was a confidence that she would respond and be available for them and would give them time and listen.

Even though we have a health visitor, (she was on the site yesterday doing the weighing), but Bernie is someone you can trust. I'm not saying the other one isn't, but Bernie's always there. Like if you phone Bernie you'll always get her on the other end of the phone or if she's in a meeting she'll always ring you straight back. You'll never wait for days, she'll always fit you in. She knows Travellers culture as well, doesn't she. She knows like, our ways. (F3 age 38)

She is good Bernie I will say. She has been coming a bit now and I think they are used to her. It takes some getting use to people. It will take a while to gain the trust, because you get them coming and you get use to them and they change job or get moved on...it happened for a few of them...hasn't it. You get different ones coming on and try to tell you how to live your life. They don't know how our life is. (M26 age47)

...they know she is a friendly face and she is there to help, not to hinder. She has worked on building that relationship with us for that many years, she is truly highly respected. .....I don't know, she just know how to talk to us I suppose .....they all think highly of her because she does an amazing job. I think the reasons why a lot of Travellers don't go to the doctors; I think it is because they struggle to talk to people. I think that is the biggest thing they struggle explaining and Bernie gives them the reassurance that is they are unwell and they don't want to go to the doctors or if they don't want to seek any medical advice then she is more than willing to it on their behalf. (F38 age 24)

If I needed to contact my health visitor I wouldn't have a clue who it was...I mean since I have moved here, I think there's been easy four different health visitors...I like to know who one person is ..Same person every time like you get to know who they are, they know who you are they know your background, you do not have to tell them everything all over again. (F36 age 32)

This developed trust has enabled some to 'open up' and seek her help when they otherwise might not have done or to access support that they previously did not feel was available.

She's explained things to me, help me sort things out. It's just been lovely having somebody who's in the system who'll help me and who I know is listening to me, because before that I felt no one was listening to me. So I got him weighed and discussed all the problems I had.....She was just really helpful because before that I didn't know who to turn to; there was no support I don't think. (F10 age 23)

I thought that he was due for injections and so I rang the doctors and they said "well if he was due for injections you would have got a letter", well I didn't get a letter so I rang Bernie and she had a look at my book and she worked out what he needed and she rang the doctors and I got an appointment and I got the injections. I was worried he was going to miss his injections. (F 38 age 24)

BCs good reputation and the trust that GRTs have developed in her have also increased her workload. Where other generic health visitors either don't have sufficient time to spend in building the relationship required for trust to be developed or do not have the level of cultural understanding required, some GRTs reject the generic health visitor in favour of BC

My first HV [generic], S, was nice and she introduced me to Bernie and then ever since I've always just seen Bernie. I mean non Travellers, once their babies get past the one year review they don't see a HV; it's a shame isn't it...... When he was first born I talked to Bernie about it, I did feel really down; didn't admit it, even to myself, but when I look back and it took about 2 months. I never got really down like some people get; like I always knew I loved him but it was worry that got me down and then A [her other child] was a bit jealous, and Bernie's always been there. My sister absolutely loves her. Every Traveller that I talk to would pick Bernie over anybody. (F6 age 27)

I don't like her [generic health visitor]. She said I couldn't cope with my kids. When he was two he wasn't a very good boy, we were having problems with him and he wasn't sleeping well at night. So we were having problems and all I ask her was "Is there any sort of system like a chart system that I could have to help with his behaviour?" and she just turned around and said "so you are not coping?" I said " yeah I am coping" so she said " well what I am going to do, I am going to refer you to the Sure start and somebody will come out for 6 weeks and social services might call ... " and one thing Travellers hate is social services." ...,,. The best thing for you" I said "is for you to get your bag and get out, I don't want you back" and then I rang Bernie and Bernie came out and she started to do the weighing and stuff after that ... I also said to Bernie I don't want that woman coming ever again and I don't want Sure start coming for 6 weeks, I just want some techniques to calm him down. I mean Bernie did that and it is all working now. (F38 age 24) Health Visitors [generic] they just want to know too much about your business, to be nosey. How do you know when it's to be nosey? Asking you awkward questions, like judging you. We know straightaway, we're not silly; it's how they ask it. If they come in they be straight in and start from the beginning, make excuses and just get around that way; so a lot of Travellers don't admit you kind of people cos you want just one thing- be nosey and see where we live and all that. So that's why a lot of Travellers pushes away for. (F7 age 47)

There were some interviewees, however, who had built up a long standing trusting relationship with their generic health visitor and didn't feel the need to use BCs service. Even though their children were older and no longer received the core health visiting service they had the trust and confidence to contact her or they would contact their GP if required for the medical needs of any family member.

I mean when I first met N, my health visitor, I made her fully aware of who we are and hopefully she accepted us. It is a nice family and I'd like to think that I and she get on really well. Yeah we had a really good relationship for the last seven years since my elder daughter was born.... (F34 age 29) For me it is not something that 'd need or want because N (generic health visitor) has been coming to me for 9 years. If I have a problem I can ask her or go to the doctors. Yes I love N. She is been my health visitor with all four. (F35 age approximately 30)

More usually the core generic health visiting service is unable to cope with the level of need and the GRT service is increasingly valued for the additional support offered. This support is recognised and valued by older GRTs as well as younger mothers

Travellers have got such a lot of old fashioned ideas about babies and sometimes they need to go and see someone and they can't be bothered to make an appointment, but if someone was here they can go and they can ask. Other health visitors look after Mums and children though? Yes but after a while the health visitor stops say after a year (F12 age 72)

It's nice now that you've got a health visitor that you can say 'Oh could you pop in I've got something I'd like to discuss with you' ..... If an old person doesn't feel right I could phone Bernie and say could you pop out and see her ..... she might be able to advise them 'I'd advise you to go the drs or I'll take you to the Drs' (F17 age 77)

#### Perceptions of cultural awareness amongst health staff

Several respondents spoke of their trust in the GRT team being partly due to their cultural competency *'they understand us', 'they know our ways', 'they know how to talk to us'* etc, so it was important to know the degree to which lack of cultural competency or actual discrimination influenced their access to services. Most respondents felt that in County Durham they received no adverse treatment as a result of their ethnic identity, although in some cases this was attributed to their hidden identity

I can't say I've ever noticed anyone professionally whose treated me any different anyway. My kids have never had a problem with bullying or things like that. I think it's different in different parts of the country; I don't think it's so bad in the North East; don't think Travellers are treated any different in this part of the country. Then again I think it's how you bring yourself across as well. (F4 age 38) They kind of like Gypsies round here, like the North East; they're kind of horsepeople.(F14 age 47)

Yeah, I haven't had no bad experience really. I've never been treated any different, but I suppose it's when you've got that accent its different. Have you seen other Travellers treated differently? Yeah, like when I see Travellers from elsewhere with that accent and I hear them then I just think 'oh that's a Traveller' and that's it but you can see other people staring. (F21 age 39)

Most had experienced racism and discrimination in other spheres of their lives and several partially attributed this to the impact of television programmes like 'Big Fat Gypsy wedding' (BFGW) influencing negative views

*I don't think they understand Travellers, they look at the TV* (programmes about Travellers eg BFGW) *and they make their decisions and that's it.* (F6 age 27)

I think these TV programmes give the wrong idea; I watched Gypsy Kids last night and that's nothing how my kids are brung up. Half of it is just made up, it's not real. Same as BFGW. Some of them on there aren't even Travellers (F5 age 21)

We do [get prejudice], people calling us names ... You get people calling you gyppos and pikeys and that. We just want a peaceful life. We're not like on BFGW. If you were a bad person I wouldn't let you in my caravan, I'd talk to you outside. You have a sense; it's a gift, it's always been a gift with Romany Travellers. We know it from being born (F7 age 47)

There were exceptions however where some respondents had experienced prejudicial attitudes within the NHS

I know we're loud but when he was in SCBU [special care baby unit] I took [4year old daughter] to the toilet and then buzzed to be let back in and my husband heard one of the nurses say "Oh it's these, they're always in and out, they're always loud"! Well that was it! He was 9 days old and I was full of hormones and I said "who do you think you're talking about and I said don't try and deny it cos we heard you.

My husband has [experienced discrimination] with work though; he had to leave his job for racial abuse and he'd been there 5 years. He was working with people with alcohol related brain injuries and it was a nurse who racially abused him.

(F36 age 32)

Others had lowered expectations of how they would be treated

Surprised they did a HNA of Travellers Why? because Travellers are neglected. They're not really recognised as an ethnic group (F29 age 32)

Some spoke of what they perceived were GRT characteristic traits that non-Travellers reacted to, particularly 'being loud', and to some extent blamed other GRTs for conveying a bad image and risking other GRTs to be 'tarred with the same brush'

I think everybody has had a bad experience at the doctor's because there is some people they just don't like us, and there are some Travellers that just don't like non-Travellers. ... I think that's where the problems come from with the doctors and the nurses and hospitals, but also lot of Travellers are that loud, they have to be seen and heard by everybody. I think that annoys the doctors, the nurses and the hospital staff, they just can't be bothered to talk to them because they are being ignorant. This is a bad thing that Travellers do, some of them can be just that ignorant..... They will be professionals about it but will not be how they would be with you or me. They will spend the minimum amount of time with you just too really get you out. (F38 age 24)

Although none could say that since the cultural awareness training sessions had taken place they had experienced any changes of attitudes or improved cultural understanding among NHS staff that they had contact with, most felt it to be something that was worth doing.

Yes I think so because a lot of Traveller women don't like men doctors or men nurse anywhere near them. Me, I don't care as long as they are going to fix you but some of them they don't want them anywhere near them and it is just the way they are

(F38 age 24)

Yes, because at times like death, you'll understand that a lot of families gather together and a lot of the hospitals don't like it. I do understand they've got other patients to see but it is a big thing in our culture that everybody goes out of support for each other, so I think that would make a big difference. (F10 age 23)

Think it's good, because like Bernie- she knows how to go about people, knows whatyou want(F37 age 30)

#### In summary

Health and Factors affecting health and access to health care

- High levels of self- reported chronic ill-health among Gyspies and Travellers
- Recognition of importance of lifestyle factors as influential, particularly diet, exercise, and also caffeine intake
- Stress seen as a significant factor; stress arising from financial worries, health of family members, bereavement, accommodation related situations
- Recognition that most 'hide' their stress or mental ill health, usually due to stigma and feelings of shame or denial/ lack of awareness that there is a problem
- High levels of experience of suicide in extended family or wider community
- Many attribute poor health of GRTs to avoidance of health care
- Reasons for avoidance reported as fear of serious diagnosis, fear of being judged, lack of trust, embarrassment, poor knowledge and understanding of symptoms, past negative associations; particularly of bereavement, stoicism/ pride in coping.
- Mixed attitudes to screening programmes and to adult vaccination but many are wary and avoid both

#### GRT Health Trainer Service

- Many are self-referring to the Health Trainers for lifestyle intervention; particularly to lose weight and to increase exercise.
- Health trainers seen as approachable, non-judgmental and supportive
- Several have completed 8-12 weeks individual intervention sessions and have attained their goals
- The health trainer service has increased motivation; many would not have sought help or set themselves goals if the health trainer service had not existed
- Many older people have been less inclined to use the service as they feel it is aimed at younger people
- Some people who are out at work in the day have been less able to access the service
- Group activities with a health focus in the holidays are valued and attended by children but also by parents

• Health promotion activities associated with public health campaigns have been attended and appreciated

GRT public health nurse service

- There has been some confusion about the wider role, especially among those who previously knew BC as a generic health visitor
- Most recognised the need for the role and appreciated that BC 'was there for everyone'
- Many stated the need for long-term continuity in the role and for necessary time to build trust
- BC highly valued for her cultural understanding, empathy and approachability and did not fear that they would be judged
- Some GRTs have rejected their generic health visitor through their lack of cultural understanding ; others have developed a long standing trusting relationship with a generic health visitor who ' understands them'
- Many valued BCs reliability and had confidence that she would respond to requests and give time to listen
- BC has increased people's confidence to 'open up' when they would not have previously done so and have gained reassurance from her to attend the GP when necessary.

## CHAPTER 9 SERVICE PROVIDER PERSPECTIVE

#### **Baseline Evaluation**

During the baseline evaluation period consultation took place with a range of services with a remit to provide health or social care either directly by the NHS or DCC, but we know from many who have attended cultural awareness training sessions, that secondary care services, for example, community psychiatric nurses, community support workers, health improvement practitioners, have mostly had only limited contact with Gypsies and Travellers in their work. Equally there are a range of services provided by charities and voluntary sector organisations, for example East Durham Trust who manage various projects to improve health and wellbeing, Cruse Bereavement Care etc, but there is minimum access to these services by members of GRT communities.

GPs in both CCGs (Clinical Commissioning Groups), ie North Durham CCG and Durham Dales, Easington and Sedgefield (DDES) CCG have reported a general limited awareness of the 2011 Health Needs Assessment for County Durham and Darlington and similar lack of awareness overall of the specific health needs and health status of Gypsies and Travellers. There is only anecdotal knowledge of Gypsy and Traveller access to services and rates of secondary referrals, as there is currently no use of ethnic codes for Gypsies and Travellers on the data collection systems.

Although guidance has been issued by the Royal College of General Practitioners (RCGP) on Improving access to health care for Gypsies and Travellers<sup>13</sup> its existence was unknown at general practice level. Similarly there was no awareness of the Primary Care Service Framework for Gypsy & Traveller Communities guidance, issued in 2009.<sup>11</sup> This lack of awareness is not specific to Co. Durham, as similar lack of knowledge of these guidance documents has been reported elsewhere in the country, and this highlights a problem of communication of relevant guidance.

From consultations, primarily with Public Health leads, GPs, Health Visitors, and School nurses, but also with other agencies and disciplines who work directly with the communities. the following health issues were identified as the most prominent:

- Cancer- late presentation
- Obesity
- Ischaemic Heart Disease
- Diabetes
- Alcoholism
- Mental Health (mainly depression), but including suicide incidence in families
- Domestic Abuse

The following service provision concerns were also identified:

- Poor secondary referral rates to mental health services despite anecdotal evidence of high need, including suicide history and suicide ideation.
- Reported high inappropriate use of A&E.
- Domestic Abuse, Drug and Alcohol prevalence –anecdotally high but limited access to specialist support services (hidden problems).
- Many GRT Carers but limited use of respite services.
- Extra time required for contacts (relationship building / trust)- and tendency only to engage on health issues that they see as urgent / important – impact on service provider time
- No community nursing (health visitor) remit for Gypsies and Travellers on unauthorised encampments

#### Two year evaluation

#### Methodology

Thirty interviews took place with service providers from primary care and from key GRT specific services between September 2016 and January 2017. All consented to their interviews being recorded.

There are nine GP practices across DDES and North Durham CCGs that have known GRT patient populations. To achieve a wide experience from different staff disciplines across the GP practices there was random sampling to include each discipline and each general practice. In addition to staff from general practices other primary care staff (health visitors, district nurse and mental health nurses) were purposively sampled. The GRT sites management

officers, GRT education lead the GRT Disc worker and a social worker from Child protection services were also included (see Fig 30 sampling grid below)

	DDES CCG	N.Durham CCG	County wide	Total
Practice Managers GPs Practice nurses Receptionists /Office ANPs	2 2 2 4 1	2 2 0 2 1		4 4 2 6 2
Health Visitors District Nurses CPNs / TEWV	4 1	0 0		4 1 3
GRT officers team (DCC)			1	1
GRT Education			1	1
Social Services			1	1
Vol Sector (DISC)			1	1
TOTAL				30

Fig.30. Sampling grid for Service provider interviews

#### Two year evaluation findings

➤ Knowledge and awareness of the GRT health team

A few practices were aware of the GRT health project and how they could use the team.

She came and spoke to myself, the partners and the practice manager and the GP registrar. (H4 GP)

The majority of practice staff interviewed though were either unaware of the GRT health team or had heard of them but were not fully aware of their roles.

Yes I have heard of her (BC) but I didn't understand her wider role.

(H17 Practice nurse)

This is not so surprising for two reasons; BC and the health trainers have focussed on delivering their service and have found it hard to arrange times to visit each practice to introduce themselves at practice meetings, and there has been high staff turnover in general practice so that some of those who had either been at the CCG cultural awareness training sessions or who had met BC, had since moved on.

These interviews were an opportunity therefore for awareness-raising about the project. Since the interviews took place BC has arranged to visit more of the practices and the team have also arranged to circulate their newsletter to the practices.

Views and impact of the GRT team

Although many of those in general practice were not familiar with the service, they as well as the other service providers thought that the service would be beneficial. There was general acknowledgement though that it would take time for any positive impact to be evident.

all these things take time to embed and to actually see the benefits. You don't see change having an effect in one or two years, it takes five or ten years but the principles are good where it is not trying to offer them their own service but to make sure that the service that exists are less intimidating (H20 GP and CCG lead)

I think it is going to be long term isn't it, I don't think you are going to discover major impact overnight but I think the little bit I have picked up from the families, they need to have that kind of close groups of professionals supporting these families, looking at their health and make sure everything is looked at . You can see the benefit of it and why it needs to be done...If they don't look after themselves and they are very wary of professionals; you need that constant support and services you can direct them to. For me I would see that Bernie as one person because once you know that one relationship they know your face, they trust you and that is it, you are sorted. I think that is what that community needs. (H3 Health visitor) I think it is a good idea, I think some of them might be reluctant to seek health advice. I think it is a good idea because it gives them the opportunity to get to know somebody, or trust somebody. (H5 Nurse Practitioner

Those in general practice were not aware of any impact because they are seeing individual patients who are presenting with health problems

It is difficult to look in the job to see an impact because you are just dealing with the person in front of you or don't really know what is happening in the background but I am sure there is an impact. Certainly from hearing Bernie talk I am sure there is an impact. It is not something that I would necessarily be aware of. Our nose is just a bit too close to the cold face. (H16 GP and CCG lead)

Generic health visitors, who have less dedicated time to spend with GRT clients, spoke of their difficulties in engaging over difficult taboo health issues

there are some difficult conversations I do have to have because I have another family going with domestic abuse. I know that through police information. I think I find it harder with the Travellers because it is much more of a taboo subject and I would like to have that conversation, but when she will be open to it I do not know. (H3 HV)

He would talk to a certain extent about his mental health but wouldn't truly open up about it. (H3 HV)

women are very very private, they don't like discussing any intimate issues, things like that and I think it has always been like that for a long time. (H24 DISC)

These difficulties for generic health visitors in having the required length of time to engage with GRT clients have been compounded since the introduction of the new core service and more detailed health assessments that they are required to complete with each new family.

It is difficult because in the core pathway you only have 5 or 6 visits and can you build a relationship in that time to get this information. We 've also got new health needs assessments at the moment that we are all learning to use, they go quite deep you know into family background, history of families, these questions that you do need to ask and then you've got the reading and the writing issues. I mean it is all the same, they are very difficult questions to ask and some of our health visitors say they tend to say to their clients " have a read through those" but with our Travellers patients you can't do that, partly because of the way they are worded generally and partly because some of them don't read or write..... there are some horrible questions in it that can open up a lot of raw wounds for a one hour visit, to walk away from. (H10 HV)

BC however has greater scope to complete these assessments over time and as she begins to build relationships with the families it will be increasingly easier to address sensitive subjects

An interview with the GRT sites management team revealed that there was a significant impact in the cultural shift of feeling more confident to discuss health matters in general (though not the more intimate health issues) when such conversations were previously considered taboo. Similar benefits were reported by the GRT education lead

Occasionally someone might have approached us with a query, it would be panic stations to try to get them to the nearest doctor. But other than that we didn't have anybody mentioned anything else ever. And since that project started first with the health trainers and then with Bernie, has that changed at all? Yes definitely, I think that people are talking about it a bit more now in the site. I mean it is not a taboo subject as much as it was. People are openly talking about their illnesses now as well. and sometimes people make requests to see Bernie through us as well. I think Bernie's role in particular has had a major impact. (GRT sites management officer)

I think it is the home visits that are the success of it, of Bernie's work, the ability to be able to go and see them because of course if your literacy levels are poor then going anywhere where you are required to read or give information, there's a real challenge. There's an embarrassment of sharing problems but when someone's sat in your own home there's not the stigma attached to it. I mean this lady said to me "the men in my family would never go to the doctors, they'll never go"... "but we know we've got Bernie" But quite whether the men would ever say there was anything wrong to then get Bernie, I don't know"...But just the idea that Bernie is there, it is a ripple effect isn't it? GRT education lead One of the benefits of the GRT health team and BCs role in particular has been the team work and cross- referrals, resulting in increased engagement and access to relevant services. There have also been collaborative projects such as the herb growing with the homework club children which has tied into health and healthy eating. Previously the DISC GRT service, GRT education and the GRT sites management team were working more in isolation with relatively little cross referrals to each other's services.

if any of my clients has any health issues, I always say "well why don't we ring Bernie, Bernie is a Gypsy and Traveller health nurse so what about if I come out with Bernie and then you can have a chat to her?" (DISC GRT worker)

The last one again that I had as well was mental health but it was of joint working. Bernie was already aware of the situation through the health worker up at Birtley and she had that link and then obviously I got involved through the tenancy management service side of things. So we had to work together. Things came to a head the other week and Bernie was there for support. She has got quite a good relationship with the tenants to be honest. (GRT sites management officer)

GPs and nurses in general practice also spoke of their willingness to refer to the GRT health team once they had been made aware of how they could do this. Generic health visitors who have GRT families have also used BCs specialised knowledge and support network that she has developed

It helps with different things like helps with funds for accessing nursery or she's said things like "oh I'll speak to so and so about this" or she has known other people who have been able to support them in different things. Yes she has been very useful. (H9 HV)

Health related issues and difficulties identified

There were a range of issues and difficulties identified by different staff members in primary care, many of which the GRT health team were in a position to help to address. A frequent problem is the difficulty in making contact with patients, either due to poor literacy or with incorrect contact details

With most of them it is verbal communication, some of them take printed material but the group that can't read or write some of them find a sister or a cousin who can read it out to them. They normally come with somebody. There is one man who comes he comes on his own most of the time, he can't read and he can't write but he takes things on. I mean he doesn't even remember his telephone number and things and that is another big area where we can't get in touch with them. Many times you find the mobile numbers are wrong, they get changed. (H13 GP)

I think the only frustration we have sometimes is the address. We got things like "well if you send it to this address it is my second cousin' house", their whereabouts is a nightmare, an absolute nightmare. And when you send things to Adventure Lane site, apparently it goes to one address and someone acts as postman (H8 Receptionist)

The person I saw yesterday, I look at her records to see had she seen the GP before and there were 14 people registered at the same address but there's only 4 living in it. It has been brought up to find out who exactly who is where. Because obviously if we are sending out letters and people aren't getting them, we are not getting through to the correct patients.... (H4 GP)

Similar problems identified by reception and office staff concern the retrieval of correct patient records. These problems are due to lack of consistent recall of names and dates of births and can cause potentially serious problems if for example test results aren't recorded in the correct patient records

Date of birth is a problem, the names of their children...someday they call them something and then they come back and they are calling them something else. It can be Billy Bob or he is Bobby Bill and he was born this month of that year. We are trying to match them up sometimes is difficult. It is a real difficulty. Sometimes they don't have their own date of birth, the adults. So trying to match them up to their national spine is an issue. (H15 Practice Mgr)

Date of births they don't really remember, and if we prompt them a little bit, they will try and ask somebody else and they'll come back with the date of birth. It is just about getting them on the system because the system asks so many questions. You try to get as many answers as you can from them and put them on the system as best you can. It wants their unique date of birth and NHS number and we try to get round that and put it on the system as best we can. (H17 Office staff)

More frequently the issues of poor engagement or reticence to attend the GP surgery or hospital were highlighted and for similar reasons early self-discharge from hospital. Some generic health visitors had found the need to increase confidence in attending by accompanying them to an appointment

they have always left it as long as they possibly can before they are referred to somebody, before they are trying to get help. I think they are very reluctant to have people in their space. I didn't get the impression they like to go to the GP or anything like that. We were a nurse led service so it was either GP referrals or other referrals or self-referral. So they self-referred but by the time they did refer themselves to us they should have referred themselves a lot lot sooner.......The Travellers I saw are very really poorly, I mean they probably should have been in hospital but they didn't want to go for whatever reason. So we looked after them at home.

(H5 ANPs previous role)

The mums don't tend to go out to the GP very often, it is mainly for the little ones. You don't want to handhold them but sometimes if it is necessary I'd say "well you know I'll go with you". (H3 HV)

The problem we have is in getting them to engage. So what tend to do when they do want to be seen, we tend to register them that day, trying to get them seen that day by a clinician. We know they don't like to come to the doctors. We do have a few registered with us, they tend to only come when they have got a problem and we tend to try to get them to be seen that day rather that tell them to come back.....

(H15 Practice Mgr)

We have had several members of the same family who have not always attended. We don't just give them one appointment, we will give them another appointment then again if we have telephone numbers but sometimes telephone numbers aren't up to date. (H23 CPN Primary care link) And when they want to go home, they want to go home. Well the paperwork's really important, the baby needs examination of the newborn done, they say "no I am just going now, because you see he has to go to Asda and he has to come and get me now, we have to go". Just recently a midwife I know went to see the baby and she went and the mum was out and she said "well I need to see the mum and the baby." "Well the baby is here, you can see the baby but there's no need to see the mum and the baby." This is like the grandad and she's been chasing round all day and they've already gone without the paperwork and without the examination

(H3 HV student, previously a midwife)

the mothers who I tend to have contact with, that's sort of "I'm ok I don't need to see anybody about this"...and then things come out and spiral out of control, like a chest infection then becomes more serious (G22 Education)

The level of mental wellbeing on the site seems to me to be quite low. I don't think some people know [recognise that they have a problem]

(H22 Equality & Diversity lead TEWV)

The reluctance of GRTs to attend the GP often results in further problems, either with inappropriate use of the Urgent Care service or in delayed presentation of potentially serious conditions. A related problem occurs when the condition seems serious enough for them to attend as they are by then extremely anxious and seek an urgent GP appointment and they often require a longer appointment time. They also often require longer appointment times because of complex co-morbidity.

they are all going out of hours they don't think of going to the GPs, they bypass the GP because they'll be worried they'd have to wait for an appointment. So it is a lot of the women wait for their husband to come home and take them so they just go out of hours. But I have had some messages from the GPs saying "well this baby has been out of hours six times can you do something about it. (H3 HV)

Sometimes they are quite determined that there is something really wrong with them and when you do an investigations and look into it you can try to convince them it is ok but sometimes they can be a little strong headed (H4 GP) Definitely the group that we have since working here for the last 14 or 15 years now, the group is particularly vulnerable to mental health and the health seeking behaviour is very different. ....Many of them are desperate and the ones who comes are the ones who have quite significant medical mental health problems. (H13 GP)

Just with the experience I've had, the patients I have visited, they've always had lot of chronic diseases, complex cases to manage really; mainly respiratory problems, COPD, heart failure, asthma. I didn't see anybody because of diabetes but we did see people who had diabetes as well. (G5 Nurse Practitioner, prior community nurse)

Insufficient or inaccurate health knowledge, coupled with awareness of historical serious fatal outcomes for family members that they associate with their presenting symptoms increase the acute anxiety that GRTs often experience by the time they attend.

We had an elderly couple coming and they just had a bad standard type of infection and he was ok ...they were so worried about him they thought he was going to die, when I told them he was fine and I gave them some antibiotics, they thought I was the world's best doctor. It was just a simple presentation and they were all so worried about it. Most people wouldn't be worried, I mean they might come and see the doctor but they wouldn't be worried they were going to die. (H4 GP) There might be one or two cultural issues as expectations around children health, partly the anxiety but also partly the feeling something should always be done even for self-limiting conditions. (G20 GP)

I am starting to pick up on patients that I probably need to spend a little bit longer with .....We do a lot of safety netting just to make sure that they understand what we're telling them to do and that the x, y or z happens...So I'll explain what's wrong with them, what the treatment is, but if x, y or z happens either to call us or to go to out of hours or A&E, I mean depending on what the problem is. I worry that sometimes they will either not follow it or follow it too quickly. (H4 GP)

*I wasn't aware* [of GRT health status] *but I can sort of see it when they come in. Like a lot of their relatives have passed away, there is a lot more bereavement.* (H4 GP)

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Lack of informed knowledge and resulting fear of vaccines that are considered new also results in poor attendance for completion of vaccination programmes. Although the media coverage of complications from the pertussis vaccine in the 1970s and the MMR in the 1990s were a long time before the current mothers of young babies would have been aware of them, the fear of these and any other 'new' vaccines persists.

The biggest has been the understanding around immunisations, the choices they have made. They will have immunisations but they won't have the MMR. (H9 HV)

This is a group who don't take up immunisations for the beliefs they have. There is an increase in the number of people doing it but we are not still able to hit the target. (H13 GP)

I do a lot with the baby imms and they do come I think, but although they do probably attend there is a reluctance to try anything new. We still got them refusing MMRs and you can't change their minds on that. They are reluctant to take the new rotavirus and now of course we have the new Men C vaccine, anything new they are a bit wary of (H17 Practice Nurse)

One of the other issues identified by service providers is the lack of continuity in care and cuts to services. There is a particularly high turnover of staff in general practice with some practices having had a complete change of clinical staff over a short period of time. This is a problem that is particularly difficult for GRT patients who have a strong need to see the same person that they develop trust in over time, whether that is the GP, the nurse or the mental health team. There is also an impact on the service providers concerning the pressures on their time and their availability to give the extra time often required for GRT appointments

We have virtually a whole new team here, a lot of the older staff have gone...a lot of the support workers are the same but it is the normal process of losing people really through ...retirement...we had three people retire since I started (H21 CPN)

I think general practice itself has changed greatly... it is seen as much more highly pressured than it used to be. It is not the easy option to take. It is possibly being less

attractive for that reason with the change of demographics in the region generally, dealing with far more elderly patients with multiple pathologies, the tendency has always been to try to shift things into primary care, and secondary care has added to the pressure over the years. (H20 GP CCG lead)

There used to be a bit of give in the system and people giving that bit extra and now there's none. For a long time, every year we've had to reduce make cost efficiency savings, we can't just keep on doing that and so now people are in and out of services much more quickly. That does not work so well for people from the Traveller communities, they need more time. The worker for [the GRT patient] who rings me, felt she needed a more flexible, not CBT based, but more problem solving listening supportive type of service. It doesn't necessarily fit it so well with people who are monitored on how many visits they do, so for a team to put that kind of resources, it is much more difficult than it was. (H22 Equality & Diversity lead TEWV)

the level of suicides is very high and again I don't know what suicide preventative work we are doing in the Trust at the moment but I would imagine that is being cut as well. Most [ GRT] families I seem to have had contact with have had some sort bereavement which is incredibly unusual. That must impact on mental health. (H22 Equality & Diversity lead TEWV)

#### In summary

- The majority of the nine GP practices with GRT patients were unaware of the GRT team and their roles, but they thought that the GRT team service would be beneficial.
- There was general acknowledgement that it would take time for any positive impact to be evident
- GP practice staff of all disciplines reported a range of difficulties and issues that they experienced concerning GRT patients, most of which the GRT health team were in a position to help to address. These included: inaccurate records of addresses; dates of birth and contact details; non-attendance for routine appointments including follow ups; bypassing GP in favour of urgent care centres; need for longer appointment times due to either complex cases, delayed presentation until urgent or lack of understanding requiring extra explanation and reassurance.
- Many generic health visitors experienced difficulty in finding the required lenGRTh of time required to full engagement with GRT families, particularly since the introduction of the new core service and the requirement to complete a full detailed needs assessment covering sensitive topics at the initial visits.
- Generic health visitors valued the GRT health team service and were willing to make referrals to the team and or to seek specialised support
- GPs and practice nurses are willing to make referrals to the GRT health team and to seek their support
- Staff in other roles, who work with GRTs (GRT education, GRT voluntary sector, GRT sites management team, social services, mental health services), value the team work and close liaison that has been developed with the GRT health team and have appreciated the increased access and engagement that has resulted with each other's services.
- There has been a recognised cultural shift amongst GRTs on the DCC sites in the willingness to talk openly about health matters when this was previously seen as taboo.

#### **CHAPTER 10**

#### CONCLUSION AND OVERALL PROJECT EVALUATION

It is premature to attempt to evaluate any long term health gains from a health project of this nature and scale, but in nearly three years since the initial elements of the project were put in place many short term gains have been identified and there is clear progress being made towards the longer term aims of the project. This progress is described under the headings of the four main aims of the evaluation and concludes with recommendations for future development

#### Evaluation of the effectiveness and economy of the interventions

#### Improving access to health services

There were two key actions aimed at improving access to health services:

- i. Production of culturally relevant health promotion resources
- ii. Provision of cultural awareness sessions to health and social care staff

A cost benefit analysis of the interventions is beyond the scope of this evaluation and the eventual cost savings would only be realised over a greater period of time, for example in NHS treatment costs saved through prevention, earlier diagnosis and improved management of chronic health conditions . Potential savings gained through alternative care pathways in two health scenarios elsewhere have been reported in a costs benefits analysis in Gypsy and Traveller Health- Who pays.<sup>27</sup> This gives an indication of the potential economic benefit of interventions to improve access to services in this project.

However the reduction of health inequality and of inequality of access to health services are the main aims of this project and although these aims will also only be realised over a greater time period there are several short term gains already realised.

The production of culturally relevant health resources is still in progress so it's not yet possible to report on their effectiveness. However interviews with stakeholders indicate that they will be used to good effect. The participation of members of the GRT community in

<sup>&</sup>lt;sup>27</sup> Leeds GATE 2013 Cost Benefit Analysis - "Gypsy and Traveller Health - Who pays?"

producing and appearing in the films are likely to increase the likelihood that they will be viewed and seen as authentic and relevant.

The cultural awareness sessions evaluated well by those who attended, with several reporting changes to their practice and heightened awareness of the health needs of Gypsies and Travellers. However, with a high staff turnover and a wide range of service providers who were targeted, there remains a large number of health and social care staff providing services to the GRT community who have not yet benefited from the training.

#### Tailoring health services to the needs of Gypsy, Roma, Traveller communities

The key actions were to develop a dedicated team of health professionals and health trainers to raise awareness of health services and support healthier lifestyles.

The creation of the GRT health trainer posts in 2014/2015 has been effective of supporting healthier lifestyles and the numbers of clients accessing their service continue to increase.

Most of those seeking the health trainers support would not have otherwise made the changes required because they had no encouragement in the sense of support to do regular exercise and they wouldn't go anywhere away from the site to access support at gyms etc. Many have also made substantial changes to healthier diets through the programmes and this has not only benefitted those individuals but has resulted in improved to the diet for the rest of their family. Through word of mouth, GRT in houses and on private sites, are also seeking support from the health trainers to adopt healthier lifestyles. Housed GRT and those on private sites have previously missed out on any GRT focused health initiatives despite having the same needs.

They are visited in their homes on self- referral or by referral from other practitioners but some are also encouraged to attend group activities on one of the sites. This also has the added benefit of helping to reduce the isolation that many GRT experience when living in houses, apart from the wider GRT community.

The creation of the GRT public health nurse post in 2015 has been successful not only in increasing awareness of their health needs but also in accessing appropriate health care and to build confidence to do so with timely presentation. The public health nurse role has been effective in the short term in improving attendance both at primary care level, secondary mental health care and also for hospital appointments. Many of those who have used her

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service would have previously avoided or delayed seeking health care, and in particular this includes 10 men who do not typically access health care services unless there is extreme need.

The many GRT who stay on temporary stopover sites or on unauthorised sites are now having their health needs met when previously no health visitors had a remit to visit them.

There is continued work to improve uptake of preventive screening and of vaccination programmes for adults and children.

By working together as a team the GRT public health nurse and the health trainers have been able to deliver health promotion events on site with a culturally sensitive approach. They have also involve parents in children's activities such as sports days and Halloween events on sites and provided the opportunity to try health food alternatives and find fun ways of increasing physical activity. Working together as a team has also enabled each aspect of their service to become more widely available to GRT in houses and on private sites as well as on the DCC sites as they make appropriate referrals to each other. By working in partnership with other services this ability to reach a wider number of GRTs has been further facilitated.

## **Exploring the barriers and facilitators for adoption and development of the intervention** (referred to as the project).

The four elements of the intervention were adopted at different stages. In adopting the public health nurse element of the project there were particular barriers in negotiating contractual arrangements between the commissioners in DCC and the Health Care Trust responsible for health visiting at the time. These mainly focused on financial costs. There were also prolonged negotiations over the proposed job purpose and focus. These two obstacles resulted in over a year long delay before the public health nurse was in post. The extra costs requested by the Trust, which were finally agreed, resulted in there being insufficient funding for a support worker post to work with the public health nurse in a community development role.

The main barrier for development of all but the cultural awareness element of the project is the necessary time required for community engagement and to build trust. This is not a true barrier but more a requirement of any project that aims to promote community health and embed change. It is essential to build in time for community engagement, particularly in a widespread community over a large geographical area that has no existing community support groups. The inclusion of a community development worker post would have facilitated community engagement.

The main facilitators for the development of the project were the enthusiasm and support of other services working with GRT communities. They both promoted the services and helped to introduce the team to community members, thus helping to build trust. The wider GRT strategy, with regular meetings to review progress on agreed key objectives, was an added facilitator which resulted in a holistic approach to reducing inequalities by addressing other social determinants.

The flexibility of those managing the services was also crucial in recognising the need for lowering target expectations and thereby allowing community members the time required to develop confidence to access services. It was important for continuity that the subsequent health trust who took over the management of health visiting in county Durham agreed to provide the GRT public health nurse post permanently as part of the health visiting service contract with Durham County Council and later employed a part time early years practitioner was appointed to work with her in recognition of the workload entailed

Team working was a facilitator for all elements of the project. By working as a team they were able to put on activities and health promotion courses that would have been difficult to organise in isolation. Each element of the project also gained from cross referrals to each other's service. The early formation of the practitioners group which facilitated wider networking was also a facilitator.

The inclusion of a service evaluation was also a facilitator to promoting awareness of the project to a wide number of stakeholders before the various elements were in place and to informing development of the project through the steering group meetings and regular meetings with the GRT health team during the course of the project.

#### **Developing capacity building through the evaluation process**

The aim of developing capacity building during the evaluation process was limited in achievement as it proved extremely difficult to generate interest in the role of community evaluator. Although three different community members did express an interest they each withdrew their interest, at different stages, due to life events, prior to commencing a day's informal training with input from a Gypsy from Sheffield who had previously carried out a similar role.

It was possible to build capacity by including two community members on the interview panel for the GRT public health nurse post. Both of these were already in paid work; one as a community site warden and the other, MC, as a ward sister in a local general hospital. MC also gained experience through being involved in the cultural awareness training for health staff in general practice and in helping to design the evaluation forms.

MT, one of the health trainers, a community member, has assisted in the evaluation through writing case studies, logging her client activity and data, and keeping a verbal (recorded) reflective diary.

It is not so surprising that it was difficult to build capacity during the evaluation process when there had been no previous organised GRT groups and no community engagement prior to the start of the evaluation, and when the evaluator was unknown to the community. There were similar difficulties in recruiting health champions from the community, even with one of the community members in post as a health trainer.

#### Added value of the intervention compared to pre-existing service delivery

Although the GRT health project commenced less than 3 years ago and the final element of the GRT public health nurse post was only in place since May 2015 there has been considerable added value compared to pre-existing service delivery:

#### **Health Team Model**

- The formation of GRT health team in County Durham is seen as a model of national good practice that widens awareness of the services available from the different team members and enables collaboration in joint ventures to deliver health promotion and wellbeing activities on sites
- Uptake of GRT health Team services is facilitated by referrals between team members

#### Community access to health services and health improvement

- Increased access to and uptake of healthy lifestyle interventions.
- Increased feeling among GRT community of knowing someone to trust about their health concerns and needs and improved access to appropriate health care as a result.
- Discussion of health matters in the GRT community now less of a taboo subject and health issues are being discussed more openly.
- Addressing previously unmet health needs of GRT communities on the road side on unauthorised encampments.
- Engaging with men on health issues that traditionally have never been addressed with this hard-to-reach group.
- Beginning to make inroads into the housed GRT community members who often have the worst health.
- Improved attendance for health appointments.
- Access pathway being developed for urgent mental health.
- Increased health knowledge and understanding through uptake of activities related to public health promotion campaigns for example sun awareness, breast examination, and stress management.
- Community participation in producing health information resources
- Health needs of home-schooled children identified
- Three health champions recruited from the community
- Increased opportunities for site wardens to learn about how to support residents with health related matters, often after services such as the Dementia Friendly service have first made contact via the practitioners group
- A course of Parenting sessions with the inclusion of an emotional wellbeing session led by the primary care mental health nurse are to commence on each DCC site

#### **Health Service Improvements**

• GRT health and wellbeing services are now much more joined up with other teams in housing, education and the voluntary sector providing a more seamless service between teams and agencies.

- Increased awareness and understanding of GRT health needs and culture among diverse staff disciplines in general practice, primary health care and allied health and social care. Increased awareness has also resulted in positive changes to practice.
- Practitioners group formed and meets bi-monthly. This has resulted in improved networking and partnership working and in improved access to other services who use the forum to introduce their services to GRT communities.
- Improved recording of GRT ethnicity and creation of GRT templates on the healthcare data system. This enables staff to continue to undertake future audits and raise awareness of significant health differences that require attention.
- Clinical leads for GRT health created in each CCG ensuring effective liaisons re GRT health needs and facilitating audit

#### **Recommendations for future development**

- Continue a programme of cultural awareness training targeted at health staff in primary health care and general practice, with GRT input and focussed on health needs. Advertise training well in advance.
- Include training on asking about, and recording ethnicity
- Hold regular liaison meetings between GRT leads in the CCGs, Public health and the GRT health team as a project steering group (replacing the core evaluation steering group)
- Improve links with nine identified GP practices with GRT patients by GRT public health nurse attending practice meetings to discuss role of GRT health team
- Develop key links with mental health teams
- Continue efforts to increase recording of GRT ethnicity and request annual audit of GRT comparative data
- Continue the health trainer roles as part of the GRT health team but include a specific community development role.
- Develop the role of health champions and aim to help them to assist other community members to attend dental and health appointments. Include health champions in planning new initiatives
- Increase awareness of GRT health team among housed Travellers through newsletters and social media and by news pieces in housing provider newsletters

- Maintain good working collaborations through regular attendance at the practitioners group and meetings.
- Improve the capacity of the public health nurse role by employing an additional team member in a band 5 support role and making extra administration support available
- Continue opportunity for peer supervision for the public health nurse role with someone else in a similar role and ensure opportunities to attend relevant conferences to keep abreast of developments and issues affecting GRT communities.

#### **APPENDIX 1**

#### **Recommendations from**

## Gypsy, Roma & Traveller Health Needs Assessment for County Durham and Darlington

- Directors of Public Health, Adult Services and Children's Services in County Durham and Darlington should share the findings from this health needs assessment with their key partners and also consider where the two authorities can benefit by working together on the issues raised.
- Each local authority and NHS organisation should identify a senior Champion to take lead responsibility for issues affecting Gypsies and Travellers whether in houses or on sites, including health promotion and ill-health prevention, social care and personalisation, housing and regeneration, and sports and leisure.
- iii) A Champion should similarly be identified amongst GPs providing services to Gypsies and Travellers whether in houses or on sites, who is prepared to help ensure that in the new commissioning environment, a proper balance is achieved between providing mainstream primary care services accessible to Gypsies and Travellers, and commissioning any additional targeted services, such as described in the NHS Primary Care Service Framework for Gypsies and Travellers
- iv) A review should be carried out of ethic monitoring in respect of Gypsies and Travellers, to establish a more effective and consistent approach, involving each local authority, health services, GPs, voluntary sector groups, social housing providers and local community-based organisations. The review should address whether ethnic monitoring categories are appropriate, whether the complexity of monitoring forms has become a problem for people with poor literacy, how staff help in the collection of ethnic data, and what can be done to encourage Gypsies and Travellers to describe themselves as such.

- v) In County Durham in particular, current data from the Education Service should be used to provide an analysis of where known Gypsy and Traveller families with children live and the housing tenures they are making use of.
- vi) Service providers working in localities shown to have a concentration of Gypsy and Traveller families whether living in houses or on sites should come together to review how they collaborate and to identify opportunities for service development, including how to make best use of specialist expertise. The area around Bishop Auckland is likely to have such a concentration.
- Where concentrations of Gypsies and Travellers are identified in older private sector housing, the cultural sensitivity of any ongoing or planned regeneration or house-building programmes should be reviewed.
- viii) Social housing providers should be encouraged to consider the findings on housing aspirations in the research recently published by East Durham Homes
- ix) Established, trusted relationships with the community should be built on by involving DISC, Sure Start, the specialist Health Visitor in Darlington and community-based groups such as UKAGW to design a capacity building programme aimed at increasing Gypsy and Traveller involvement in healthrelated initiatives, to increase their confidence in identifying themselves as such when using public services and to gradually identify "under-recorded" single and older Gypsies and Travellers.
- An audit should be carried out of community buildings on sites and their current usage, linked to the capacity building programme.
- xi) The development of a programme of peer-to-peer Health Ambassadors should be considered, aimed at Gypsies and Travellers living in houses and on sites, drawing on experience from the East Midlands Strategic Health Authority (i.e. Leicester City PCT), to raise awareness amongst Gypsies and Travellers of ill-health prevention and social care services, and focussing on the needs of the whole family, including men. The objective should be to improve the community's direct

access to mainstream services and gradually decrease its reliance on intermediary agencies.

- xii) Cultural awareness training should be provided to all staff who deal with Gypsies and Travellers (including senior managers) in local authorities, the health service and the voluntary sector. Community-based groups should be involved in the design and delivery of this training.
- xiii) Best practice should be shared between County Durham and Darlington on carrying out health and welfare assessments at temporary or unofficial encampments, including how children's dental health needs are addressed.
- xiv) GP Practices with an interest in providing healthcare to Gypsies and Travellers should be consulted about any health promotion activities occurring in their locality, including on temporary sites.
- xv) The results of evaluations on patient-held records for mobile Gypsies and Travellers should be monitored, with a view to co-operating with services across the country on the introduction of an effective system to improve the care of temporary patients, including any new IT-based solutions that may be developed in future.
- xvi) Bids should be submitted to CLG for site refurbishment or re-provision funding from 2012 and a programme should be in place to meet any needs of older Gypsies and Travellers for on-site life-time homes.
- xvii) A further stage of gravestone analysis for the family history strand of the Health Needs Assessment should be carried out to increase understanding of any distinct pattern of mortality affecting Gypsies and Travellers.
- xviii) Consideration should be given to commissioning further work on the long term future of the Gypsy and Traveller way of life, including any implications such an assessment may have for ethnic record keeping and service planning, and identifying any benefits to well-being associated with the culture and lifestyle.

- xix) There should be collaboration with the Education Service to consider how any contribution can be made to improving the educational prospects of Gypsy and Traveller children, through understanding more about why Gypsy and Traveller children are being assessed as less school-ready than other children, how completing secondary education can become a bigger priority for Gypsy and Traveller parents and what can be done to make every aspect of the educational offer as culturally sensitive as reasonably possible.
- xx) The findings from this report, which concern probably the largest ethnic minority in County Durham and Darlington, should influence the approach taken by each authority to the production of its enhanced Joint Strategic Needs Assessment and Health and Wellbeing Strategy, and be reflected in the patterns of commissioning which result from them.

#### **APPENDIX 2**

Cultural Competency Workshop

## COURSE EVALUATION

Name (Optional):				
Course Title:				
Date(s) of Course:				
<b><u>Please tick the appropriate box.</u></b> If you answer Average or Unsatisfactory to any of the questions below, please make comments overleaf.				
	Very Good	Good	Average	Unsatisfactory
PREPARATION Joining Instructions / Pre-Course Informatio	n 🔿	$\bigcirc$	$\bigcirc$	0
<b>VENUE</b> Training Room Refreshments	0	0	0	0
ABOUT THE COURSE How well were the course objectives stated?	0	$\bigcirc$	0	0
To what extent did the course meet the objectives?	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Pace of the course	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Level of the course	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Length of the course	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Mix of presentation, discussion and other participation	0	$\bigcirc$	$\bigcirc$	0
COURSE MATERIALS Visual Aids	$\bigcirc$	0	0	0
Handouts	$\bigcirc$	$\bigcirc$	0	0
Activities / Exercises	$\bigcirc$	$\bigcirc$	$\bigcirc$	0
TRAINER/S Knowledge of Trainer/s	0	0	0	0
Trainer/s organisation and Preparation	$\bigcirc$	0	0	$\bigcirc$

Very Good Good Average Unsatisfactory

Trainer/s response to questions	$\bigcirc$	0	$\bigcirc$	0
Participation encouraged throughout the course	$\bigcirc$	0	$\bigcirc$	0
Trainer/s enthusiasm for the subject	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Trainer/s delivery of course	0	0	0	0
WORK Experience Do you work in direct contact with Gypsies and Travellers? How would you rate your understanding of Gypsies and Travellers cultural and health needs prior to this workshop?	0	Infreque Good	ntly Not at all Fair Very limited	
<u>SUMMARY</u> Overall, how would you rate the trainer/s	0	0	0	0
Overall, how would you rate the course	0	0	0	$\bigcirc$
OUTCOMES FOR SELF Will this experience change your work pra Please describe how:	ctice?	Y ()	NO	
Has the experience improved your level of Please describe how:	f knowledge?	<b>Y</b> ()	NO	
Would you recommend the course to othe How could we have improved this course		<b>Y</b> ()	N ()	

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We have an independent Evaluator of DCCs Gypsy, Roma, Traveller Health Project, Patrice Van Cleemput. She would like to carry out a short informal consultation with various staff who have attended this course. Please give your contact details below if you would be wiling for her to speak to you at a time convenient to yourself:

Name

Workplace

Contact details

Other Comments:

Follow up Evaluation Questionnaire using Survey Monkey

## Evaluation of impact of workshop- Health Needs of Gypsy, Roma and Traveller (GRT) Communities in County Durham

- 1. Demographic details, job title and role, and date of attendance at workshop
- 2. How often does your current work involve actual or potential direct contact with Gypsies or Travellers?

Very Frequently - at least once a week Infrequently- less than weekly but at least monthly Rarely- less than monthly My work does not involve direct contact

3. To what extent has your level of contact changed since attending the workshop?

My level of contact has increased My level of contact has decreased My level of contact has not altered

4. To what extent did the workshop meet your needs in benefiting your work practice with Gypsies and Travellers?

Very Frequently - at least once a week Infrequently- less than weekly but at least monthly Rarely- less than monthly My work does not involve direct contact

- 5. In what ways has attendance at the workshop made a difference to your work practice with Gypsies and Travellers ; please give examples
- 6. To what extent have you shared specific knowledge gained from the workshop with other colleagues?

I have shared specific knowledge with one or two colleagues

I have shared specific knowledge with the wider team (more than 2 colleagues)

I have not shared specific knowledge with colleagues

7. How do you imagine that the majority of Gypsies and Travellers would view their experience of your service if they were asked?

Positively- I think that most would access the service without hesitation if necessary Negatively- I think that most would be reluctant to use our service I am unsure

8. Have you or your team implemented any changes to your service since the workshop to improve access and/or cultural acceptability for Gypsies and Travellers?

Yes, we have made specific changes No we did not feel that any changes were required because access and cultural acceptability were already satisfactory No we did not or have not yet implemented any changes because of insufficient resource

9. Do you OR members of your team currently attend the quarterly GRT Practitioners forum, or intend to do so?

Yes No; I / we are unable to get time to attend but would like to No ; I/ we don't feel that it would be useful for us to attend

10.If we were to run a further workshop on improving health and access to health and social care for Gypsies and Travellers, have you any suggestions for content and format that you or your team would find most beneficial?

## Gypsy Roma Traveller Health Trainer

#### Initially point 14, £16,382 per annum pro rata (Point 17, £17,528 per annum pro rata once qualified and competent) 16 hours per week Fixed term until 28<sup>th</sup> February 2016

Initially this post is a trainee position; the successful candidates will be required to achieve the City & Guilds Level 3 Health Trainer Award. Once qualified the successful candidate will undertake the following:

#### Job Purpose

To work in a range of settings to assist with improving the health of individuals and the local community through:

- Applying community engagement and consultation techniques as appropriate to engage the target groups/individuals.
- Working as part of the Lifestyles team to develop a programme of health related activities for the local community.
- Carrying out research and preparing suitable resources for the successful delivery of activities.
- Supporting a group of Health Trainer Champions (volunteers)

#### Key tasks:

- To manage a caseload of individuals and maintain regular supportive contact with each person to assist them to achieve their health goals.
- To facilitate the development and delivery of personal health action/activity plans and source a holistic package of support to assist the development of each individual.
- To plan, prepare and deliver a range of interactive health workshops.

#### Key skills/experience required:

- Willing to work towards completing the RSPH Level 2 qualification in Understanding Health Improvement
- Excellent communication and listening skills
- Ability to influence, negotiate and motivate individuals in relation to health related behaviours

Email: <u>hr@pcp.uk.net</u>

# Closing Date for applications: 12 noon on Wednesday 12<sup>th</sup> November 2014

## **APPENDIX 5**

## Gypsy RomaTraveller Health Project Referral to Specialist Nurse

Name :	DOB:
Address:	NHS No:
&	
Postcode:	Contact No:
Registered GP:	
Ethnicity	
Children: 1.	DOB:
2.	DOB:
3.	DOB:
4.	DOB:
Any Known Risk to Lone Worker (if yes, please give details):	YES/NO
Family Health Visitor/School Nurse:	
Base & Contact No:	
Registered with Sure Start:	YES/NO
Other professionals involved:	
Referral Source:	
Urgency of Referral: Urgent/ASAP	

Reason for Referral (brief details of any medical issues)
Referrer'sSignature:Date:Designation:Date:
Please Print Title and Name
Contact Address
Contact Tel Numbers:

### **APPENDIX 6**

## Key Performance Indicators for GT Public health Nurse

Activity	Measure
Discuss and promote the importance of ethnic identity with all contacts	Discussion recorded with each contact
Support all contacts to enable ethnicity to be recorded /changed appropriately with primary care and other service providers.	Record number of contacts that act on ethnicity recording
Ensure that all contacts are health promoting	
Assessing health and wellbeing informally or formally	Record activity
Offering brief advise/interventions if appropriate	Record activity
Signpost and support access to relevant services	Record activity
Promote awareness and earlier diagnosis of long term conditions including Diabetes, Cancer, CHD and COPD.	Monitor and report on interactions and or actions in this area
Promote uptake of screening services	Increase uptake of screening
Promote uptake of immunisations	Increased uptake of immunisations
Reduce inappropriate use of A&E /urgent care centres through training and support on health service usage	Number of GRT community members trained on use of health services
Increase engagement with health services for chronic disease/ long term conditions management.	Increase number of routine appointments for chronic disease of long term conditions kept
Promote action on mental illness	Increase mental health referrals

**Traveller Times Article about GRT Health Trainer** 

## Traveller Michaela Tyers works to improve the health of her community

02 March 2016 / Travellers' Times

Michaela Tyers is a Health Trainer working with the GRT community across County Durham the project aims to improve the health of the people from the community whether they live on sites or in bricks and mortar.

Michaela started working on the GRT Health Trainer project in January 2015. Since starting she has completed her Level 3 Health Trainer course and Level 1 IT course. Michaela is from the Traveller community and has been using her new skills to help support her community with lifestyle changes they wish to make.

Michaela and fellow GRT Health Trainer Catriona Grime offer one to one or group support to eat healthier, become more active, stop or reduce smoking and reduce alcohol intake. They also offer NHS Check4Life health checks including a blood pressure check, cholesterol check\*, height and weight and lifestyle assessment. Michaela's family have benefited from the health trainer services on offer

"My Dad has had a health check; he hasn't even been to the doctors in 30 years! So that is a big thing for him. My little sister comes to the drop in and gets weighed in so she is starting to get more conscious of the way she eats"

Michaela is passionate about improving the health of the GRT community and has seen improvements first hand with the provision of healthy cooking sessions increasing awareness of sugar, salt and fat content of food and clients who have been supported to stop smoking. "The changes have benefited the whole family's health and wellbeing"

Michaela has faced challenges along the way getting back into work after maternity leave, and she couldn't even turn a computer on in the beginning so had to learn those skills "I am most proud of passing my health trainer course because I thought I would never be able to do anything like that."

If you would like any further information about the project or live in County Durham and would like to access the GRT Health Trainers please contact us on 01325 321234.

#### **APPENDIX 8**

#### **Topic Guide for Interviews with GRT**

- 1. How would you describe your health / family's health?
- 2. What is the most important thing that affects your/ your families health( makes you more healthy/ less healthy )
- 3. What would you do first if you had any worries about your health?
- 4. Would you talk to anyone in your family? Is there anyone outside of your family who you would trust to discuss any health worries?
- 5. How do you learn/ like to find out about what is good for your health?
- 6. Do you use the internet( explore) ?
- 7. Would you use You tube or any other site to find out about health isssues
- 8. (Do you know about) What contact have you had with the GRT health team?
- 9. How did you get to know about the team?
- 10. What do you think the main purpose of the GRT team is?
- 11. Did / do you think that the team can do anything to help your/ your family health?
- 12. If not, what are the reasons?
- 13. What is good about the health service you get?
- 14. How could the GRT health team improve the health service you get?
- 15. Do you identify yourself as a Gypsy/ Traveller when asked about your ethnic identity
- 16. Has going to a doctor's surgery changed for you in any way since the start of this project ( GRT health team)
- 17. Have you learnt anything new about the health service and the staff in it?
- 18. How well do you think health staff understand Gypsies and Travellers; do they understand better or worse than other agencies?
- 19. Would you recommend the GRT health team to others? Why/ why not?
- 20. Is there anything the GRT health team could do better/ should change?
- 21. How important is it that there is a Gypsy in the GRT health team?
- 22. Would you be interested in becoming a health champion (explore)?
- 23. What is the most important thing for you about who should be part of a GRT health team