An Evaluation of Leeds CCG Gypsy and Traveller Health Improvement Project

Final Report October 2018

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Executive Summary

Background

The Gypsy and Traveller Health Improvement Project aims to build bridges between the community and health-related services in Leeds. It utilises a partnership approach between the NHS in Leeds, the City Council's public health team and Leeds GATE (a local Gypsy and Traveller-led civil society organisation). A Specialist Nurse was employed for the project duration, with the aim of leading health improvement within the Leeds Gypsy and Traveller community to ultimately improve health outcomes.

The project was initially funded for one year (2017-2018) but this was subsequently extended until March 2019, due to additional funding provided by the NHS Leeds Clinical Commissioning Group (CCG). The Centre for Health Promotion Research evaluated this intervention from the start of its delivery until October 2018.

Key Findings

- The nurse role is greatly appreciated with very high acceptability. The role is holistic in focus and goes beyond the medical remit –involving discussing many issues and providing broad based support. It includes giving voice to community members and a range of engagement work to establish trust. The main area of health advice provided by the Nurse related to mental health – particularly depression and stress / anxiety. The characteristics of the role-holder are important for the success of this intervention and the importance of the outreach aspect needs noting as other health care delivery models do not allow such freedom and flexibility. Providing access on site as well as a flexible approach was also important.

- Building relationships and trust are essential prerequisites for engagement. The well-established relationship with Leeds GATE was an important mechanism within this project, to enable access to the community via a long-serving and trusted voluntary sector provider.

- Gender played a role in engagement with the outreach nurse, with men less willing to discuss health and, in some cases, affecting women's engagement. Women were more likely to interact with the nurse, although 42 men did choose to engage during the period of the evaluation.

- The nurse assisted with accessing health-care by registering community members, explaining conditions, encouraging attendance, accompanying people and helping ensure better quality appointments. Health checks were unpopular, with community members preferring a more conversational approach, which works well given

literacy levels and the accompanying challenges. The outreach nurse was most likely to advocate with Primary Care and Mental Health Services. There were high rates of signposting (108 incidences) most commonly to Primary Care and Leeds Gate.

- Very high rates of illiteracy emerged. 78% had no or some literacy – only 3% had good literacy. The ability to read is required for health system navigation, and therefore is a significant barrier to accessing health services within this community.

- Help cards appear to have permeated the population with 66% of interactions with people who either already had one or did then accept one. Level of literacy was significantly related to accepting a help card. Whilst Health help-cards were appreciated by many but needed to supported by changes within healthcare (flagging up patients that could not read and write, then communicating differently). There was less good uptake of health checks with only 29% of interactions with people who had one or accepted one.

- Roadside Travellers face great challenges accessing healthcare including difficulty registering and accessing continual care.

- Existing services are not always receptive to working with Gypsy and Traveller community members, and their rigid structures and processes serve as a barrier.

- Health service usage data showed that the Gypsy and Traveller Community's average systolic blood pressure is slightly above the recommended value of 120mmHg. It also illustrated that some of the community were found to have been attending Accident and Emergency (A&E) multiple times since 2016. Finally, amongst the life-advice referrals made, the topic mostly discussed was smoking cessation advice.

Outcomes

- The work of the nurse has enabled increased access to health services for some community members and there is qualitative evidence of health improvement. However, the health issues experienced within this community are not only complex, but are situated amongst a range of difficult social circumstances.

- The out-reach component of the Specialist Nurse role was important, in terms of serving as a pathway into appropriate services, thereby potentially improving access to health care. In some instances, there may be increased service use in relation to previously undiagnosed needs e.g. mental health.

- There was mixed findings regarding Primary Care's willingness to engage with the project. Whilst some positive changes had been made (e.g. Health Visitors going to Roadside families) more changes are still needed.

- Stakeholder identified positives because of the project, including building on past relationships, learning more about the way in which the community engages with services, and understanding the barriers to access.

Key Recommendations

For Leeds Clinical Commissioning Group:

1. Retain the Specialist Nurse post, using outreach, in the medium term. This is needed until health literacy improves and empowerment is built within the community.

2. Ensure the Specialist Nurse is supported in her role with appropriate mentors and a location to work from.

3. Advocate for similar services in other areas.

4. Ensure there is senior management support within healthcare for a more flexible service for members of the Gypsy and Traveller community (e.g. longer appointments, tailored communication).

5. Work with partners to address negative attitudes within health care services towards the community.

6. Support voluntary sector organisations working with the community.

7. Appreciate that attending Accident and Emergency may be due to fear or inflexible health systems.

For the Partnership:

1. Work together to improve literacy rates in the Gypsy and Traveller Community and address social determinants of health.

2. Keep focusing on reaching and engaging with male members of the community.

3. Work together to empower women so they can access healthcare and other critical services independently.

4. Training needs to ensure people are aware of the patriarchal nature of the community and how this may affect both gender's uptake of services.

How we did the evaluation

Using a theory of change, the evaluation team supported internal monitoring data collection, and conducted a range of interviews with stakeholders, and service users. Qualitative and quantitative methods were used to strengthen findings and allow some triangulation between different data sources.

Contact/further information

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1: Introduction

1.1 The Health Improvement Project

The Gypsy and Traveller community experience significant health inequalities, including decreased life expectancy, lower wellbeing and increased risk of suicide. They face significant barriers to accessing healthcare due to low levels of literacy, isolation and previous poor experiences.

The Gypsy and Traveller Health Improvement Project aims to build bridges between the community and health-related services in Leeds. It utilises a partnership approach between the NHS in Leeds, the City Council's public health team and Leeds GATE (a local Gypsy and Traveller-led civil society organisation).

The project was initially funded for one year (2017-2018) but this was subsequently extended until March 2019, due to additional funding provided by the NHS Leeds Clinical Commissioning Group (CCG).

A Specialist Nurse was employed for the project duration, with the aim of leading health improvement within the Leeds Gypsy and Traveller community to ultimately improve health outcomes. An asset based community development approach was utilised - the nurse used outreach to link residents to mainstream services. Importantly, the role also included working with health-related organisations to improve access and care pathways for community members.

Cottingley Springs, a local authority Gypsy and Traveller Site in the Wortley ward, was the principle focus of the work but the nurse also worked with members of the community living in houses or roadside.

This report outlines key findings from an evaluation conducted by Leeds Beckett University. The project was still on-going at the time of writing, but there was sufficient information to report.

1.2 Evaluation Aims and Objectives

The evaluation aimed to discover whether the intervention worked or not (effectiveness) as well as how and why (process information).

Objective 1: To examine the relationship between the Gypsy and Traveller Community and Primary Care/Health Services

a. To assess whether the intervention has led to an increase in satisfaction with primary care amongst the Gypsy and Traveller community in Leeds

b. To explore whether understanding of the needs of Gypsy and Traveller people has improved within Primary Care

c. To explore whether the Gypsy and Traveller community have a better understanding of how to engage with Primary Care and health services generally

d. To explore whether the intervention has led to a changes in the use of services e.g. reduction in use of accident and emergency, engage with and/or use of primary care services, referrals to social care

Objective 2: To evaluate the intervention itself

a. To explore the role of the Specialist Nurse; specifically, to assess whether the nurse has been able to reach community members and deliver health advice / improve understandings of health conditions, signpost

b. To explore perceptions of nurse outreach post (acceptability of the intervention)

c. To explore perceptions of the help-cards

Objective 3: To examine health outcomes

a. To measure whether the intervention has led to an improvement in self-rated Health & Wellbeing amongst the Gypsy & Traveller community

b. To explore whether knowledge and attitudes towards cancer screening have changed / improved

General

To identify any recommendations and offer areas for consideration

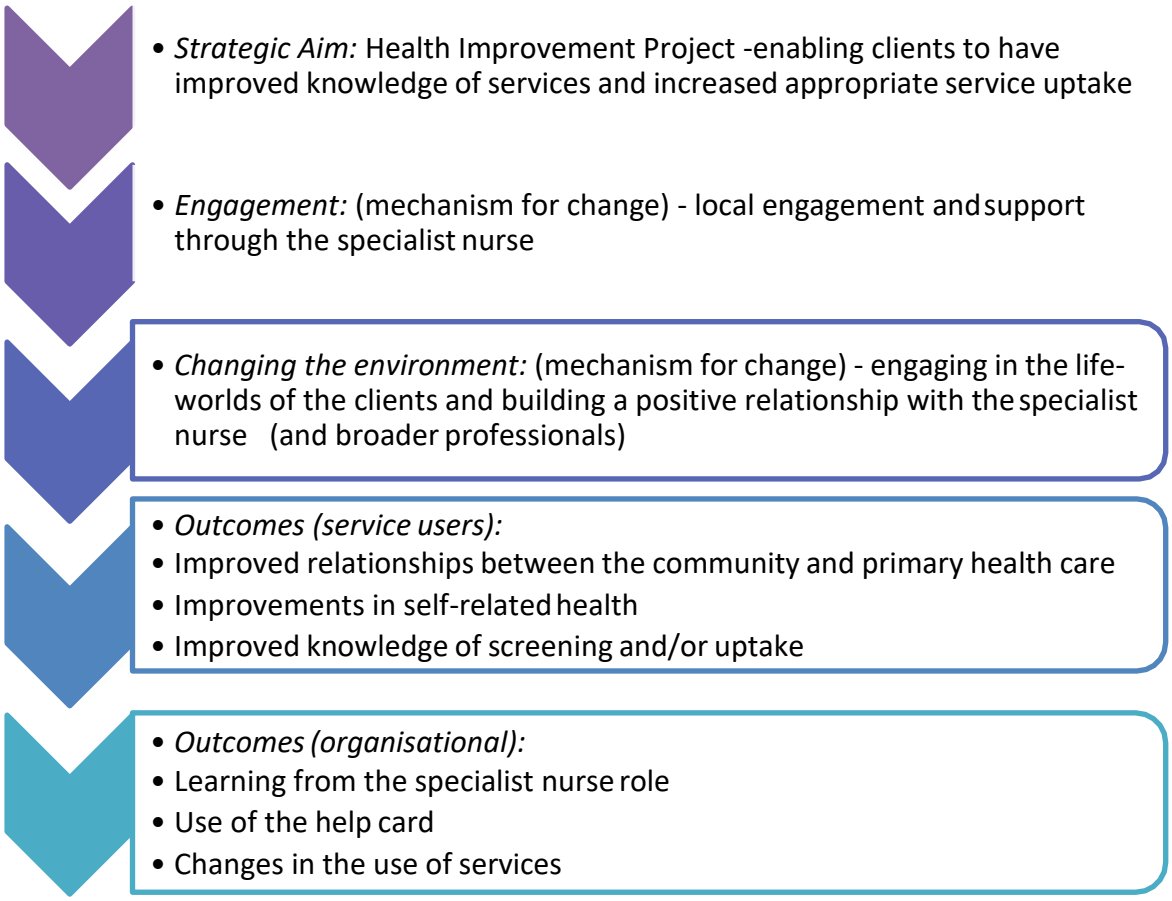
2: Evaluation Methodology

2.1 Approach

The evaluation placed the project staff, partners, stakeholders and service users at the centre. To ensure rigour we used a Theory of Change (TOC) to provide an overall framework for the evaluation (Judge and Bauld, 2001) - this helped make explicit the links between project goals and the context in which it was being implemented. Our previous work shows how important it is to appreciate the context in which programmes operate as this can be critical for success – or otherwise (South et al., 2012). See appendix 7 for an overview of how the TOC relates to the findings.

Qualitative and quantitative methods were used to strengthen findings and allow some triangulation between different data sources.

Figure 1: Theory of Change



2.2 Evaluation Methods

Data provided by Specialist Nurse

In order to ensure regular and systematic data collection across the project period, the Specialist Nurse provided three types of data (see below) at agreed intervals. For each, the evaluation team produced a template based on discussions with key stakeholders. The Specialist Nurse completed the template and the evaluation team analysed the resulting information.

- **Service User Monitoring data**
  For each interaction with a member of the Gypsy and Traveller community, the Specialist Nurse logged anonymous data on; demographics (gender / age / literacy) plus GP registration, the interaction (length and place), whether or not health checks and help-cards were given plus logged key areas of information or advice given plus signposting and advocacy work. See Appendix 1 for the template.

  Data were supplied for interactions between 18th January 2017 and 21st June 2018. The total number of interactions was 334 with 140 individuals.

- **Service User Case Studies**
  For a more in-depth perspective the Specialist Nurse completed case-studies of some of the service users she had worked with. This included information on how the interaction came about, the individual's circumstances, the intervention itself plus benefits for the individual and project learnings. See Appendix 2 for the template.

- **Specialist Nurse Learning Log**
  The nurse kept a record of activities undertaken and her reflections on the role, for example, awareness raising sessions with community members or work undertaken with GP Practices. Her reflections are reported as quotations within the findings. See Appendix 3 for the template.

Qualitative interviews

The evaluation team undertook semi-structured interviews with members of the community and key stakeholders.

- **Stakeholders**
  Qualitative interviews with stakeholders captured learning related to service delivery, project progress and perceived user outcomes. See Appendix 4 for the interview schedule. Participants were sampled purposively based on their role in, and contribution to, the project. The evaluation team worked with the CCG, Leeds GATE and the Nurse to identify these individuals.

Interviews took place either face-to-face or via telephone. One participant (the Specialist Nurse) was interviewed twice due to their pivotal role in the project, to capture their learnings / reflections at different stages.

- **Service Users**

The team conducted interviews with members of the Gypsy and Traveller community who had experienced the project. See appendix 5 for the interview schedule. The service user perspective was crucial to determining acceptability of the project to the community and whether it had been successful.

A researcher from the evaluation team visited Cottingley Springs twice with a Leeds GATE staff member and visited Roadside families on another occasion. Leeds GATE were crucial in advising on the suitability of service users for inclusion and, the trust and connections they had with the community helped ensure individuals spoke openly to the researcher.

Participants were asked about the role of the Specialist Nurse and its acceptability to them, any perceived improvements to their health and wellbeing and their future recommendations. See Appendix 5 for the interview schedule.

Health service usage data

Health service usage data for service users was supplied by Leeds CCG via System One. This was for all service users for whom a 'read-code' had been allocated by the Specialist Nurse i.e. there had been a clinically relevant interaction, they had a Leeds GP, they had given the nurse their identifying details and permission to access their records. This came to a total of 68 people. Please note this is less than the total number of people from the Gypsy and Traveller community seen by the Specialist Nurse (numbering 140) as some may have had fairly fleeting encounters or not agreed to the above conditions.

The clinical commissioning groups (CCGs) datasets contain data about breathlessness, primary care appointments, blood pressure level (i.e. systolic and diastolic blood pressure), attendance to Accident and Emergency (A&E), and life-style advice referral. However, breathlessness and primary care appointments had a very limited number of cases, and therefore they were excluded from our analyses.

Table 1: Evaluation data collected and analysed

Data type	Number and profile	Notes
Service User Monitoring Data	334 interactions, of which 140 individuals	Collected by Specialist Nurse in XL template

Service User Case Studies	13	Collected by Specialist Nurse
Learning Logs	4 learning logs	Specialist Nurse's reflections on project
Interviews with key stakeholders	6 –telephone interviews	Five individuals, one interviewed twice
Interviews with Service Users	9 – all female. 7 face to face, 2 by telephone 7 at Cottingley Springs, 2 Roadside	Attempted to recruit men but unable to.
Health Service Usage Data	68 individuals	Data including: Cohort, Breathlessness, Blood Pressure, Referrals, Accident & Emergency attendance.

2.3 Ethics

The evaluation was given ethical approval through Leeds Beckett University ethics procedures. The following practices were adhered to ensure ethical rigour:

- Informed consent. This was attained from all interview participants – due to low literacy levels amongst service users verbal consent was accepted, as opposed to written. The information sheet for service users was adapted to take low literacy levels into consideration. See Appendix 6.
- Confidentiality and anonymity – no personal identifying information was used in reporting data;
- Secure information management – security was maintained through password protected university systems.

2.4 Analysis

Qualitative

Interviews were transcribed verbatim and analysed using thematic analysis methods (Braun & Clarke, 2006). This method i s u se d for identifying, analysing and reporting patterns (themes) within data. Cross cutting themes are described and reported using direct quotations from the participants to illustrate them.

Quantitative

Monitoring Data. Descriptive statistics were calculated using Excel and SPSS software, and presented in the form of tables to report demographics and other information about the interaction. Due to the low levels of literacy emerging from these results, we tested a series of hypothesis to find out whether some of the variables collected for this study could

have an effect on participants' literacy level.[1] In particular, we hypothesised that younger people might present a higher level of literacy compared to older people. We also assumed that there could be a difference in terms of gender in access to education or that contextual variables such place of interaction and the current place of residence could be related to literacy. To test our hypotheses, we ran a series of cross tabulations in IBM SPSS v. 24 and used the Chi-square test to assess whether the hypothesised relations could be due to chance[2].

2.5 Limitations

One limitation was that the evaluation team were unable to speak to any men as part of the service user interviews. This was despite specific efforts to do so by the team. Conversations with female service users and stakeholders attribute this to men's unwillingness to talk about their health and that, in this community particularly, women often take responsibility for their husband's / son's health. To counter this the evaluation team spoke to the wife of a man who had received support from the Specialist Nurse. In addition, case studies from men were collected by the Specialist Nurse.

The evaluation team did not interview GP Practices, and therefore are unable to report upon their perspective within the findings.

The Monitoring Data did not enable individuals to be tracked i.e. it was not possible to say how many times each person had been seen. This has been improved for subsequent projects. In addition, it did not link to System One so we could not investigate patterns across the two types of data (monitoring data collected by the nurse and system one data on health service use).

[1] In order to obtain the most accurate results, we decided to remove the category 'unsure' from 'level of literacy',

[2] As common practice in social science, we assessed statistical significance though a 5% alpha level (i.e. $p < .05$)

3: A brief scope of the literature

Cemlyn et al (2009) note a range of health inequalities experienced by the Gypsy and Traveller Community. For example, Gypsies and Travellers die earlier than the rest of the population and despite experiencing worse health outcomes they remain less likely to be in receipt of continuous health care. There are also high suicide rates within the communities. Peters et al (2009) also report that being a Gypsy and Traveller is associated with poorer health outcomes when compared to other ethnic minority groups in England (specifically Pakistani Muslim and African Caribbean community members). The 2011 Census included Gypsies and Travellers as an ethnic category for the first time, and found that Gypsy and Irish Travellers across England and Wales had the lowest proportion of people who rated their general health as good: only 70% compared to 81% of the general population (ONS 2014).

A health needs assessment of the community based at Cottingley Springs (Thompson 2013) noted high self-reported rates of low literacy and relative isolation associated with the geographical location of the site itself. Those who participated generally had high rates of GP registration (92% of respondents) and positive experiences of using GPs. However, there were lower rates of registration with dentists (31% of respondents), and recognition of the difficulties associated with getting GP appointments. Those who participated in the data collection reflected knowledge of poorer health outcomes for Gypsies and Travellers as well as awareness about the broader impact of the many determinants of health (education and poverty) upon their own wellbeing as a community.

4: Evaluation Findings

In this section the evaluation findings are presented in the following order:

- Service User Monitoring Data
- Qualitative interviews - presented by theme, service user and stakeholder data
- Case study information
- Learning Logs
- Health Service Usage Data

4.1 Service User Monitoring Data

Monitoring Data were supplied for interactions between 18th January 2017 and 21st June 2018 (17 months). The Specialist Nurse inputted information (some categorical data and some free text) at the end of each interaction.

334 interactions were recorded in total. Of these 140 (42%) were 'New Contacts' and 194 (58%) had been seen previously.

The data is reported either by unique Interaction or by unique Person, as relevant – for example, demographics are reported by person (to assess reach) but other data (e.g. intervention length) is reported by Interaction.

Interaction venue and length – reported by unique interaction (n=334)

The most common place for interactions to take place was at Cottingley Springs, second was Roadside, as indicated in Table 2 below. Other venues included Leeds GATE, a residential home, private yards and 'other site'.

Table 2 – Location of interactions with the Specialist Nurse

	Number	% of interactions
Cottingley Springs	244	73%
Roadside	36	11%
Housing	14	4%
Lee Gap	15	4.5%

The average length of an interaction was 37 minutes with a mode of 30 minutes. There was a wide range of interaction length - from 120 minutes to 10. The majority of the ten minute appointments were at the Lee Gap horse fair (a popular Gypsy and Traveller Community Event attended by the Specialist Nurse).

Most interactions (248 or 74%) came about via Outreach - others were by appointment (59 or 18%) or opportunistic (21 or 6%).

Demographics – reported by unique person (n=140)

For this section repeat appointments have been removed from the analysis.

Gender. More women than men participated in the intervention – 70% being female (98) and 30% being male (42). Comparing this with the data by intervention suggests women have more repeat interactions.

Age. The most common age category was 25 to 44 years, followed by 45 to 64 years. Relatively few were with people aged 65 years and over. See table 3 below. When the data is analysed by intervention the two older categories increase in value, suggesting more repeat interactions with those 45 years and above.

Table 3 – Age of clients engaging with the Specialist Nurse

	Number	% of interactions
16 to 24 years	31	22%
25 to 44 years	63	45%
45 to 64 years	38	27%
65 and over	8	6%

GP Registration. The majority of people (95 or 68%) are registered with a GP, compared with 44 (31%) who are not. One was unsure.

Literacy – reported by unique person (n=140)

Most people interacted with were categorised as having “no literacy”. See table 4 below.

Table 4 – Level of literacy of service users

	Number	% of total
Good literacy	4	3%
Some literacy	26	19%
No literacy	82	59%
Unsure	28	20%

Current Residence– reported by unique person (n=140)

Most people either lived at Cottingley Springs (49 or 35%) or were homeless (44 individuals, 31%). See table 5 below. When the data is compared to that analysed by interaction it suggests more repeat interactions with residents at Cottingley Springs.

Table 5 – Residential location of clients

	Number	% of total
Resident at Cottingley Springs	49	35%
Visitor at Cottingley Springs	17	12%
Resident of other Leeds site	3	2%
Living in housing	9	6%
Homeless	44	31%
Other	18	13%

In "other comments":

- 15 had a GP in another city
- Concerns re child was mentioned 7 times

Health checks – reported by interaction (n=334)

It was recorded whether or not a revised health check was given. In most cases they were not offered, or it was 'Offered but refused'. See table 6 below.

Table 6 – Health Check Offer

	Number	% of total
Yes	41	12%
Not this time – have previously done one	56	17%
Offered but refused	78	23%
Did not offer	157	47%
Other	1	0%

Help cards – reported by interaction (n=334)

It was recorded whether or not a 'help-card' had been offered. Nearly half already had one, whilst another 18% accepted one. In a quarter of interactions, it was not discussed, whilst 7% refused one. See table 7 below.

Table 7 – Help Card Offer

	Number	% of total
Yes – accepted	60	18%
No – already have one	160	48%

No - refused	23	7%
Not discussed	87	26%
Other	1	0%

Health Advice Given – reported by interaction

It was recorded what advice had been given (main and secondary), with a range of options given in a drop-down menu.

313 interactions recorded a main area of advice with 187 interactions also recording a secondary area of advice. See table 8 below – sorted by ''total' column.

Of the defined categories, advice was most often given about depression, stress / anxiety and 'other mental health' plus medication. Relatively little advice was given about lifestyle behaviours e.g. smoking / alcohol / diet. The largest category however is 'other' – indicating either a very wide breadth of advice given or the pre-defined categories did not include key issues for this community.

Table 8 – Health Advice Offered

	Main Advice Given		**Secondary Advice Given**		**Total (% of advice given)**
	Number	**% of interactions**	**Number**	**% of interactions**	
Other	115	34%	54	16%	34%
Depression	73	22%	19	6%	18%
Stress / anxiety	23	7%	37	11%	12%
Medication	25	7%	21	6%	9%
Smoking	22	7%	6	2%	6%
Diet	18	5%	13	4%	6%
Other mental health	16	5%	10	3%	5%
Physical Activity	12	4%	10	3%	4%
Alcohol	6	2%	4	1%	2%
Sleeping	2	1%	8	2%	2%
Losing weight	1	0%	5	1%	1%

Cancer Screening – reported by interaction

Cancer screening recommended included:

- Breast cancer – 9 interactions
- Cervical – 7 interactions
- Bowel – 3 interactions

Prostrate, AAA (abdominal aortic aneurysm) and chest were recommended once each.

Advocacy – reported by interaction

Which organisations were contacted by the Specialist Nurse following the interaction was captured. In total this happened 219 times. See table 9 (sorted by value).

The most common service contacted was Primary Care (108 times), then Other (60 times), Mental Health Services (25 times) and Dentistry (10 times). Social Services and education were contacted relatively few times. (NB The numbers are summed for main and 'other' organisation contacted).

Table 9 – Contact with other services

	Number	% of total advocacy contacts
Primary Care	108	49%
Other	60	27%
Mental Health Services	25	11%
Dentistry	10	5%
Social Services - children	4	2%
LA housing	4	2%
Social Services - adult	3	1%
Education	2	1%
Social Services - adaptations	3	1%

Organisations entered as free text included: Midwifery (x4), Health Visiting (x3), CAHMS and Cluster (x2), Acute Trust (x2). Others were mentioned once, including; Podiatry, Pharmacy, Patient Advice and Liaison Service, sports centre, musculoskeletal, spine fit, stop smoking, school, Traveller team, palliative care, get active.

Signposting – reported by interaction

There were 108 signposting interventions. These were categorised as 'main' and 'secondary' but have been added together for this report. The most common organisation signposted to was Primary Care (GP) (33 times), then 'other' (23 times) and Leeds GATE (21 times). See table 10 below.

Table 10 – Signposting interventions

	Total
Primary Care (GP)	33
Other	23
Leeds GATE	21
Primary Care (other)	8
Pharmacy	7
Health Trainers	6
Dentistry	3
Health Advocacy	3
Bereavement services	2
PEP	1
Forward Leeds	1
Debt organisation	0

Due to the high levels of literacy reported above we tested whether literacy was related to age, gender, place of interaction of place of residence. The results of our analyses[3] showed that there is no significant relation between age range and literacy level (value = 9.931, p = .077). Similarly, no statistically significant relation was found between level of literacy and gender (value = 2.349, p = .275), place of interaction (value = 15.076, p = .469) or current residence status (value = 10.679, p = .328).

These results show that low literacy levels are common across the Leeds Gypsy and Traveller community unrelated to age or gender. Please note however all participants were adults – it could be that young people and children have improved literacy rates.

We also tested whether the level of literacy of our participants is related to being or not being registered to a GP. Since being registered to a GP often requires a set of literacy skills (e.g. signing forms, reading leaflets etc.), we hypothesised that people with low levels or no literacy might be discouraged to do so. The results of our analyses suggest that there is no significant relation between literacy level and being registered to a GP (value = .155, p = .744). However, we found a highly statistically significant relation between level of literacy and acceptance of a help-card (value 11.177, p = .008). This result is also supported by the qualitative findings, which suggest that the help card was well received by the participants to this study.

[3] Fisher's exact test was used in place of the Chi-Square test due to the presence of more than 20% of cells with expected frequencies < 5.

Figure 2 – Word cloud summarising free text internal monitoring data

(100 most frequent words of 4 letters or more)

Some of the most common words emerging relate to the role of the nurse i.e. support, listening, understanding, discussed and advised. This relates strongly to the qualitative data - see later.

Summary

This Service User Monitoring Data records information from 334 interactions and 140 people.

Most interactions took place at Cottingley Springs but there is also evidence of working with people Roadside. The most common length of interaction was 30 minutes, showing the in-depth nature of the work taking place. Outreach was the most common method of contact with relatively few appointments, demonstrating the importance of this way of reaching people.

Women were more likely to interact with the nurse, although 42 men did choose to engage. People tended to be between 25 and 64 with relatively few older than that – again perhaps reflecting the profile of the population. 68% were registered with a GP and 44 people were not.

Very high rates of illiteracy emerge. 78% had no or some literacy – only 3% had good literacy. This was not found to be significantly related to either age, gender, place of residence or place of interaction. No significant relation between level of literacy and being registered to a GP was found.

Help cards appear to have permeated the population with 66% of interactions with people who either already had one or did then accept one. Level of literacy was significantly related to accepting a help card. There was less good uptake of health checks with only 29% of interactions with people who had one or accepted one.

The main area of health advice related to mental health – particularly depression and stress / anxiety. Much of the advice given however did not fit within the categories provided.

The outreach nurse was most likely to advocate with Primary Care and Mental Health Services. There were high rates of signposting (108 incidences) most commonly to Primary Care and Leeds Gate.

4.2 Qualitative Interviews with Service Users and Stakeholders

To aid understanding and gauge levels of consensus the findings from both sets of qualitative interviews are combined –the source of opinions and level of agreement is made clear.

4.2.1 Working with the Gypsy and Traveller Community

Acceptability of the Specialist Nurse role

This theme includes perceptions of the Specialist Nurse role – mainly from service users but also with insights from stakeholders. The factors influencing acceptability are explored.

There was **universal agreement** from service users and stakeholders that the Specialist Nurse role was highly acceptable and greatly appreciated;

> "Well I think Travellers should have the support that they have in Leeds from the nurse through the NHS for the Travelling community in Leeds, and it would be a lot better if that was in a lot more places in England. But they don't have that support really." *Service User*

> *"*And she listens to everything you say, where a lot of people maybe don't, you know what I mean. But she listens to you and she's helpful, do you know what I mean. I think it would be a good thing for the people here, you know." *Service User*

The **factors influencing** this high level of acceptability are many and varied, incorporating both **practical and emotional** aspects.

The Specialist Nurse gives **clear, understandable information** to community members about their health. She spends time with them explaining their condition and putting it into language they can understand. This is greatly appreciated and clearly counter to many participants' previous experiences with healthcare services;

> "I really understand half the things they say (referring to other health care providers) Do you know what I mean? And she tells ya…she comes every Friday and has a chat." *Service User*

> "She's very good, like explaining things and one thing and another, I think to the doctor as well. She can put things in language that we don't know." *Service User*

> "Like with [husband's name] and that, stuff that I ask the doctors and they go, 'It's a disease of the liver.' Yes, but I know it's a disease, but I want to know how he's got it. She tells you. She'll get a diagram out, or she'll Google it and she'll try and explain to you the best way she can…and make you have peace of mind." *Service User*

The ***general support*** she provides, often helping with literacy and bureaucracy, is greatly valued by community members and helps build trust and a positive relationship;

> "If she come in like you could ask her for, or if you've had a letter from, some saying, you could ask her what it means, you know. And she would explain in detail. And a lot of people would need her, you know what I mean like, a lot of people wouldn't need her for thing. If it was only to need to explain, or knowing things about medical, or help them some way, you know. But she is very helpful. If you ask her anything she'll do it. Very nice person." *Service User*

> "[Referring to the support provided by the nurse for her mother] Loads of different things with doctors. And filling in forms, for disability and that. Because my mam's on PIP. And helping with stuff. And getting her on the right medication and that… she helped me out loads. And it wasn't just a little five-minute thing. She had to get in touch with the head of the doctors, the practitioners. She had to get in touch with them." *Service User*

Helping participants **navigate** the health-care system and acting as **a bridge** between the system and the community also positively influenced acceptability. Many participants mentioned being aided by the Specialist Nurse to get a health care appointment and she will accompany them if necessary. This is greatly appreciated and, again, helps to build trust;

> "Cause that day I weren't well, I couldn't get up to doctors, and she made me the appointment and brung me up to the doctors, and brung me back*." Service User*

> "She seems a nice person…. she helps you with anything you want. She went me to the, I can't remember the places, to, it's up near Beeston, and she brought me to another place for like depression and things, you know what I mean…" *Service User*

> "…Travellers who are pregnant, I have seen [the Specialist Nurse] do a lot of signposting to the outreach midwife" *Stakeholder*

Having **access to support** on the local site was noted by many service users as important, given that many of them – particularly the women - lack access to transport;

> "No, I think it's better on site…half of 'em (community members) if it was off-site they couldn't, they can't get, you don't go. It's no good saying like if you've got somewhere on a Friday for people to go, that they don't go. Because half the time you can't get there. It is a good thing what, when they come on site. Same as when the doctor's bus used to come on. It was a very good thing for some people." *Service User*

> "Because I wouldn't have had anybody to take me (to appointments). Because where we're living is isolated as well." *Service User*

> "And not only that, a lot of women are vulnerable where they can't get out and they don't have cars and that. She'll come to you. She'll make her way to you… Whereas if you're on the site and all the men have gone off to work and there's no cars about…" *Service User*

Stakeholders emphasised how the Specialist Nurse, in this role, was able to provide **tailored support** to individuals;

> "(the project is able to provide) appropriate support for a lot of people, whereas existing provision quite often doesn't have the flexibility to [do so]." *Stakeholder*

> "being able to help deliver on health messages and issues around public health in ways that suit individuals, rather than in a community one size all fits, I suppose. So, family by family, person by person." *Specialist Nurse*

The **approach** taken by the Specialist Nurse is critical to ensuring acceptability. Spending time **building relationships** with community members listening, explaining and having discussions was very well received;

> "Well she comes twice a week and sometimes it's a very good help for me when I'm really down, to have someone to talk to." *Service User*

> *"*I don't know like if I would need her, do you know what I mean, but it is nice to talk to her. Like if I did needed her she would help me." *Service User*

Very **high levels of trust** in the Specialist Nurse were evident with some service users feeling able to disclose health issues to her that they had not openly discussed before. Being from **outside the community** was advantageous in terms of confidentiality;

> "You can tell her your problems and things. It's finding trust in people… I mean I will tell [nurse] things that I wouldn't tell anybody else where we are. And what I wouldn't speak to my family about." *Service User*

> *"*This has been going on for years, depression. I've had it years and years, but I've never telled nobody about it, because I thought it would go. Not laughing, not laughing, I thought I was going mad. So I thought I'm not going to tell anybody, they'd think you were mad. You know what I mean." *Service User*

> "With somebody like [nurse], she's 100% confidential. You can tell her anything, and you and walk away knowing, 'Should I have said that?' You don't have to feel like that." *Service User*

The Specialist Nurse understood the importance of being trusted by the community, explaining;

> "my understanding is that people don't make health changes or any changes by being told what to do. And generally people work better with somebody that they feel that they trust, and then feel able to think about changes themselves."

Having one dedicated person as **a point of contact** was deemed of utmost importance by several stakeholders. As one participant remarked;

> "I genuinely believe the success of this project has been that there has been a person to go to." *Stakeholder*

Stakeholders reflected on how crucial it was to recruit the **right person** – someone that can earn trust whilst maintaining independence and impartiality. The consensus was that much of the success of the project was reliant on having found such a candidate;

> "I think a big part of that role is [Specialist Nurse's name] as a person and her approach to the community. There's definitely something about personal characteristics to make this role work." *Stakeholder*

Reaching the Community

When first in post, the nurse began doing **outreach** work by regularly visiting Cottingley Springs. Later this extended to families living road-side. This involved having conversations, listening to people and often helping practically – thus becoming **a familiar positive presence** in the community. Whilst this took time it was critical to building trust - only then would people open up about their health;

> **"**Initially I outreached to the site twice a week, knocking on doors and introducing myself to community members, explaining the job role. This has initially felt quite uncomfortable, like "cold calling". What has worked well has been the freedom to just have conversations with people, health related or not. This is the start of an interaction that could lead in to a community member having trust in me and the service that I represent. Conversations start the relationship which enables me to hear their story and see the full picture as they see it. Helping always starts with a relationship so this process can't be rushed…."
>
> "… that took quite a period of months really to become known and a familiar face. Only when I've become familiar with community members after a period of months has it become evident that they've begun to trust me with telling me about difficulties in their health and in their health access, their understanding of their own health, and their health literacy, I suppose." *Specialist Nurse*

Word-of-mouth was key – if it became known the nurse could help members of the community, others were more likely to engage;

> "It's being a presence on the site. So therefore, she's observable by the community. I think good stories are then being heard about the outreach nurse, so that people are more likely to have that conversation. That's not really happening if you're not regularly going in onto the sites." *Stakeholder*

Engagement with the community was aided by having "the freedom to work in a different way and to take time to build relationships with people without always an agenda." (*Specialist Nurse*). This flexibility, allowed by the project, enabled the nurse to reach out to patients in a responsive and sensitive way that acknowledged the **complexity of patient's needs and wider determinants to health**;

> "…what I've been doing hasn't always been health related…However, what I would say is that it's been invaluable in building relationships. So generally, if somebody trusts you with one aspect of helping them with an area that's important to them, then they will trust you with discussing areas about their health as well." *Specialist Nurse*

> "…it is that in reach and ability to look at things from a much wider perspective. So, it might not just be about the link to the GP because of a health problem; it could well be that the environment itself isn't helping that person's long-term condition. So, it might be an issue around housing; it could be an issue around financial inclusion. And of course, the nurse is able to think about that, provide and support herself or make links with other services." *Stakeholder*

Engaging with men was more difficult and took longer, although progress was made. The nurse highlights the practical issue of men not being on site when she visited, but other interviews suggest men, particularly in this community, feel less comfortable discussing their health (see later);

> "I continue to work with women although I am noticing that men feel more comfortable with me on site. In December 2017, two men tentatively discussed a mental health need with me. This is slow progress and more difficult to follow-up with men, who are not always on site during the day." *Specialist Nurse*

Building on experience and existing relationships

Stakeholders reflected that the relationship **Leeds GATE** had with the Gypsy and Traveller community was vital to success. The fact that key contacts had already been established and there was a high level of trust in the organisation greatly helped engaging with the community;

> "[Leeds GATE] are an organisation that's very trusted by this population. So, if it is known that I am working with them, or affiliated with them in some way, then, that's been really good currency. So that's been really helpful." *Specialist Nurse*

> "… [the nurse] works so closely with GATE, and we have the trust already, so we passed on some of our currency of trust to [her] through introducing her to people ... I don't think it would have worked if we hadn't been in the picture because it's just been too short a timeframe to establish those relationships from scratch." *Stakeholder*

The Nurse also commented that she was able to draw on Leeds GATE's professional experience for advice and link up with community development activities they may already be doing.

Understanding the community's objectives and the needs they sought to address was part of the underlying approach of the project and, some stakeholders emphasised, proved effective from early on in the project;

> "working with communities to identify what those needs are"
>
> "working with, rather than doing to' – involves 'engaging, joining up, trying to understand their issues from their perspective and link it up."

4.2.2 The relationship between the Gypsy and Traveller Community and Health Services

This section includes any findings regarding perceptions of healthcare services by people from the Gypsy and Traveller community and describes any barriers to use. It then explores the role of the Specialist Nurse in aiding access to healthcare.

General perceptions of healthcare services

Participants voiced **mixed feelings** towards General Practice – some emphasised that their own experiences were positive whilst also mentioning other community members or previous less positive experiences;

> **"**I don't mind them doctors up there. They're not bad doctors. 'Cause I've had them doctors for about fifteen year now. Because there's a lot of, there's a lot of the community doesn't know things like I know. They're not as, I'm not really educated, but there's some worser than me. Do you know what I mean? Some can't even read and write." *Service User*
>
> "One doctor I didn't like, I stopped seeing him. I definitely don't like him, but the other doctors is all very nice." *Service User*
>
> "I don't (attend the GPs), because of bad experience with doctors in the past and things. Do you know what I mean?" *Service User*

Dissatisfaction with primary care was related in some cases to **capacity issues**, with the difficulty in securing doctor's appointments frequently mentioned;

> "It's actually impossible nearly to get a doctor's appointment. You know now if I rang up now it might take three weeks. I've rung up before and they say "well next month you could get". I said to her "I could be dead". Do you know what I mean…it's hard to get appointments sometimes." *Service User*

Issues / barriers to accessing healthcare

This section details the key barriers / issues affecting the community's use of healthcare services. Please note these are not all exclusive to the Gypsy and Traveller community – many are shared with the general settled population.

One barrier to utilising healthcare services was an **unwillingness to discuss or share health problems**. This was seen as particularly evident in Gypsy and Traveller culture, possibly more so regarding mental health;

> "We're funny people who don't talk to our families. I mean there's things that I wouldn't tell my daughters what was wrong with me." *Service User*

> "Travelling People are very private people. The people [keep] to themselves". *Service User*

> "Part of their culture is that they don't talk about their health…It's taboo, and I think this project helps them to break down those barriers" *Stakeholder*

This tied into **privacy concerns** when using GP Practices;

> "I just wanted to tell you something. I had a talk with my doctor like I'm talking to you. And everything I said to him, he wrote down on my records." *Service User*

Gender related issues were noted. One aspect of this is that men are seen as unwilling (more so than in the settled population) to talk about health or attend services;

> "A lot of Travelling men rarely go to the doctor until they're really, really poorly." *Service User*

> "I think the men would be less likely to want to talk to [name] about their health. But if they had I imagine any concerns about their health or worry, they would discuss it with their wife, and their wife then would discuss that with [nurse]… I think it's just because they're a bit embarrassed. They don't really speak very openly, Travelling men." Service User

The other aspect is that some women may not wish to attend GP appointments with their husbands, due to privacy issues;

> "You can't speak to your husband about some stuff. And he might want to be there when you go to the doctors and that, because they're very clingy. (…) Because a lot of Gypsy women if they're booked into their GPs with their husbands and that, they won't tell a lot to them. (…)" *Service User*

Poor literacy acted as a significant barrier to the effective utilisation of healthcare services and previous bad experiences affected future engagement. Again, this was seen as especially relevant to the Gypsy and Traveller Community;

> "We have no help like, do you know what I mean. And as I say with not been able to read and write, and not understand. We don't understand much about medical things, you know...a lot of Travellers don't understand the big words, you know what I mean like" *Service User*

> "I've gone in (to the GP practice) and I've handed something in (paperwork), because I couldn't, someone filled it in but they couldn't fill it in right. And then when I went to the desk they said you haven't done this and you haven't done that. I said "I hadn't done it". So she went well "can you do it?". I said "no, but I can't read and write, can you do it?" So she went "well I am really busy". There were three people behind me. "Well you'll have to go to back of queue, when I've seen to these come back". So I had to line back up, go round in a circle. And then I got to one person in front of me and I went "oh forget it", and walked out." *Service User*

Related to this is a **lack of knowledge or understanding** about some health issues;

> "And then a lot of Travelling mums are quite worried about the MMR…Because there has been a lot of Travelling children, and children from the settled community, affected by the MMR, such as leaving them autistic. It has been proven – there has been medical evidence of the MMR giving children the defect of later on in life… I mean it doesn't happen to everybody, but it has been in cases. And they're worried about that then." *Service User living roadside*

This could lead to **fear** and potentially 'inappropriate' use of health services;

> "As I say a lot of kids gets poorly and a lot of people don't understand, it's like one of my grandchildren broke out the other day in a big rash, do you know what I mean. And I was so frightened of meningitis and all that there, because one of my children years ago nearly died of meningitis, you know. So I said the best thing to do is bring him to, you know, the hospital if got rashes. But, it didn't, turned out to be just some kind of allergy or something like that, you know. I thought it was, I said that "I think it's only an allergy, but get the, you should bring him, you know, just in case." *Service User*

The **isolation** of the site and **limited travel** options particularly affect the uptake of health services amongst those living at Cottingley Springs;

> "There's a lot of people that can't drive, and as you know yourself it's very far from anywhere. Do you know what I mean? (Describing one GP surgery) it's a long ways from here, as you know. And if people can't drive, a lot of old people." *Service User*

Particular challenges were noted for **roadside families.** Difficulties ***registering with a GP,*** as well as being ***unable to access continuous care*** was discussed;

> "It's a problem, yes, to permanently register when you haven't got a permanent address, when your address is just off the road, the side of the road. It's very difficult…" *Service User living roadside*

> "You're not going to be there for more than 15 days… if they've got an appointment, say they've got an antenatal appointment, and say it could be their five-month scan or three-month scan when they're pregnant, they have to come back to where that was. And they could be living then maybe in Kent. It could be the other end of

London. It could be Scotland…then they have to travel all that way back to there again. Because by the time they reschedule it will change, another practice or antenatal clinic or a scan in the hospital, it's always like, then they can miss their appointments or they haven't got one available for when it's due. Stuff like that." *Service User living roadside*

The potential for **missing appointments** was particularly acute for roadside Travellers:

> *"*Or you could be maybe a month on a piece of unofficial ground, like really illegal. And there again you might be just one night there. And you can have an appointment, but you'll get moved off tomorrow. You can't then get the vehicle off the caravan to take you for your appointment, because you need it to move the home around. So they don't understand things like that." *Service User living roadside*

A stakeholder endorsed these issues remarking that some roadside families are resistant to registering with a local GP because they believe it will impact on their permanent GP registration elsewhere.

The **bureaucracy** involved in dealing with referrals or specialist support was challenging – especially for those with low literacy;

> "You have these psychiatric nurses, if they come and then they stop because they're dismissed after so long, then you have to go through the doctor again to get them, through the doctor, then to another place to be referred. And it's one big circle that goes round and round." *Service User*

> "The [services] rely on the person that needs the referral to ring up and make that call themselves, and to take the lead in that… if literacy is low … generally people aren't able to do that, because they're not able to read the information." *Stakeholder*

Fatalism within the community regarding specific long-term conditions and illnesses also emerged as a theme;

> "(the) fear that if you have cancer, that that's a life sentence" *Stakeholder*
> "We don't really talk about it (referring to depression). But if you have it you have it, there's nothing you can do about it is there? *Service User*

Other barriers or issues utilising health care, cited by stakeholders, included:

- **Stigma** regarding mental health and related services

- A **lack of confidence** attending services on their own;
  "…there's a need to attend services, but not the confidence to be able to attend them without support and advocacy." *Stakeholder*

- **Previous negative experiences** of engaging;
  "They expect to have a poor service, or they expect to be turned down when they get into the GP practice because they've had numerous experiences where they've tried to register and they've been turned away. And that's quite demoralising." *Specialist Nurse*

  "There are practical barriers… (…) [and] quite a big emotional barrier there, given histories of discrimination and a lack of trust which goes both ways…" *Stakeholder*

The role of the Specialist Nurse in improving access to healthcare

The Specialist Nurse performed many functions in helping the Gypsy and Traveller Community overcome barriers and access healthcare – from encouraging people to talk about their health and attend appointments to coaching them in how best to navigate the system. Her role is broad, supportive and, for many, on-going.

Helping to locate a Doctor who was willing to **register** a new, heavily pregnant, patient was critical for one young woman. The tenacity of the Specialist Nurse in doing this was highly praised;

> "Helping like for the baby, and she helped get a doctor for her. Because she got no doctor. Like she (nurse) helped me find a doctors. Told we couldn't, like nobody else couldn't, do you know what I mean? And I couldn't me-self. But she did, like she never stopped" *Service User*

Explaining health care issues reduced some of the fear and addressed misconceptions associated with treatments;

> "And then a lot of Travelling mothers, they're quite afraid of getting the children the immunisations until somebody explains to them details…and what it's for, and what it does… She (the Specialist Nurse) can explain it all in detail to them, and then it gives them a lot of – a nice peace of mind." *Service User*

The close relationship the Nurse had formed with people meant she was able to **encourage those disconnected** with the healthcare system to engage;

> **"**Lately I've been suffering with depression. I can't be bothered, I don't have no life no more, just give up me life, no end. And like she's talked to me, and think that, so I went to doctors. Only for her would I have gone places like that." *Service User*

Being able to get a doctor's **appointment** for people was greatly appreciated by many;

> "And she's done a lot to help me and my husband, like talking-wise and things like that and getting prescriptions and appointments and things like that." *Service User*

> "Yeah, the doctors. We've no, appointments. So I told [nurse], I said I'm finding it hard, I've got to get a doctor's appointment". So she rang then up and sorted it out for me straight away. And I suffer from anxiety and stress and it was phew, it was like phew, lifted off me." *Service User*

Some Service Users appreciated being **accompanied** to appointments by the nurse – potentially overcoming their lack of confidence or apprehension re attending;

> "Cause like, not being rude love, I wouldn't really be going there (to the GP) by me-self. I wouldn't like to be there by me-self. You know what I mean. I'd like someone with me, so [nurse] come with me… it give me more support, you know what I mean? Like give me more. 'Cause I wouldn't really go there by me-self." *Service User*

Having support from the nurse meant that people were able to ***get into the system***, and ***access the right type of care***; especially for those with low literacy;

> "She helped like get the ball rolling with the doctors and that. She like wrote to the doctors and things, and they've got a knee scan.." *Service User*

> *"*Well she [referring to the nurse] shows you how things can be done. And she can connect you. Because I can read a bit, but I'm not the world's best. And most of them can't read and write, and we do need help in things, in a lot of things… she's a 'god-bless' to the site to be truthful with you – because a lot of Travelling People don't get the help they need off the right people. And [nurse] is one of these people that she can put you on to them and things like that. Do you know what I mean?" *Service User*

The Specialist Nurse was also active in trying to ensure people **used appointments effectively**. This included role-playing to increase confidence;

> "I've made a number of different referrals to mental health services, but also coached people in order to be able to use them. So generally almost role playing what that must be like; attending appointments with people until they've got enough confidence to attend them by themselves." *Specialist Nurse*

The Nurse was particularly active in helping **young mothers living roadside** navigate the healthcare system, including connecting them to other services;

> "And then, [nurse] is very helpful I feel as well, because she can always – I've seen lots of young women here having babies. While they're pregnant, and when they're ready to have their baby, she books the appointment and she arranges an appointment for them. And if they think they're going to miss that appointment and

they can't get to that appointment, then she'll rearrange the appointment for them and things like that. And she does have a lot of nice other practitioners to see the Travelling women, or even like to give the children their immunisations or things." *Service User (living roadside)*

Issues

Participants were asked for any issues or problems regarding the project. The only issue raised was how long the project would last – its **sustainability**. This is based on previous experiences of building relationships with workers, only for them to be withdrawn;

> "They usually, anybody comes around for a while they take them away again, you know. Like there was a woman used to help 'cause we can't read and write, you know what I mean like? She used to help with the forms, and then came another one, I can't remember, she wasn't here for long. I can't remember her name. And then she was gone as well. So we didn't really, you know I mean, have people to help with us." *Service User*

> "Well I think that it's a great advantage for the Traveller People to have somebody like that all the time. I mean they used to years ago, and then they stopped it. Because there used to be a doctor's bus come on, and there used to be a nurse, like [name of project nurse] and she was lovely. And she used to come round. And we used to talk to her. But they didn't keep her long. And this is what they do. You get used to somebody that you can talk to and things like that. And then they take them off." *Service User*

> "Well I think it's a good thing what they've done, and if there's any way possible that we could keep it on, I think it would be a good thing." *Service User*

> "I think she's got, I do think she done good for like Travellers, because as I said Travellers don't, sometimes you don't get that down, for appointments and things like that. It's hard, do you know what I mean. She's good with that, she's a good person. I think she should stay on a bit longer." *Service User*

Stakeholders were aware of the importance of building sustainability into the project;

> "…when you have a short-term funding arrangement, it's important that you try and build sustainability into that." *Stakeholder*

4.2.3 Perceptions of the health-help card and health checks

The health-help card is in the format of a business card, with NHS branding. It explains that the person presenting the card needs help with reading and writing and was designed to minimise the embarrassment associated with being illiterate. The Specialist Nurse both distributes the cards to community members who would like one and introduces the

concept to services they are likely to use e.g. GP practices, pharmacies, dentists, Get Active sport centres.

Acceptability

Community members were broadly **supportive** of the help-cards. Trying to access health-care without being able to read or write is both challenging and embarrassing, with some health-care staff lacking understanding;

> "I think they would be, because show them that you can't read and write they'd maybe understand more. Because on the computers you type computers in them doctors, don't you? I looks at the sometimes, they say "put your name on top of the computer", I say "I can't read and write". *Service User*

> "Well I could've done with that two week ago when I went to (name of geographical area), because they insulted me to the ground. Because I went to (hospital) about me shoulder was kept hurting, every time I lift me arm up it hurts. When I went for the scan and that, well before I went in and handed the letter in, but I didn't know the letter said no children was allowed into this part. So when I handed the letter in the woman said to me "did you not read your letter?". So I went "no, love, I can't read. So she went "well how did you know to come to your appointment then?" I felt like a child, yeah. I felt like I'd had just had a telling off." *Service User*

Stakeholders reported anecdotal feedback that the card has been well received by members of the community and primary care staff. One participant commented that they have 'definitely got **a lot of potential**', explaining that;

> "… they are met with enthusiasm by both community members and administration and reception staff, which are largely the people that I've talked to about them. And people think that they will work and be effective." *Stakeholder*

The Specialist Nurse is also generally supportive "I think it just removes some of the embarrassment when you're trying to register" but noted that it did not entirely solve the problem – there had been some negative responses re the extra time required for registration;

> "…it's worked really well in some instances. And in other instances, people have still felt a little bit embarrassed because there's been a little bit of impatience sometimes when people have needed more time in order to register or do something."

Help-cards and Primary Care

Several stakeholders emphasised the need to get healthcare staff on board by explaining the value of the card and thereby raising awareness of the issues regarding low literacy within the Gypsy and Traveller community;

> "And I think it's a very good idea because we do assume as healthcare professionals that people do read and write." *Stakeholder*

> "[it requires working] quite forcefully with primary care about, ensuring that we've got that implemented" *Stakeholder*

The **need to combine** use of the health help-card with updating patient record information was emphasised by the nurse. She had been updating GP systems to ensure that, if someone was unable to read or write, that was on their records. This, she believes, "works well with the health card", and the combined approach "should stop a reliance on a written format of things to try and discourage nonattendance on not understanding a letter."

Health-checks

One aspect of the Specialist Nurse role was to conduct health checks with the community. These were not popular with community members, who whilst willing to talk about health with the Specialist Nurse and receive advice, do not want a formal check;

> "I spent a lot of time adapting a comprehensive health check template. The uptake of health checks has been very low, most community members not interested. The few that I have completed the Health check with found some areas too long, happier to just have shorter conversations." *Specialist Nurse*

Another participant observed that community members preferred a conversational format that was more bespoke and tailored to their particular issues.

4.2.4 Working with Primary and Healthcare Services

This section presents qualitative findings relating to how the project worked with Primary and other Healthcare Services. These come from the Stakeholder Interviews.

The Approach

Stakeholders highlighted that the project approach is a **two-way process** involving working directly with families on the one hand, and with GP practices on the other, with the aim to improve access to healthcare. All the stakeholders viewed this as a **'bridging role.'** In the words of one stakeholder; "It's about **building relationships** between the community and GP practices."

The Specialist Nurse role was the **driving force** in this process. One stakeholder described how she has worked; "as much with the GPs to make that access better, as she has with community members on an individual health level."

Monthly group meetings set up by the Specialist Nurse were one mechanism for this. Described as a "valuable forum" that has changed the way healthcare professionals from across Leeds communicate. the group discuss issues relating to their work with the Gypsy and Traveller community, whilst the project nurse provides **specialist information** and **shares knowledge** of best practice.

One stakeholder stressed the importance of **working across healthcare pathways;**

> "It's around a whole range of services. And I think the more that we can see things in that way, in a more holistic way, then we genuinely start to make the differences we want to see in terms of our bigger aspirations about improved life expectancy and reductions of the number of long-term conditions for this community."

Stakeholders emphasised the importance of continuing to strengthen these relationships in the **long term**, as one remarked;

> "to work with the practices to make them more welcoming and have a more long-term sustainable relationship".

Healthcare Systems

Working with healthcare organisations (**'in-reach')** to understand how **current systems** may be acting as a barrier to access for the community and how to improve them is a critical part of the role;

> "… starting to drill down into actually what are some of these barriers to people accessing services and what flexibility can we have within systems to overcome some of those things without needing specialist services." *Stakeholder*

> "trying to identify within systems and processes of primary care what the barriers to those positive relationships and positive access pathways for Gypsy-Traveller People are" *Stakeholder*

Outcomes

The Specialist Nurse had been successful in meeting with healthcare staff to discuss the needs of the Gypsy and Traveller community, but emphasised that **changing the current approach to health care delivery is difficult**;

> "Spending a reasonable amount of time with health visiting trying to get a commitment to visiting roadside families. Health visiting not wanting a "pathway" however trying to embed visiting roadside families is so far fraught with difficulty. There is an acceptance of wanting and needing to offer a service but a reluctance to do this differently." *Specialist Nurse*

There had been some **successes**. The Specialist Nurse had managed to connect a cancer screening project to the community whilst one stakeholder felt she had managed to bridge between healthcare and the community;

> "I am aware that there is a 3-year cancer screening project that has been commissioned for vulnerable groups. So far they have not approached this community. I am now part of their steering group so will be able to share when they start their work." *Specialist Nurse*

"… [the nurse] has come in and built that trust in order to help people navigate those relationships to primary care providers, and equally help primary care providers navigate that relationship back to Gypsy-Traveller People in order to get better outcomes for people." *Stakeholder*

Healthcare professionals working with the community appreciated having **expertise to draw on**. One stakeholder recalled the support received when consulting the nurse about a family who were having difficulty registering;

"[She] knew all the policies and legislation around people's rights to register. So that was useful. It was a good resource for me to tap into."

The nurse's success was attributed in part to her **influence as a health professional**. As one stakeholder reflected, "when it's a nurse saying that [i.e. to register a patient who does not have a permanent address] to the receptionist, that's far more of an impact." Possessing the right combination of skill and tact were also highlighted as key to success in such negotiations;

"...it takes such skill to manage that and make changes. And probably it's that kind of skill that makes people think that it's their own idea and not your idea that [the nurse] has had to bring to this post, to make these changes." *Stakeholder*

Barriers

In addition to the inflexible systems noted above, the Specialist Nurse noted that at times the biggest barrier was people's **negative attitudes** to the community;

"I wasn't aware that people felt so negatively … generally a massive barrier has been how people within the health service don't recognise their own bias, I would say; or haven't recognised how their own unconscious prejudices are affecting their practice." *Specialist nurse*

4.2.5 The Role Itself

The Specialist Nurse Role

All the stakeholders believed this role was **specialist and senior**, requiring a wide range of attributes, skills and experience in order to resonate and communicate effectively both with the community and primary care workers.

A number of **challenges** were identified. The main one was the **isolation** of the role, with the Nurse working across rather than within a team;

"…it's a tough job. And it's quite an isolated job, working in this community. And you would need a certain set of personal attributes and character to be able to do it. *Stakeholder*

"[the Specialist Nurse has] got places to work from, she's probably quite happy with her management…she's a bit out on a limb, and she's not really doing what anybody else within the offices she sits in does" *Stakeholder*

> "Slight negative in that it's been quite an isolating job, in terms of always lone-working; not having a team around me. Being the only person really who's doing this role has sometimes been quite difficult, I would say. However, that's not a complaint. That's just the way it is." *Specialist Nurse*

This **marginalisation** partly reflected the position of the community itself;

> "…if you talk to any Gypsy-Traveller healthcare worker, they normally say the same thing – where it's almost like they end up mirroring the position of the community. So in their role they end up quite marginalised by the system as well, and people seeing their role as kind of like a bit out on a limb, doing some kind of outreach, but never really as a key part of essential service delivery, and never really embedded in wider systems and structures." *Stakeholder*

Several participants commented on specific challenges in relation to the **management and supervision** available to the nurse, and the professional support and teams she has been aligned to over the course of the project. The issue of isolation and how to protect against it figured in many of these comments. As one participant noted;

> "…it's trying to find the right person, but it's then for that person, how are they getting the right support themselves. And I think that's one of the things that the nurse themselves would say: they feel slightly perhaps outside of some of the teams." *Stakeholder*

The Specialist Nurse agreed with this –although emphasising it had not stopped her getting on with the job. She had however sought out additional supervision and mentorship for herself – something she feels needs to be part of similar roles in the future.

Working in Partnership

Stakeholders emphasised the importance of **working in partnership** with a range of organisations from the outset. A determination to **include the voices of the Gypsy Traveller community in the decision making of the project** is considered crucial;

> "I think the most important thing about this piece of work has been, we did spend a great deal of time building those relationships at the beginning, and seeking out that support... And the particular focus we've had right from the very beginning was the number of engagement events" *Stakeholder*

Flexibility

Stakeholders spoke positively of the **flexibility and responsiveness** of the nurse's approach. As one remarked:

> "… she's made it what it needs to be, rather than she's been given a written project plan. I think she's developed it herself, which was useful, because she's engaged the

community to understand what they need, rather than going in there and telling them what they need." *Stakeholder*

4.2.6 Impact

This section attempts to convey the impact of this project – on the community itself and on healthcare systems. It draws on both Stakeholder and Service User interviews.

Difficulty measuring

Stakeholders expressed the view that measuring the impact of this project is challenging. This was ascribed to:

- The holistic nature of the intervention;
  "I think the benefit of being listened to in a therapeutic way is quite difficult to measure. … it's difficult to see what an outcome of that would be." *Specialist nurse*
- The small scale nature of it – involving relatively few people and only one health professional
- How short-term it is (initially one year)

One participant proposed that the project provides an example of '**emerging good practice'**, rather than hard evidence.

Within the Community

Improved access to healthcare

There are many examples given (see earlier sections) on Service Users having better access to healthcare due to the intervention.

In some cases, this could be in relation to an undiagnosed condition. In the example below advice from the Nurse led to the person accessing healthcare, a diagnosis and a change in lifestyle, thus preventing future more acute problems;

> "We need her 'cause another time (name of community member) was sick, and she told him to get to doctors. And straight away he told him he had to go on a diet, had high blood pressure, or he'll kill yourself. Like in the diet, and he's lost two stone since. He went to the GP, and they called him straight in and he got seen to like that. And then he had to go to hospital, and then it's all sorted from then. They told him if he don't lose weight, from gout, I think it's something to do with gout and all that, if he don't lose weight he could die or whatever because he's that fat. He's short but fat. And he lost two stone over it." *Service User*

Supporting a patient in accessing palliative care is another example. As the nurse explains,

> "the family and the [person] in question, didn't trust other services, but they did trust me. So actually, being able to bridge those services was really helpful. And that facilitated her being able to die where she wanted to die really, and be able to receive the right care."

In general, stakeholders felt that members of the community now had greater **awareness of health condition**s and **appropriate services,** were more **confident** in accessing them and **skilled** in using them;

> "…there's just more one-to-one stuff that [the nurse] has done that's been really great, that's been building up trust, that's been getting people more confident in accessing the GPs."

> "I would say probably people's options have increased in terms of the kinds of services that they can access, and their awareness and knowledge of that. I would say that people's confidence has probably increased in communicating with healthcare professionals through being coached by [the Specialist Nurse] almost in how to get what you want out of that appointment."

Mental health

The project is thought to have played a particularly positive role in improving access to **mental health services**. As the Specialist Nurse explained,

> "there's quite a lot of fear within this community that mental health services will take your children off you if you have a mental illness, or that you're mad, or that there's you know, some stigma really that perhaps is less so in other populations."

It was felt that services are difficult to access as Gypsy Traveller patients' needs often "haven't been recognised by their GP" and "it's not been recognised that things are as difficult as they are".

Stakeholders emphasised that there was a lack of awareness of the range of types of support available for mental health issues. The nurse had worked to increase awareness of 'emotional and social support rather than just medication' and accompany people to appointments to increase their confidence;

> "to know what those things are, understand what they are, and have the confidence to have that conversation with a GP, and request those things. Sometimes through actually physically being in that appointment." *Stakeholder*

The Specialist Nurse believes this to have been a particularly impactful aspect of the project;

> "I think there's more understanding of what services can work with you. I think in terms of mental health services, there's definitely more people working with mental health services that there were before I started. And that's taken a great deal of work, just to get people to that stage really."

Long-term conditions

Being better able to manage long-term health conditions was identified as an area where the project had had an impact. The Specialist Nurse remarked;

> 'some of the people that I've worked with feel more confident in managing the conditions that they are experiencing'

One community member noted that, despite experiencing chronic health issues, the support from the nurse was still valued and helpful:

> "Our health conditions are conditions that won't get better. But she helps by telling you things – try this, or try that, or do this. I mean she has the doctor, like they're changing my tablets and things like that. Do you know what I mean? Managing how to take my medication and things like that." *Service User*

Stakeholders agreed feeling that the project had led to improved access to services for these community members;

> "I think if you looked across the board there would probably be instances of people's health improving and especially their ability to deal with long-term conditions…"

Improved confidence / self-efficacy

The Nurse believes some individuals have become more independent in accessing healthcare because of the project, noting,

> "I can definitely identify people, where **their self-efficacy is higher** from the time that I have been working with them."

As a result of her approach "using coaching and motivational interviewing", she has witnessed that "people are more able in some areas of their lives" and is "hopeful that this will continue."

Sense of inclusion

Another significant impact identified by stakeholders is the **value to the community of** being the focus of a project to address health issues and the **sense of inclusion**. As one stakeholder reflected,

> "I think there's a psychological impact for the community of having a project funded that addresses some of the health inequalities that we know have been there for a long time. "…it does a lot for improving trust and relationships across the board. And I would hope that that would have a longer-term impact of people feeling included and able to access things."

Stakeholders also feel that Gypsy and Traveller people's engagement in the project has brought about **a change in attitudes towards services.** Reflecting on discussions he has had with families, one participant observed,

> "I don't think they've ever had a service where a nurse is willing to go out to them at roadside to discuss health. I think they've always been asked to go somewhere else. …they quite like the fact that somebody would come to them in their environment."

Other

Having reflecting on these examples, the nurse suggested that "the impact has been to individuals, rather than a massive impact to the whole community". She believes that the most significant impact of the project to date is;

> "being able to engage with and be trusted by a community that many people felt that wouldn't be possible, or that there would be risks involved, I think has been an achievement really." *Specialist Nurse*

Healthcare Services

Raised awareness of needs of Gypsy and Traveller Community

There were **mixed views** as to how effectively the project had been at raising awareness of the needs of the community amongst primary care staff.

Two GP Practices (at the time of interviewing) had embraced the project. One stakeholder saying;

> "…in my practice we definitely have an increased awareness around the needs of the Gypsy-Traveller community. I think everybody understands now that it's not as simple as giving somebody written information. We need to take time and explain things."

Reception and administration staff were felt to have been more responsive to the project (compared to medical staff) and had participated in the training provided, using it as an opportunity to "reflect on their own practice". Given the key role front-of-house staff play, as a link between members of the community and primary care services, this was seen positively. As one participant remarked, they are the ones "that give a welcome, and deal with appointment bookings and stuff like that, how important they are in healthcare access." One stakeholder observed a conversation between reception staff at a training session;

> "…it was a really positive discussion about how they might change their services to better accommodate Gypsy and Traveller people. But that was something around temporary registration, and members of staff challenging each other."

Others were less positive about this aspect of the project, reflecting that some GP practices had not engaged with the project and showed little enthusiasm. Several participants believed that to have a greater impact and bring about significant changes **further work was required** and the project needed to be embraced and prioritised at **senior management level**.

The fact that individual support is still needed for there to be a good outcome at a GP appointment was a disappointment for one stakeholder;

> "I think when somebody has advocacy attending a GP appointment, the outcome is better for that person… that shouldn't be the case. Should it really, that it's taken another professional to attend an appointment with somebody for there to be a better outcome"

Changed healthcare systems / processes

The fact that **health visitors are now visiting roadside communities,** was considered to be one of the major successes of the project to date. Of particular note is the positive impact on **maternal care**. One stakeholder considered this achievement 'massive' whilst another explained how long it had taken;

> "… [and therefore illustrates] how long change takes, and how much it has to be thought about, and planned out. And resources have to be joined in all of that. So, you know that's about two years to get that change to happen. But a fantastic change."

This participant stressed the crucial importance of nurse in this successful outcome, observing,

> "[The] relationships that she had to health visitors, and her understanding of health-visiting, and the challenges within it, were really, really good in helping those changes happen, which was a perspective that I would never have had."

The part played by the Specialist Nurse in **developing relationships with screening services** was also highlighted by one stakeholder;

> "I think that yes, the outreach's nurse role in terms of linking with the public health teams and the cancer screening teams, there is a voice there and there is a link with that community which will definitely bear fruit."

Other

One stakeholder emphasised that an important part of its impact was that *it provides* ***a model for working in partnership*** *– "it shows good partnerships between the council and NHS and the community."*

Another was that stakeholders now have a **clearer understanding** as to what the Gypsy and Traveller community aspire to in terms of healthcare provision;

> "I think one of the key messages we got from the Gypsy and Traveller community was they don't want to have different services from everybody else. They want to have the same services. But they want them to be kind of culturally sensitive." *Stakeholder*

Better/more effective use of health resources

Stakeholders suggested several ways that project may have led to more effective use of health resources, but emphasised they did not have 'hard evidence' for this.

The Specialist Nurse mentioned the support health visitors are providing for families with infants and younger children at roadside camps. Highlighting the **anxieties over infant mortality** within the Gypsy and Traveller community and the fact that "most mothers know of somebody who has lost a young child", she suggested that mothers now feel more reassured that they are being taken care of by an expert, and no longer feel it is necessary to use emergency services each time a child is ill.

Another participant suggested that the project has brought about a number of benefits in terms of the use of services, including a **reduction in missed appointments**, which 'we know are costly'; and "increased take-up of secondary healthcare options and preventative healthcare options" whilst others thought it had led to **a reduction in the inappropriate use of emergency and walk-in services**;

> "… anecdotally … it feels like they've had a reduction of people attending [emergency and walk-in services]. But maybe that's because communities have moved on, or it's because we've actually got people registered. But there's definitely been a reduction."
>
> "… we've probably seen a reduction of people coming through the walk-in centre since [the Specialist Nurse] has been in post."

Summary of interview findings

Barriers to accessing healthcare services
These include literacy levels, difficulties in securing GP appointments, lack of access to transport (for some women), a reluctance to discuss health and privacy concerns.

The ability to read is required for health system navigation, and therefore is a significant barrier within this community. A lack of trust in existing provision may also be an issue for some community members.

Roadside Travellers face great challenges accessing healthcare including difficulty registering and accessing continual care.

Gender plays a role, with men less willing to discuss health and, in some cases, affecting women's engagement.

Existing services are not always receptive to working with Gypsy and Traveller community members, and their rigid structures and processes serve as a barrier.

Engaging with the Community

The nurse role is greatly appreciated with very high acceptability. The role is holistic in focus and goes beyond the medical remit –involving discussing many issues and providing broad based support. It includes giving voice to community members and a range of engagement work to establish trust.

The characteristics of the role-holder are important for the success of this intervention and the importance of the outreach aspect needs noting as other health care delivery models do not allow such freedom and flexibility. Providing access on site as well as a flexible approach was also important.

Building relationships and trust are essential prerequisites for engagement.

The Nurse assisted with accessing health-care by registering community members, explaining conditions, encouraging attendance, accompanying people and helping ensure better quality appointments.

The well-established relationship with Leeds GATE was an important mechanism within this project, to enable access to the community via a long-serving and trusted voluntary sector provider.

Health checks were unpopular, with community members preferring a more conversational approach, which works well given literacy levels and the accompanying challenges.

Health help-cards were appreciated by many but needed to supported by changes within healthcare (flagging up patients that could not read and write, then communicating differently).

Outcomes
The work of the nurse has enabled increased access to health services for some community members and there is qualitative evidence of health improvement. However, the health issues experienced within this community are not only complex, but are situated amongst a range of difficult social circumstances.

The out-reach component of the Specialist Nurse role was important, in terms of serving as a pathway into appropriate services, thereby potentially improving access to health care. In some instances, there may be increased service use in relation to previously undiagnosed needs e.g. mental health.

There was mixed findings regarding Primary Care's willingness to engage with the project. Whilst some positive changes had been made (e.g. Health Visitors going to Roadside families) more changes were still needed.

Stakeholder identified positives because of the project, including building on past relationships, learning more about the way in which the community engages with services, and understanding the barriers to access.

Process Issues

Challenges identified by stakeholders include:

- Difficulty recruiting to the post (delaying the start of the project's delivery)
- Professional support and supervision for the Specialist Nurse
- A limited time frame in which the nurse post was available (12 months). Given the complexity and depth of the community's needs, this led to questions about sustainability.

Service Users greatest concern was the sustainability of the project due to previous negative experiences when trusted workers were withdrawn

4.3 Case studies

The Specialist Nurse completed 13 case study templates during the evaluation time-frame. The templates were designed by the evaluation team and are summarised within appendix 6.

Analysis of case studies content offers several learning insights:

The health needs of this community are complex, and multi-faceted. Many community members are dealing with complex, co-morbidities alongside social disadvantages such as isolation and low literacy levels.

Case Study Example - complex health needs

Homeless with one young child. Several problems reported including homelessness, literacy (needs help to complete housing forms), no health registration (no local GP or dentist).

Self-reported depression and anxiety. Feels isolated, poor family relationships and has partner in prison. Benefits sanctioned. Smelling of alcohol, and demonstrating chaotic, uncontained behaviour.

Some health problems also reported for the child, who was also "lost" to services and not attending school.

Existing services can be inflexible (e.g. GPs) and do not recognise the issues caused by low literacy levels. For example, the choose and book system is impossible to navigate without literacy. Not opting in leads to being discharged and then needing a further appointment with GP to refer again. Despite alerts on some patient's records system this still remains a problem.

Health check criteria excludes some who would benefit; one community member not eligible for NHS health check for another 15 years due to age, but did receive one, following advocacy work from the Specialist Nurse.

Services need to engage with some families as they are unable to access themselves. Thus the outreach component model of the Specialist Nurse's role is important within this community.

Case Study Example – the need for outreach

Young woman aged under 20, living on site, 38 weeks pregnant. Living with family on local site. Not registered with GP (had tried but was refused having experienced issues with ID and boundaries) Health visitor not visited at time of meeting with Specialist Nurse

Linked to GP, and other services following outreach.

Wider circumstances can limit access to services for example, one community member needed support but staff were unable to travel to site due to an alert which caused delays.

Nurse role enabled access into a range of services including with statutory providers in many instances due to her operating in a bridging capacity.

Where would some community members be now without the health improvement project? E.g. other services, professional support requirements would likely be missed by mainstream services.

Some existing conditions may have progressed without treatment causing further ill health, possible permanent damage, and therefore may have led to acute hospital admissions, with less options for treatment.

Support from the Specialist Nurse is not always accepted at first, time is needed to build trust and relationships. The project design has allowed the nurse to spend lots of time getting to know community members and their families, with this approach allowing a trusting relationship to build as well as confidence that the nurse can be trusted to work with the family. With this community, many community members are related to each other. Building a trusting therapeutic relationship with one member greatly influences how other members perceive the service. Most models or systems do not allow the time it takes to do this.

Case Study Example – the need to build trust.

Male, mid 40s. Attended health check after *9 months of prompting* during wider conversations with family. High cholesterol and pre-diabetes noted at health check

Working with Specialist Nurse to increase knowledge of CVD. *Not willing to work with other services* e.g. in relation to cannabis use

There is a gap between being advised to self-refer to a service and having the skill, confidence, knowledge, motivation and self-efficacy to access it.

4.4 Learning from implementation

Learning logs completed by the Specialist Nurse show several areas of learning from the implementation of the health improvement project.

Engagement with community members takes time, and it is important for community members to be able to build trust with workers as the starting point for engagement for health-related work. Furthermore, not all professionals wish to understand the needs of travellers and existing services (e.g. GP provision) can be inflexible. Some practices do not wish to participate in training related to the needs of Gypsy and Travellers. Threshold criteria for some services such as age limits for health checks may need revisiting, to enable earlier implementation.

The outreach component model of the Specialist Nurse's role is important when working with the Traveller and Gypsy community. The nurse role enabled access into a range of services including with statutory providers in many instances – her position and relationship with the community enabled her to work as a pathway into appropriate services. In some instances, this may reduce health care costs (e.g. less accident and emergency access) but in others may increase it (e.g. via increased uptake of mental health provision). Specialist workers need supervision and good quality support to facilitate the delivery of their roles.

4.5 Health Service Use-age Data

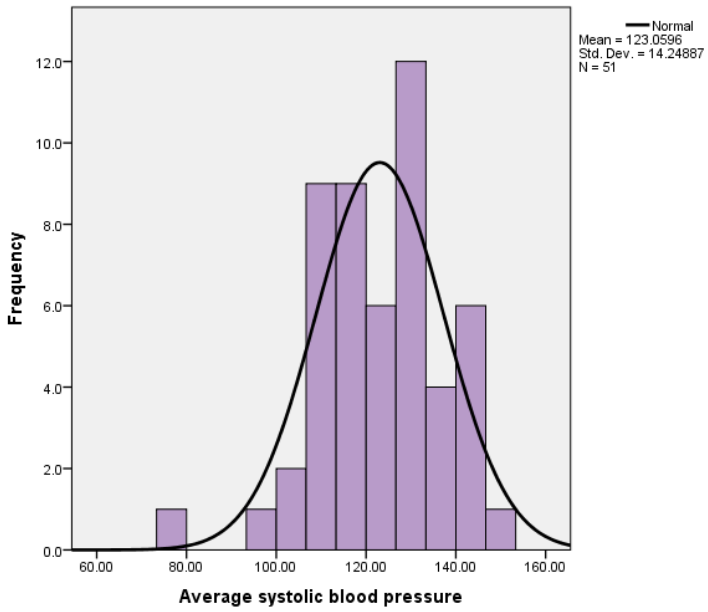
The following pages show the results of the analyses carried out on blood pressure level, attendance to A&E, and life-style advice referral. This is for the 68 people who interacted with the Specialist Nurse and gave her the necessary information to input information on System One.

Blood pressure

The participants' blood pressure has been monitored at different intervals since 2016, with some participants being tested only once, and others up to 20 times. Overall[4], the participants were checked for their blood pressure on average 4.93 times, with a standard deviation – which indicates the spread around the mean value – of 3.81.

As Figure 3 shows, the average systolic blood pressure is slightly above the recommended value of 120mmHg (Mean = 123.05)[5] and presents a relatively large standard deviation of 14.24, which indicates that at least 34.1% of the participants can reach a blood pressure up to 137mmHg.

Figure 3: Distribution of systolic blood pressure

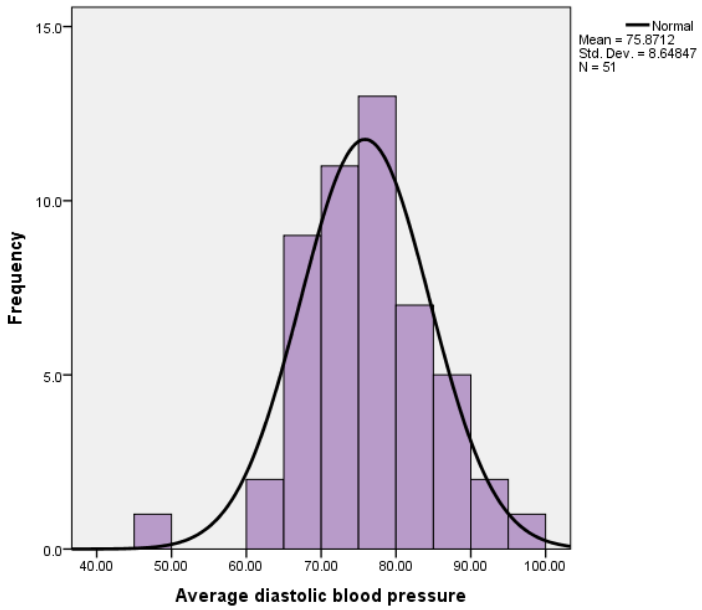


Conversely, the diastolic blood pressure for this population falls within the recommended value of 80mmHg (see Figure 4).

[4] Whenever we refer to overall values, we refer to result obtained through to the mean of the group means.

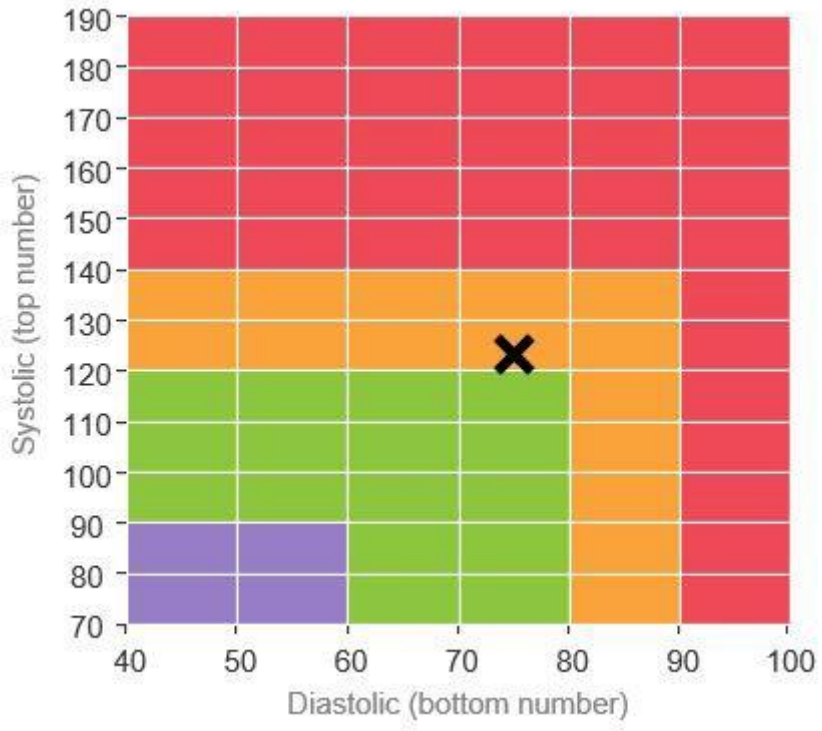
[5] Ideal blood pressure is considered to be between 90/60mmHg and 120/80mmHg (see https://www.nhs.uk/common-health-questions/lifestyle/what-is-blood-pressure/)

Figure 4: Distribution of diastolic blood pressure



The systolic and diastolic values combined together indicate that the Leeds Gypsy and Traveller cohort who saw the Specialist Nurse taken under exam presents a pre-high blood pressure, as we can see in the chart below (Figure 5).

Figure 5: Blood pressure reading chart

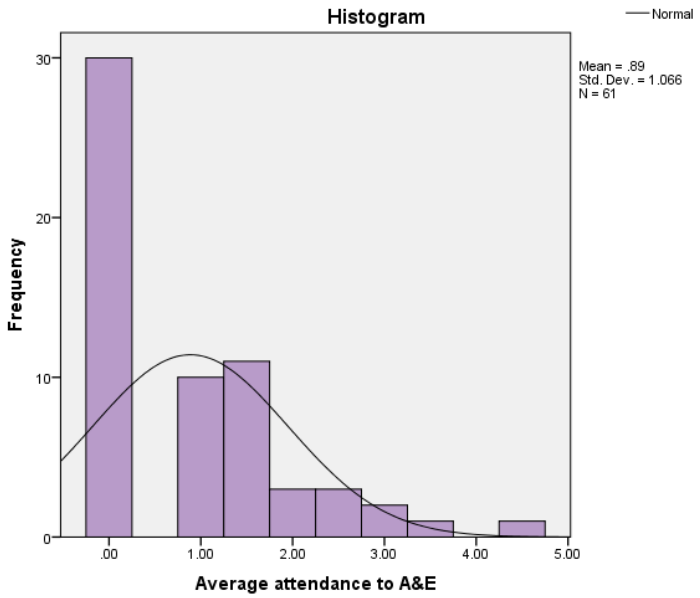


Source: https://www.nhs.uk/Tools/Pages/blood-pressure.aspx

Attendance to Accident and Emergency (A&E)

Since 2016, different participants have attended the A&E at different intervals, up to a maximum of 24 visits. This is over a period of 2.5 years. These include both self-referral and other forms of attendance. If we exclude extreme cases[6] – which include people who have attended the A&E on average between 5 and 12.50 times – the average number of visits for this sample is .88, with a spread around the mean (i.e. standard deviation) of .13 (see Figure 6).

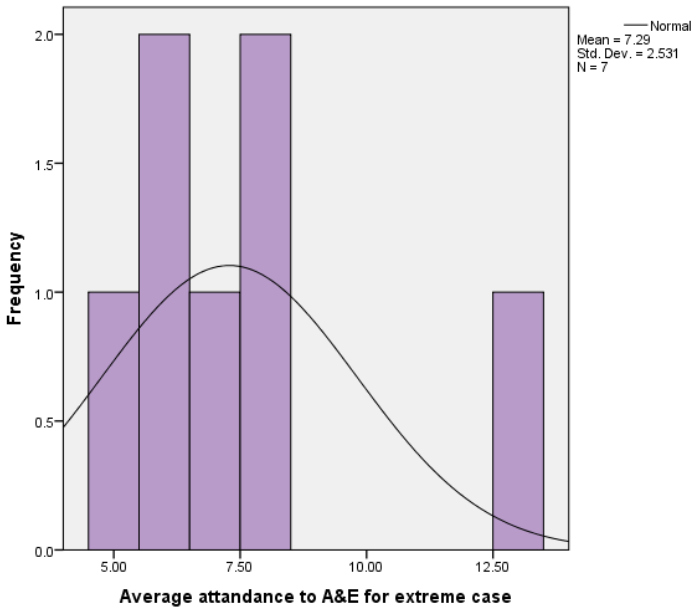
Figure 6: Average of attendance to A&E



Nonetheless, our results suggest that some participants to the study show an extremely high attendance rate to the A&E. with an average of 7.28 visits and a standard deviation of .95 (see Figure 7).

[6] Cases were excluded based on *z* scores > 1. 96

Figure 7: Average of attendance to A&E for extreme cases

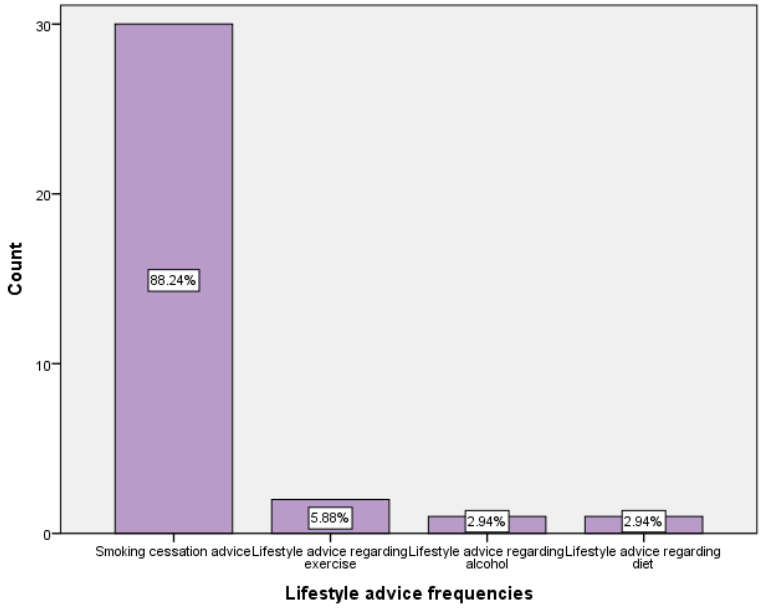


It is advisable to monitor the conditions and reasons for attending the A&E of this specific group of people.

Life-advice referral

Similar to the variables analysed above, participants received life-advice referrals multiple times since 2016, when seeing the Specialist Nurse. As we can see in Figure 8. the most common referral was given regarding smoking cessation (88.2%), followed by advice regarding exercise (5.9%), advice regarding alcohol (2.9%), and advice regarding diet (2.9%)

Figure 8: Frequencies and counts of life-style referrals



Summary of Health Service Usage Data

- The Gypsy and Traveller Community's average systolic blood pressure is slightly above the recommended value of 120mmHg. This indicates a pre-high blood pressure and therefore the condition of this group of people should be kept under control and actions taken to reduce further risk of high blood pressure.

- Although the average of attendance to A&E tends to be quite low, some participants were found to have been attending A&E multiple times since 2016. These extreme cases raise some concerns; therefore, it is advisable to monitor the conditions and reasons for attending the A&E of this specific group of people

- Amongst the life-advice referrals, the topic mostly discussed is smoking cessation advice. This suggests further investigation, particularly on the outcomes that followed the advice.

5: Discussion and Recommendations

The data that we gathered as part of the evaluation of the Health Improvement Project illustrates that many of the issues identified within the Health Needs Assessment of the Gypsy and Traveller community in 2013, remain a challenge at the time of writing in 2018. Low levels of literacy remain and difficulties securing GP appointments, and accessing a range of health services were discussed as challenging by community members when they were interviewed. Those interviewed by us also showed knowledge of their poorer health when compared to other majority populations as well as the wider range of challenges that they often experienced. The support provided by the Specialist Nurse was often about more than health needs, reflecting the broad nature of the challenges experienced by community members.

Cemlyn et al (2009) note a range of inequalities that are experienced by Gypsy and Traveller communities across Britain, whilst recognising that there are gaps within the formal evidence base in relation to some aspects of exclusion and inequality. They note the impact of racism and associated discrimination for members of the Traveller and Gypsy Community throughout the life-span. The Specialist Nurse reported experiencing negative attitudes amongst from other professionals. However, Hodgins et al (2006) note that it is difficult to untangle the effects of racism within this community because of the complexity of cultural influences as well as socio-economic deprivation.

In their research, Cemlyn et al (2009) found high rates of anxiety, depression and self-destructive behaviour (substance abuse and /or suicide) within Traveller and Gypsy communities. They argue that such behaviours are responses to cultural trauma due to the lack of equity experienced by community members. Our data also confirms high rates of poor self-reported health, both physical and mental. Our evaluation data also illustrates the importance of the social determinants of health with high poverty rates being common and low educational attainment. There may also be lack of cultural recognition within wider society (Cemlyn et al 2009.

The low literacy levels noted within our research are a significant barrier to accessing health care in a system that is based upon the ability of patients to read in order to navigate appointments, use the choose and book system and to understand information provided in the form of leaflets. Other studies also confirm literacy and language as barriers to accessing health services, as well as discrimination and economic disadvantage (Siebelt et al 2017). In a systematic review of the literature McFadden et al (2018) also note evidence of such communities struggling to exercise their right to health care as the result of multiple barriers and broader disadvantaging determinants.

The approach evaluated here was based upon an outreach model of care delivered within community locations where Gypsies and Travellers were based, both at a permanent site (Cottingley Springs) as well as to road-side families visiting the city. The specialist nurse spent time engaging with community members, and building trust as a mechanism to work with them on health related issues. Berlin et al (2018) note the importance of health professionals needing to gain a better understanding of Gypsy and Traveller Health beliefs (and practices) as a mechanism to be able to work with them, which mirrors the approach used. Furthermore, Berlin et al (2018) also point out that as a result of societal

discrimination including from health services themselves, engaging with Gypsy and Traveller communities is likely to take both time and effort. Our evaluation findings support this as the Specialist Nurse found time was required, especially to engage men within the community. The focus of the research conducted by Berlin et al (2018) was upon lay understandings of cancer, with the findings noting that lay understandings of both cancer and indeed illness within the Gypsy and Traveller Community vary between ethnic groups, therefore current approaches to educating and treating people with cancer in such communities may not work. Thus, tailored approaches (such as the one evaluated here) are required. Finally, Berlin et al (2018) note the need for cultural awareness training amongst health professionals especially in relation to gender-related issues within the Gypsy and Traveller community. Our data shows different levels of engagement with health services according to gender, with women more likely to work with the Specialist Nurse, men taking longer to engage or engaging via their wives and women experiencing different barriers to accessing support for their health as a result of their gender.

The need to build trust as a mechanism to work with Traveller and Gypsy communities is noted within our evaluation findings. Putnam's (1995) concept of social capital is of use here, with Gypsy and Traveller's having high levels of bonding social capital (strong connections) between themselves as they are often segregated and do not trust institutions (Berlin 2005). Berkman and Glass (2000) argue that bridging social capital (looser connections between different groups of people) is needed to support people in accessing health services, and increasing their psychological well-being via improved trust and self-esteem. Our research echoes this as those interviewed reported being private people, who take time to trust outsiders such as health professionals like the Specialist Nurse. It is also worth noting that service users didn't want other community members on their site and on occasion their own families to know their personal stuff. She also acted as a bridging mechanism between the community and a range of other services. Despite the evidence that networks play a role in shaping health behaviours, some studies show that this depends upon the social context of each Gypsy Traveller groups, as well as the status of such groups in relation to wider social structures. The more hostile the external social world is perceived to be, then the more likely it is that Gypsies and Travellers will withdraw into their own communities (Smith and Ruston 2013). Hostility was reported by the outreach nurse and service users within our data within the context of health service usage experiences.

Siebelt et al (2017), recommend several approaches to enhancing engagement with health services in Gypsy and Traveller communities including the use of named specialist workers (e.g. the nurse used in Leeds), cultural training from professionals (offered to GP surgeries across the city), and tailored or flexible systems (inflexibility was noted by community members, and the outreach nurse). This echoes the point made by Dar et al (2013) who similarly stated that there needs to be access to services which are culturally sensitive as well as responsive to the needs of Gypsies and Travellers, because despite the provision of specialist services in some areas of England, service uptake and immunization rates remain low. Our evaluation findings reflect this in relation to the need for services to be flexible, specifically in response to low-literacy levels amongst Travellers and Gypsies.

The success of the nurse within the Health Improvement Project evaluated here was also aided by support from a long established advocacy service (Leeds GATE) based near to the permanent site itself, who introduced her and us as a research team to community members. Siebelt et al (2017) point out that research within such communities often

depends upon the use of trusted gatekeepers, which was true in this evaluation as researchers were accompanied on data collection visits by a trusted gatekeeper.

Furthermore, the Specialist Nurse reported the need for support within her own role, due to a lack of cultural awareness amongst wider service providers, and her own isolation as lone worker providing support to the Gypsy and Traveller community. This echoes the research findings of Van Cleemput (2012) who argue that practitioners need good management, support and supervision when providing health care to Gypsy and Traveller communities.

Recommendations:

For Leeds Clinical Commissioning Group:

1. Retain the Specialist Nurse post, using outreach, in the medium term. This is needed until health literacy improves and empowerment built within the community.
2. Ensure the Specialist Nurse is supported in her role with appropriate mentors and a location to work from.
3. Advocate for similar services in other areas.
4. Ensure there is senior management support within healthcare for a more flexible service for members of the Gypsy and Traveller community (e.g. longer appointments, tailored communication).
5. Work with partners to address negative attitudes within health care services towards the community.
6. Support voluntary sector organisations working with the community.
7. Appreciate that attending Accident and Emergency may be due to fear or inflexible health systems.

For the Partnership:

1. Work together to improve literacy rates in the Gypsy and Traveller Community and address social determinants of health.
2. Keep focusing on reaching and engaging with male members of the community.
3. Work together to empower women so they can access healthcare and other critical services independently.
4. Training needs to ensure people are aware of the patriarchal nature of the community and how this may affect both gender's uptake of services.

6: Conclusions

Table 11 provides a narrative conclusion of the evaluation data, mapped against each component of the Theory of Chance which underpinned the evaluation methodology used.

Theory of Change component	**Evaluation findings**
Strategic Aim: Health Improvement Project - enabling clients to have improved knowledge of services and increased appropriate service uptake	Our evaluation evidence shows that there are complex health needs within the Traveller community and that service uptake is linked to literacy levels. The Specialist Nurse was able to increase service knowledge, and improve health literacy via her interactions with community members.
Engagement: (mechanism for change) - local engagement and support through the specialist nurse	The mechanism for change within this project worked very well, with the Specialist Nurse initially gaining the trust of community members to further enable them to work with her and gain appropriate support.
Changing the environment: (mechanism for change) - engaging in the life-worlds of the clients and building a positive relationship with the specialist nurse (and broader professionals)	The Specialist Nurse was able to work with community members in a range of contexts via a positive relational approach. The Nurse was also able to improve some pathways with professionals such as GPs and Health Visitors. However, not all professionals were willing to work alongside the Nurse, therefore challenges remain in this area.
Outcomes (service users): Improved relationships between the community and primary health care Improvements in self-related health Improved knowledge of screening and/or uptake	Our evaluation evidence shows improved relationships between community members and the Specialist Nurse providing Primary Care. There were some qualitative self-reported health improvements from community members. Finally, the community members who participated in the evaluation tended to already engage in screening, but the Specialist Nurse added value by offering a more localised health check for other Travellers and Gypsies.
Outcomes (organisational): Learning from the specialist nurse role Use of the help card Changes in the use of services	There is a raft of learning associated with the implementation of the Specialist Nurse role, with recommendations from our evidence drawn from this.

	Community members were supportive of the Help Card, and some had used them. However, health systems require literacy to navigate in full (especially secondary care) therefore many Travellers and Gypsies still face barriers to access. There has been some change in the use of service uptake with community members supported by the Specialist Nurse to access the care that they required. The Nurse role involved a significant bridging component between community members and existing health care providers.

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8: Appendices

Appendix 1 – Monitoring Data Spreadsheet

Categories as below – supplied as a spreadsheet, completed for each interaction

The Interaction

- Date (free text)
- Place (free text)
- Length (free text)
- Previous contact? (Drop down list)
- Any other comment re interaction (Free text)

The Person

- Gender (Drop down list)
- Age (Drop down list)
- Are they registered with a GP? (Drop down list)
- Level of literacy. (Drop down list)
- Current Residence. (Drop down list)
- Any other comments re the person (Free Text)

Any Intervention?

- Was a revised health check given? (Drop down list)
- Did you give them a help-card? (Drop down list)

Health Advice Given

- Main advice given. (Drop down list)
- Any other advice given. (Drop down list)
- Any other advice given. (Free text.)

Cancer Screening

- List any cancer screening they suggested you attend. (Free text)

Advocacy

- MAIN organisation or service you spoke to on the person's behalf. (Drop down list)

- Other organisation or service you spoke to on person's behalf. (Drop down list)
- Any other organisation or service you spoke to. (Free text).

Signposting

- MAIN organisation or service you signposted the person to. (Drop down list)
- MAIN organisation or service you signposted the person to. (Drop down list)
- Any other organisation or service you signposted to. (Free text).

Any other comment at all (free text).

Appendix 2 – Case Study Template

Describe the intervention What was the benefit? Were there any issues? What was the change?

Appendix 3 – Learning Log Template

What went well at this stage in the project, building up relationships and delivering activities?
What did not go as well at this stage in the project, delivering these activities?
What can you learn from this? With hindsight what would you do differently?
Are you aware of any other activities taking place locally that may affect the impact of this project? If so, please provide as many details as you can including; what the activity is, where it is taking place, how long it is lasting for and what resources are being used. Feel free to include links or scan any leaflets / resources being used.

Appendix 4 – Stakeholder Interview Schedule

Introductions: Stress that we want to talk about the project in a general way rather than trying to obtain specific information about any of the people referred into the project/involved. If names or identifying factors come up in the conversation, then reassure that the information will be anonymised.

Background/Introductory information

1. Please could you tell me about your role/what you do?

Questions relating to the project

2. What do you know about the Leeds West CCG Gypsy and Traveller Health Improvement Project?

   Probes:

   How did you find out about it?

   What type of connection have you had with the project? In what capacity? (referral? Information-seeking? Joint working?)

   Who did you first speak to? Why did you make contact with (this person)?

   What happened next?

3. Can you describe the project approach?

   Probes:

   How is it different? What makes it unique?

   Do you think the approach is effective? If so, how and why (what features make it so?)

   What are your views about the specialist nurse role (can she reach the community members, is this approach acceptable?)

   What are your views about the health-card?

4. What impact has the project has on the people who have been involved with the project?

   Probes:

   What changes have you seen in their situation/circumstances? Can you give some examples? Which of these might be as a direct result of her involvement with the (Leeds West CCG Gypsy and Traveller Health Improvement) Project?

How do you think the project has supported the people who have been referred? Is this different in any way to existing provision?

Is the project engaging with people in a different way to existing services? (Value of the specialist nurse role?)

5. We are interested in trying to determine outcomes and indicators for all of the people who have engaged in the project. What difference is the project making to those who come into contact with it?

   Probes:

   Improved satisfaction with services

   Changes in understanding about appropriate use of services

   Knowledge and attitude changes in relation to cancer screening

6. Can you describe/ give examples of how the project has made better/more effective use of health resources?

   Probes:

   Less use of Accident and Emergency?

   More use of GP/other primary care e.g. pharmacy?

7. If the project were to be delivered again, are there any recommendations that you would make for changes?

   Probes:

   Areas for improvement?

   Changes to delivery?

   Issues?

   Learning?

Closing questions

Why is the project important? (Changes in use of services, changes in understandings of the needs of Gypsy and Traveller community members from professionals?)

Is there anything you would like to say about the Leeds West CCG Gypsy and Traveller Health Improvement Project which we have not discussed/talked about?

Thank you for your time etc., etc.

Appendix 5 – Service User Interview Schedule

General schedule for service users on Cottingley Springs

Introduction:

Explain who we are, what the evaluation is for and normal guidelines re doing an interview. They can give verbal consent to take part (signed by us).

Ensure the interviewee has the opportunity to introduce themselves.

General questions*:*

Tell us about how you met the nurse (name)….

Why did you decide to speak with her? / What did you hope to gain?

What do you think about her role? *(Both positive and negative perceptions – What is good about her role? What could be improved?)*

What do you think about the help cards? *(Again both positive and negative perceptions – What is good about them? What is not good about them?)*

Questions which focus on improvements:

Has the project / Liz changed your health at all? *(If so, in what way (examples)? If not, why not?)*

Do you know more about health services because of this project? For example, Accident and Emergency? Cancer Screening?

Has it changed how satisficed you are with your local doctors (GPs)? (if so, how)

Has it changed how satisfied you with any other local services? (if so, how)

Are you likely to use services differently because of this project?

Questions focusing upon learning:

Has there been anything about this project that has surprised you?

Are there any drawbacks or negative aspects to this project?

If this project was to happen again, are there any changes that you think need to be made?

Finally, is there anything you would like to say about the Leeds West CCG Gypsy and Traveller Health Improvement Project which we have not discussed/talked about?

Thank you.

Interview schedule for 'people roadside' or 'people in camps'

Introduction:

Explain who we are, what the evaluation is for and normal guidelines re doing an interview. They can give verbal consent to take part (signed by us).

Make it clear that we will NOT be asking about their health or anything personal to them – we are just asking what they think about Liz's role and their thoughts on the health-service in general.

Ensure the interviewee has the opportunity to introduce themselves.

General questions about the role:

What do you think about the idea of having a nurse able to work with your community? Have they met Liz? If so, tell us about how you met the nurse (Liz)…. What do you think about her role? *(Both positive and negative perceptions – What is good about her role? What could be improved?)*

Would you feel able to speak to her? (if not, why might this be?)

What do you think about her role? *(Both positive and negative perceptions – What is good about her role? What could be improved?)*

What do you think about the idea of help cards? *(Again both positive and negative perceptions – What is good about them? What is not good about them? Do they know about them? Would they use them?)*

Questions which focus current access to health services:

Are you registered with a GP? (if yes, are you satisfied with them? If no, they would they consider registering, would it be possible?)

If you needed medical help, where you would you go to get it?

If there was a nurse who you knew about in one area (such as the one employed here in Leeds), do you think that you would use services differently because of her?

Questions focusing upon service usage:

Do you have any general ideas for us about what you think people living roadside need in

terms of health care?

What types of services would they use?

What do you think about cancer screening services? Are you aware that these services exist? Have you used them? If you haven't used them, would you consider using them? If not, why not etc.?

Finally, is there anything you would like to say about health and health services for people living roadside which we have not discussed/talked about?

Thank you.

Appendix 6 - Case Study Overviews

Case Study 1

Issues	Actions	Benefits	Remaining challenges	Alternatives	Changed use of services
Homeless individual living in caravan at the local site, at the time of the interaction. Has 1 child. Several problems reported including • literacy (needed help to complete housing forms) • no health registration (no local GP or dentist) • Self-reported depression and anxiety • Feels isolated, poor family relationships • Has partner in prison. • Benefits sanctioned. • Some health problems reported for the child, asthma, eczema.	Checked child's regime. Arranged to see weekly on outreach. Gathered information. Supported with housing application, Benefits, GP and dentist registration. Asked Leeds GATE to see. Made phone calls to School, health, Travellers education. Gave information on Local GP and NHS dentists. Follow-up after A and E attendance (accidental paracetamol overdose as unable to read instructions) Accompanied visit to GP to support registration, housing	Medication and services for child More "eyes" on the needs of the family and emotional needs of the child More opportunity to assess alcohol use and impact. Priority housing application Booked in for cervical screening Tackling the social isolation that was maintaining the vulnerability of the family.	Poor literacy, unable to read and understand written instructions and write, can manage some texts but this is limited Lack of transport a barrier to accessing services and support	Services needed to be able to engage the family not the other way around. Family vulnerable and "lost" to services. Needed to have professional build a therapeutic relationship in order to be able to help. Potential safeguarding concern kept at early help level due to being able to encourage professionals to	Family now registered with GP/ dentist. School nursing aware of child and have arranged health needs assessment. Cervical screening arranged. Housing application done. Traveller services, school and school nursing coordinating care for the child.

• Child “lost” to services and not attending school. In addition, nurse noted that this service user smelled of alcohol, and demonstrated chaotic, uncontained behaviour.	forms completed and link with school for child’s attendance, and referral to Forward Leeds (for alcohol issues).			engage with the family in a proactive rather than reactive way.	Child has appointment was asthma review.

Case Study 2

Issues	Actions	Benefits	Remaining challenges	Alternatives	Changed use of services
Cottingley springs resident, late 40’s. Multiple medical and social problems. Chaotic presentation. Several long-term conditions including pain, COPD, some neurological problems. GP had noted chaotic thoughts, no referral to mental health services.	Engaged over 6 months by small conversations on site, took this length of time for trust to build. Not able to follow a conversation, chaotic thoughts, negative view of the world, appeared afraid. Eventually client consented to referral to CMHT, only if the nurse would attend assessment appointment with her. This appointment did not go well, presented as chaotic, not able to express difficulties. Mental	No health improvements but trust in her relationship with the nurse allowed her to consent for a referral to mental health services.	The nurse had many appointments with this service user that were ineffective due to the chaotic nature of her life, but the outreach model allowed an assertive approach and eventually more positive progress.	Continuing with medical model of care, over reliance on medication, potential of organic cause undiagnosed.	Service user attended a secondary care service with support and consented to a psychiatric assessment.

Visits GP regularly, about weekly. Notes suggest GP struggling to view holistically.	health practitioner accepted "story" as truth and did not feel there was any mental health difficulties. Nurse able to discuss after and advise that what client was describing was fantasy, no basis in truth, needed psychiatry assessment which is now arranged.				

Case Study 3

Issues	Actions	Benefits	Remaining challenges	Alternatives	Changed use of services
Cottingley Springs Resident 40s. Long term health condition. No literacy. Not understanding condition. Diagnosis of polymyalgia, rheumatoid arthritis, depression.	Seen on outreach, another community member recommended accessing the nurse. Nurse spent time discussing and advising of long term health condition, ensuring understanding, using media to explain. Nurse used YouTube videos and completed casework around looking at managing	Community member has more knowledge of her condition, had previously been given written information and had not been able to read it, leading to fear of prognosis. Outreach model allowed the nurse the availability to engage with this service user on her terms. This model also gave me the freedom to attend an outpatient appointment	If the nurse had been working within a service that discharged people for not attending appointments the community member would have been discharged for not engaging.	Likely continued poor understanding of condition, increased fear, not being able to or having the confidence to access other services that could help.	Likely more confident due to increased knowledge and understanding. Service user enabled to have more choice over treatment other than medication.

	the condition including self-help. Nurse liaised with GP to ensure practice was following NICE guidance. Nurse also worked with service user on her confidence in relation to a referral to adult social care for occupational therapy assessment and liaison psychiatry to help with the depression and feelings around having this condition.	with her which helped build our relationship and give her more confidence to ask the Doctor more questions. Outreach has allowed me to work with her in a way that meets her needs and not necessarily the needs of the organisation.			

Case Study 4

Issues	Actions	Benefits	Remaining challenges	Alternatives	Changed use of services
Young woman, pregnant Living with family on local site Not registered with GP (had tried but was refused, issues with ID and boundaries) Health visitor not visited due to late presentation.	Applied for healthy start, Sure Start grant Discussed role of HV clinical lead so that the service did offer an antenatal visit despite late presentation due to vulnerability. Assisted in taking to GP practice to register. Raised as incident with the CCG	Community member aware of how and where to register with primary care once instructed however struggling with having motivation due to previous experience. Outreach model enabled direct support at a vulnerable time in her life.	This community member needed support at a time when there was an alert on visiting site so Health and Leeds Gate were not visiting, delayed some of the support needed.	Delayed further in accessing Primary care, baby did need urgent treatment within first week which was delayed due to no GP access. Less coordination of services including Health	Now registered with Primary care and accessing health care, confident in using this service and Health visiting service.

Midwife from Haamla team aware and was visiting.	about not being able to register with GP initially. Emotional support to build upon self-efficacy.	Has since attended appointments alone.	Visit was offered off site which was not accepted. Nurse had been seeing the family and wider extended family on outreach previously who had not reported any concerns or wanted/ needed to engage with the project - Emphasises the need and the time taken to build relationships with community members in order to be trusted to help.	visiting service, less confident in accessing services. More risk to Mum and baby.	

Case Study 5

Issues	Actions	Benefits	Remaining challenges	Alternatives	Changed use of services
Local site resident, mid-40s lives with children. Seen regularly on outreach. After several home visits began to talk about various concerns, very	Relationship build to be able to hear her story. Referral to Touchstone IAPT, also Aspire to ensure no	Outreach model allowed the time to relationship build with the community member ensuring trust to be able to move forward with	Needed a lot of time to build up to talking about referrals in order to build trust. Services can be accessed but there appears to be a role	Likely to have carried on as before, frequently accessing GP with only short term benefits, no behaviour change, possible escalation in	Potential increased confidence in having her voice heard, more trust in

low mood, depressive symptoms, anxiety. Some long term health conditions, good understanding however taking medication chaotically. Concerns also around teenage son, feels he is hyperactive, immature emotionally. Not in School, mainly due to not being able to manage exclusions rather than a desire to home school. Leeds Gate advocacy had also been working with her which had likely given her confidence to engage with me. Was "stuck" within needing to access services and needing confidence to attend appointments and to ensure primary care listening to what the concerns were. GP needed encouragement to see more holistically, less medical approach.	new psychosis. Also accepted by CMHT. Referred child to CAHMS and liaised with cluster support. Joint visit with cluster worker as unfamiliar with visiting the site. Accompanied visits to GP and mental health appointments. Discussions with GP and pharmacist around medications, arranging dossett box to make compliance easier. Used family approach, looking at health and wellbeing of whole family.	plans and changes that she wanted to make. Outreach model has allowed me to attend appointments with the community member at her request. Community member has more awareness of depression and anxiety and how they affect health and wellbeing. Has given her confidence to access mental health services. Potential increased confidence in having her voice heard, more trust in mental health services.	for a "bridging" service to build self-esteem and self-efficacy in order for someone to engage with services. There is a gap between being advised to self-refer to a service and having the skill, confidence, knowledge, motivation and self-efficacy to access it.	mental health concerns. Child would continue to be unseen by services, may have unmet, unassessed needs. Potential for deterioration in condition due to poor medication compliance.	mental health services.

Case Study 6

Issues	Actions	Benefits	Remaining challenges	Alternatives	Changed use of services
Local site resident, late 60's terminal diagnosis, however well and active. Not working with other health services at beginning of my work with her, not confident in services from GP or palliative care service. When an episode of acute illness was able to liaise with ED, organise GP to do home visit, coordinate with palliative care nurse to arrange bed. Before my visit the illness had been perceived by ED to be a result of the cancer not an acute illness.	Several interventions: relationship building and emotional support. Liaison with other services including palliative care, provided a "bridging" service to encourage confidence in using palliative care. Liaison with GP on several occasions to organise different medications or supplements.	Was able to assess acute illness and arrange assessment and care in hospital. More uptake of services, especially from Palliative care team, more confidence in using this service. More contact with GP, including a home visit, raised awareness of palliative care register pathway/ access and entitlements Emotional health and wellbeing, community member able to discuss her prognosis, explore her feelings around this including discussions around dying. Acute episode of ill health missed by medical staff and left untreated as presumed	The project allowed the nurse to spend lots of time getting to know this community member and her family, enabling a trusting relationship and confidence to build. Most models or systems do not allow the time it takes to do this. With this community at Cottingley Springs, many community members are related to each other. Building a trusting therapeutic relationship with one member greatly influences how other members perceive the service. Time spent relationship building and "tea drinking"	This service user had the right systems in place however there was a lack of awareness of what being on the palliative care register meant or what pathways/ services were open to her. The project allowed the community member and her family to gain a trusting relationship with the nurse which led onto further access to other services and a more coordinated approach. Without good relationships and	Community member and her family are more aware of what services are available and how to access. Initially despite the increased knowledge, the family continued to use the nurse as a bridging service between and thus required continued work around confidence to contact directly.

		related to cancer diagnosis. Was able to assess member as acutely unwell and arrange treatment with assistance of specialist palliative care nurse. Potentially if left untreated would have led to pain, suffering and exacerbation of condition. Community member and her family are more aware of what services are available and how to access.	has been an investment and an approach of sensitively considering the needs of the whole family.	the family and being able to navigate health systems, this lady would an acute episode of ill health untreated.	

Case Study 7

Issues	Actions	Benefits	Remaining challenges	Alternatives	Changed use of services
Seen opportunistically at local site Man in his 20s. Offered health check whilst visiting another family member.	Some of the health check completed, did not want urine or blood sugar testing. Was Hypertensive. Did not want to see GP, agreed to see nurse. Not eligible for NHS health check due to age. Rang practice nurse who agreed to re	Community member made some lifestyle changes, had joined a gym. Community member has started to make changes including doing more exercise, drinking less alcohol and eating less fat.	Community member may not have attended appointments if had not been able to remind and encourage on outreach.	May have been missed by mainstream services. Not eligible for NHS health check for another 15 years. Engagement	Service user started to engage with Primary care staff and appeared to have more confidence in accessing this service.

Has GP but does not go. Unable to read/ write. Had some health problems: excessive thirst, very loud snoring, poor sleep, very tired during the day. Short of breath on exertion. Obese, concerned about lifestyle, diet poor, ate mainly from petrol stations and fast food. Concerned over alcohol use.	check blood pressure and do bloods. Made appointment (he did attend) Did see GP to follow up blood results. Was referred to sleep clinic to assess for sleep apnoea. Referred for Liver ultrasound. Referred for Spirometry and given inhalers for asthma.	Community member has started to make changes including doing more exercise, drinking less alcohol and eating less fat. Community member responded well to advice to see practice nurse and GP. Outreach model allowed me to remind him on site of appointments. Project allowed me to liaise with Primary care to offer health check when not eligible and share information regarding concerns raised from health check offered on site. Potential serious conditions assessed and diagnosed. Including asthma, Liver failure and sleep apnoea.	Community member did not want to engage with some services i.e. forward Leeds, Health trainers, however motivated to make some changes without using these services. GP surgery did not initially want to do health check as not eligible. Was able to negotiate this. Some surgeries this may have been more challenging. Community member has started to engage with Primary care staff, appears to have more confidence in accessing this service.	with primary care was poor. Liver damage, asthma, sleep apnoea may have progressed without treatment causing further ill health, possible permanent damage, may have led to acute hospital admissions. May have been less options for treatment.	

Case Study 8

Issues	Actions	Benefits	Remaining challenges	Alternatives	Changed use of services

Man, mid-40s originally hard to engage with, felt health was something to speak to “women about” Became more engaged and drawn in to conversations when visiting other family members. Some familial risk factors of cardiovascular disease, Smokes cannabis and tobacco.	Advised and booked for 40yr health check following mini health check at home. (Attended after 9 months of prompting). Health check found high cholesterol and pre-diabetes. Worked with nurse following health check.	Working with the nurse increased service user knowledge of CVD, enabled him to make his own goals using health coaching. Became confident in his relationship with the nurse enough to discuss health concerns and screening and eventually attend for over 40 health screening. Worked with the nurse to change behaviour and reduce risk factors. Service user has more knowledge of men’s health issues and started to discuss mental health concerns also. He also encouraged his brother to attend for screening.	Initially and for several months felt that health/ screening was not something to be discussed and directed the nurse to female family members. Some challenges overcome through time and investment in relationship building.	Likely to have not had over 40 health check, unknown high risk of cardiovascular disease, no behaviour change to reduce this.	Attended GP practice for health check, was unlikely to have done this previously Has not wanted other services to be involved – nurse recommended that this service user works with Forward Leeds to address cannabis use however he was unwilling to.

Case Study 9

Issues	Actions	Benefits	Remaining challenges	Alternatives	Changed use of services
Elderly female service user living alone but supported by family members. Long term health conditions including COPD, and Arthritis. Has had several hospital admissions due to COPD, newly diagnosed, poor understanding of condition. Unable to read, struggling with compliance of medication, poor pain management.	Seen on outreach. Initially liked to discuss medical concerns, however this prompted further conversations around mood, mental health and depressive symptoms. Nurse was able to arrange dossett box and to explain in detail.	Was originally taking medications incorrectly which was resolved. Poor inhaler use addressed via demonstration and technique assessment with practice nurse. Pain causing poor sleep addressed via pain/ medication review with GP (arranged by the nurse). Better understanding of COPD and awareness of lifelong condition, able to discuss and personalise ways to stay well.	Involvement in other services in the area which are more sustainable beyond the nurse is ideal. However, such services do not generally outreach and this service user feels too unconfident to engage with anything else.	Likely continuing with poor knowledge of long term condition, poor medication compliance and inhaler use, may have led to exacerbation of condition, more inpatient visits.	Nurse's relationship with the GP practice and their awareness of this population enabled her to arrange more personalised care for the service user, and to be seen for more than one problem with the GP.

Case Study 10

Issues	Actions	Benefits	Remaining challenges	Alternatives	Changed use of services

Male, mid 50s, multiple medical problems, COPD, CVD, previous MI, IDD, Chronic Pancreatitis, Alcohol dependant, has seizures secondary to withdrawal, dysphasic, mobility poor.	Advised to see by recommendation from another family member, so seen on outreach. Following an incident in which the service user was discharged from hospital unsafely and without proper process, the nurse complained to PALs on his behalf. PALS then contacted him directly to apologise. Nurse also discussed the service user with ward staff so that when he is in hospital they have a documented record of his home life to ensure further safe discharge	Following 11 months of the nurse visiting, the service user started to share details of his alcohol dependence and the issues surrounding that, including some reflection of his life, family or origin, reflection of behaviours around alcohol. Service user able to make some small changes around having less sugary drinks and has more awareness of the importance of carbohydrates. He felt more confident after nurse complained on his behalf and felt listened to.	Service user requires specialist services yet does not want to engage with them. He has capacity however he is vulnerable, prone to falling and has a number of serious health concerns. He does not want any care outside of the family. Another challenge is the client's locus of control and acceptance that he is unable to make changes to improve his health. Due to his experiences within his family he feels that 55 is elderly and does not have expectations that he will live much longer or aspirations to do so.	There are services that to help this man with some of his health conditions, and generally he engages well with things that fit with a medical model, attends GP, hospital, hospital appointments.	Service user has been unwilling to accept referral to specialist services for addiction

Case Study 11

Issues	Actions	Benefits	Remaining challenges	Alternatives	Changed use of services
Female, late 40s. Several medical problems, fibromyalgia, depression, arthritis. Lives with adult children. Isolated, including feeling isolated from other community members. Self-esteem and self-efficacy low, feels unable to speak to people easily. Lots of "minor" problems not sorted out as feels overwhelmed by them.	Over the course of 10 months the nurse built a therapeutic relationship with this service user. Took many months of visiting using motivational interviewing before this lady could identify any goals. Nurse referred and facilitated engagement with CMHT including taking her to appointments until felt able to attend alone. Nurse worked with her on self-identified goals such as getting glasses and hearing aids. Nurse liaised with GP and pharmacy over having dossett box and having patches rather than oral analgesia.	Uptake of services is improved. Has been identified, treated medically for several years for depression but never referred to mental health services. Would have unlikely attended mental health appointments without advocacy to attend. Has more knowledge of own condition from recommendation to watch videos on YouTube, as there is no easy read information for conditions available. Communication and understanding better now that the service	Engagement was not difficult however the nurse needed time to build a relationship in order to understand what was important for the service user.	Service user was isolated and not having investigations due to a lack of understanding of choose and book. She was also not receiving services for her mental health problem, and had a poor understanding of her health conditions.	Has increased access and use, but in a more meaningful way, less reactive following support from the nurse.

	Lots of referrals to services for investigations which she had not attended due to being unable to use the choose and book system (due to literacy levels). So further support provided.	user has hearing aids and glasses.			

Case Study 12

Issues	Actions	Benefits	Remaining challenges	Alternatives	Changed use of services
Lady, mid 40s, with multiple health problems. Chronic pain due to spine condition, Arthritic symptoms, Depression, suicidal ideation. Anxiety symptoms causing isolation. History of non-compliance with appointments. Had 7 referrals to Musculoskeletal, spinal and pain service since 2013 but not attended any. No support offered or investigations into why not attending.	Met on outreach and began to work with nurse after 6 months of doorstep conversations. Liaison with GP to have further blood tests. Referral to Spinal and MSK/Pain service. Referred to Adult social care for assessment for home adaptions. Referral to primary care mental health service. Ongoing home visits to support with organising and	Uptake of services has increased, with the service user attending appointments beyond GP for the first time in over 4 years. Mental health needs started to be addressed. Social care involvement secured to address safety and home adaptions. Service user has more understanding of her condition, and more understanding of referral systems.	Took significant amount of time to build trust and address what the needs of the community member were. Choose and book system and opting in systems are very challenging to people without literacy. If literacy is recorded as an alert on a system then it should affect the pathway that the patient follows, but this did not happen.	Service user would have continued to suffer with conditions that need specialist support and diagnostic tests. Service user likely to continue to miss appointments. Service user's health likely to deteriorate both medically and in terms of mental health.	Service user attending appointments with support. GP appointments more meaningful.

Seeing GP for Depression for over 3 years with no support from therapeutic services. Had been offered IAPT, opt in service. Many appointments missed due to not being able to read and understand the choose and book system, subsequently discharged due to not opting in. Re-referred many times by GP who mistook as a compliance issue. Recorded on System 1 as an alert that this lady did not have literacy and needed support with choose and book, needed phone prompts not texts or letter, this did not trigger any different pathway for the patient to follow and was still sent appointment letters and choose and book appointments.	attending appointments, making choose and book appointments. Ensuring understanding of medication and compliance, therapeutic support and listening, all provided by nurse.	Raised approach (regarding literacy) as a concern with GP surgery and CCG.	Primary care not able to see the "bigger picture", no holistic view of what was happening for the patient and seeing each GP appointment individually.	Increased risk of accidents due to needing home adaptions. Poorer quality of life. Increased cost to NHS due to multiple missed appointments.	

Case Study 13

Issues	Actions	Benefits	Remaining challenges	Alternatives	Changed use of services
Female, late 30's. Seeing GP about a range of issues including chronic pain, poor sleep, limb and muscle weakness, depression and anxiety. Experiencing increasing social isolation due to condition, as well as decreasing mobility. Has had full screen of medical tests, diagnosed as a "functional problem" and given written information over a year ago. Condition addressed medically by GP despite information about the condition advising occupational therapy and psychological therapy.	Received referral from Leeds Gate. Needing casework to address many areas; health literacy, understanding of the condition, discussing at length and directing to videos due to literacy. Looking at reliance on medical model and gently exploring how other therapies are advised and can improve the condition.	Following several consultations with the nurse and liaison with GP, the service user booked a double appointment with GP. She then reported feeling that, it was a more meaningful consultation and felt more listened to. Service user agreed to referral to Occupational therapy and Community mental health service.	Literacy issues not being recognised by GPs.	Service user likely to still be having multiple GP appointments which were not meaningful, and not continuing to understand her condition. Condition unlikely to improve as it is cannot be made better with medication. Mental health issues likely to continue - low in mood, isolation due to low self-esteem, self-efficacy and not feeling like she has any control or power over her own health and wellbeing.	Service use has increased but in a more meaningful way. Service user accessing community mental health services and occupational therapy. Increased confidence seen in the request for a longer GP appointment and the service user noting that she felt able to be active in this appointment rather than just a recipient of advice.

Appendix 7 – Theory of Change

Figure 1: Proposed Theory of Change linking the intervention to outcomes

Theory of Change	Evaluation objective	Research methods	Areas of measurement	Indicators of success
CONTEXT Strategic Aim: enabling clients to have improved knowledge of services and increase appropriate service uptake	To examine the relationship between Gypsy and Traveller Community and Primary Care/ Health Services	Existing monitoring data Case studies from the specialist nurse Service user's views Stakeholder views Health service usage data	Project delivery and activity mapped to strategic objectives Case studies mapped to demonstrate need and outcomes Clients views recorded (semi-structured interviews/FGDs) to demonstrate differences made Stakeholder views (semi-structured (telephone) interviews Service uptake/service pattern changes	Recruitment of clients to the project Clear case study documentation of experiences of clients Positive difference documented through the voices of the clients themselves Positive difference documented through the voices of stakeholders Changing patterns of health service usage
ENGAGEMENT Local engagement and support through the specialist nurse	To evaluate the intervention itself	Existing monitoring data Case studies from the specialist nurse Service user & stakeholder views Interview – Specialist Nurse	Number of clients and support documented How and why being supported has made a difference (service users and stakeholder's views) Perspective of the specialist nurse and her voice, collected via interview and learning log	Evidence of changes in relation to: ▪ Numbers of clients worked with ▪ Support as a process ▪ Types of support provided ▪ Successful support ▪ Referrals made ▪ Pathways and any associated outcomes

			Success of specialist worker role	
Theory of Change	**Evaluation objective**	**Research methods**	**Areas of measurement**	**Indicators of success**
CHANGING THE ENVIRONMENT Engaging in the life-worlds of the clients and building a positive relationship with the specialist nurse (and broader professionals)	To evaluate the intervention itself	Existing monitoring data Case study data Clients perspectives Stakeholder views, including specialist nurse Health service usage data	How and why being supported has resulted in changes to the lives of the clients involved in the project Identification of positive changes in relationships with Primary Health Care Changes in service uptake/usage patterns	Evidence of changes in relation to: ▪ Increased support (specialist nurse) ▪ Improved individual outcomes (self-reported health) ▪ Health check (numbers) ▪ Creation of referral pathways ▪ Health service usage

Theory of Change	Evaluation objective	Research methods	Areas of measurement	Indicators of success
SERVICE USER OUTCOMES *(a)* Improved relationships between the community and primary health care *(*b) Improvements in self-related health (c) Improved knowledge of screening	To examine health outcomes	Service user interviews/views Stakeholder interviews/views Case studies Health service usage data Monitoring data	Identification of types of individual positive outcomes (stakeholder and service user perspectives) Self-reported health improvements Case studies illustrating outcomes Types of engagement/service usage	Evidence of • Improved/changed pathways and support for clients • Number of health checks • Improvements in self-related health • Increased knowledge and/or uptake of screening • Increased understanding of how to engage with Primary Health Care appropriately
ORGANISATIONAL OUTCOMES (a)Learning from the specialist nurse role (b) Use of the health card (c) Changes in the use of (appropriates) services	To identify any recommendations and offer areas for consideration	Specialist nurse learning log Monitoring data Stakeholder interviews Service user interviews Health service usage data	Service delivery changes Perspectives/learning from the Nurse Perspective of the service users Stakeholder views	Evidence of • referral changes/increases • Differential usage of health services • Uptake/usage of health card • Views of health cards • Views/acceptability of nurse role • Lessons for practice/wider dissemination