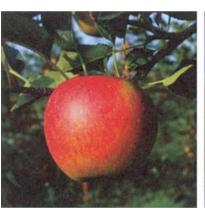
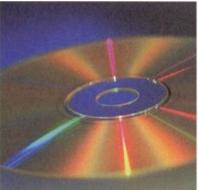
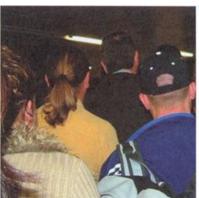


Preparation study of gypsy/traveller health needs









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Centre for Health Services Studies University of Kent

April 2010

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ISBN 978-1-902671-68-0

Preparation study of gypsy/traveller health needs

April 2010

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Commissioned by: Mark Lemon, Head of Policy Kent Public Health Department Kent County Council

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Acknowledgements

We would like to thank staff at KCC Gypsy Traveller Unit and KCC Children, Families and Education for arranging introductions to travellers, and to the Kent & Medway Public Health Observatory for help with the literature review and analysis of schools census data. The willingness of members of the traveller community in Kent to give their time and views was particularly appreciated.

I. Introduction and Background

'Population health care needs assessment... includes both components of incidence (of different degrees of severity of a disease) and prevalence (of its effects and complications) on the one hand and the efficacy and effectiveness of whatever the health (or other) services can do for them on the other. Ineffective services are not needed; and effective services for which there are no potential takers are not needed.' (Stevens & Raftery 1994).

This small-scale study is about the health needs of Gypsies and Travellers in Kent. It is prompted by the fact that there are significant numbers of the Gypsy and Traveller population living in Kent. There is also evidence from various parts of the UK that traveller health status is low compared to other sections of the population, and that this is combined with low use of health services.

A health needs assessment for Gypsy and Traveller communities in Kent would ideally describe the size of traveller population, patterns of health and illness experienced, uptake of health services and the outcomes from these encounters. However, precise numbers and locations of the traveller population in Kent are not available. Although accommodation needs assessments have been carried out regarding the number of pitches and sites, there is a lack of comprehensive data because to date neither the Census nor the NHS has recorded Gypsies or Travellers as a distinct ethnic category. There is no up to date local health profile of Gypsies and Travellers or readily available data on how this community uses health services.

Poorer health status and lower than average life expectancy among travellers is an important inequalities issue, and one that should be addressed. Its importance in the Kent area was clear from the many interested parties and wide-ranging views expressed by participants at a meeting on 'Travellers' access to GPs: Kent & E Sussex' hosted by the KCC Gypsy and Traveller Unit in March 2009.

This study was commissioned by the Public Health Department of Kent County Council (KCC) to carry out initial work to establish what has been done locally and nationally to build on work assessing the health needs of Gypsy and Traveller communities in Kent (Pahl & Vaile 1988) and across the UK by the University of Sheffield (Parry et al 2004). It consisted of a review of the literature, looking particularly for potential solutions to improving travellers' access to health

services, a search for suitable data for needs assessment, and interviews to hear the views of travellers.

The definition of gypsies and travellers has been kept quite broad to include Gypsy/Roma and travellers of Irish heritage whether they in transit, living on traveller sites or 'housed' (in bricks and mortar). This definition is likely to exclude show people and New Age Travellers.

Ethical approval for the study was given by the University of Kent (SRC Ref 0077).

2. What was done

The first part of the study was to carry out a literature review and website search. The literature review started with searches of EMBASE, MEDLINE and through PubMed. The search dimensions were:

- Gypsy, traveller
- Health, health status, well-being, illness, health inequalities
- Health services, access, use.

The search looked for actions and interventions within the intersection of the above topics.

The search was considerably widened by following up references in key documents, searching websites relating to people and organisations active in the topic, looking for relevant NHS policy and guidance, and carrying out internet searches of material relevant to Kent.

The aim was to identify interventions or recommendations for improving health services that would lead to greater access for Gypsies and Travellers.

The second part of the study was to see what data was available for assessing the health needs of travellers. Relevant information about the population would be the size and location of the Gypsy Traveller population in Kent, local assessments of need, and data on use of health services. Some data will have been identified through the literature review.

Sources of local data were the Kent County Council Gypsy Traveller Unit website, Communities and Local Government figures, Gypsy and Traveller Accommodation Assessments (GTAAs), Kent & Medway Public Health Observatory and schools census (PLASC) data.

The third part of the study was to speak to travellers to get their views and hear about their experiences of accessing health services. The study plan was to carry out two interviews and two focus groups with travellers, aiming to include adults of various ages, family circumstances and health needs. Arranging focus groups proved difficult within the available time and resources, so the focus groups were replaced with more interviews. (See Information sheet and Consent form in Appendices A, B.)

An interview schedule was drawn up of topics to cover (Appendix C), such as asking travellers about their health, what they do when they are ill, changes they would like to see in local health services, specific experiences they had had, whether they believed that traveller health was poorer than average, and why travellers are making less use of health services.

The intention was to use the schedule sensitively and that the interview should be more of an open and informal conversation. The schedule was to be used for prompting as needed. If additional topics of interest were mentioned by interviewees, these were added to the prompts and used in subsequent interviews.

Four interviews were carried out, with a total of seven travellers taking an active part. KCC's Gypsy Traveller Unit provided introductions for three of the interviews through staff with management responsibilities for authorised traveller sites in Kent. The Minority Communities Achievement Unit in KCC's Children, Families and Education department arranged the fourth interview with a housed family.

The interviews were audio-taped.

3. What was found

3.1 Literature search

This found a mixture of published papers, reports and other documents, work in progress, and material on websites. These are described in sections below under the main themes, the small number of actions or interventions actually undertaken to improve travellers' access to health services, and the more general and recommendations put forward. The suggestions for possible interventions or solutions for improving traveller health and use of health services have been extracted onto a spreadsheet. Policy and strategy documents have been included.

3.1.1 Traveller health and use of health services - main themes

• Unjust, unfair

The Marmot Review makes a robust argument that reducing health inequalities in society is a matter of fairness and social justice that must be addressed (Marmot 2010), and more specifically about travellers, the Equality and Human Rights Commission research report on 'Inequalities experienced by Gypsy and Traveller communities' contains a wealth of evidence of the problems, including health, experienced by this group of society (Cemlyn et al 2009). A report on economic inequality by the National Equality Panel identified the wide-ranging problems experienced by Gypsy and Traveller communities, and the how the educational achievement of boys and girls was falling further below that for other ethnic minority groups (Hills et al 2010).

The Equal Opportunities Committee in Wales carried out a review of service provision for Gypsies and travellers (National Assembly for Wales 2004) which included health and made many good recommendations, especially for improvements in information and making services more attuned to the needs of this population.

Geographical spread

To some extent the literature reflects the density of the traveller population, for example there are pockets of work in Wales, Ireland, Scotland, Sheffield/Leeds, Leicester, East Sussex/Kent and South West England.

• Lack of an evidence base

The lack of information or systematic data collection on traveller health and use of services is a common theme in the literature (Parry et al 2004, Pahl & Vaile 1988, Feder & Hussey 1990, Tavares 2001, Van Cleemput 2001, Doyal et al 2002, Aspinall 2005, Patel 2005, Fountain 2006, Van Cleemput et al 2007, Matthews 2008). National strategies highlight the need to build databases. The All Ireland Traveller Health Study was set up to include a census of this population (see University College Dublin website). Also in the UK, 'Gypsy or Irish Traveller' is an option on the 2011 Census question on ethnic background, but it will be several years before good quality data becomes available from the census.

Burden of illness

Along with other economic and social inequalities it is not surprising to find that the Gypsy Traveller population experiences a heavy burden of physical health problems, depression/ anxiety and low life expectancy. A study for the Department of Health carried out by the University of Sheffield made a major contribution to the evidence base (Parry et al 2004), along with a number of other papers from the research team (Van Cleemput 2000, Van Cleemput 2001, Parry et al 2007, Peters et al 2009). The inevitability of poor health in adverse circumstances is to some extent acknowledged by travellers themselves (Van Cleemput et al 2007). Poor quality traveller sites and pitches, and strong local opposition to travellers have been seen as a contributory factors (Pahl & Vaile 1988, Galway Traveller Movement 2009, Van Cleemput 2008, Duncan 1996).

Mental health

The traveller community has been found to suffer higher levels of anxiety and depression compared to the settled population (Goward 2006, Parry et al 2004, Cemlyn et al 2009).

Drug misuse

Drug misuse is seen as an increasingly serious problem among travellers, which is exacerbated by social exclusion, poor information and poor coverage by drug services (Fountain 2006, Drugscope 2004).

Cultural issues and use of services

Poor access to and uptake of services is clearly a problem (Matthews 2008), and specific attitudes to illness and the response among the traveller population have been described that can lead to fewer and less satisfactory encounters with health professionals (Van Cleemput et al 2007, Lehti & Mattson 2001). Parry et al (2004) found pride in self-reliance, tolerance in chronic ill health and when finally accessing health services many barriers were experienced. Travellers are less likely to be registered

with or visit a GP, and are more likely to use of hospital accident and emergency services as the first point of contact (Beach 2006).

Comparisons with other minority ethnic groups needs

Even though ethnic disparities in health have been studied for some time, best practice examples are few and poorly documented (Aspinall & Jacobson 2004). Even with their lack of visibility in population and health statistics, the evidence for traveller health to be significantly worse than any other ethnic group has now emerged (Parry et al 2004, Peters et al 2009). Even when those in ethnic minority groups or low socioeconomic position do access services, they experience barriers in diagnosis, referral and treatment, which can be due to the way the patient presents their symptoms, communication difficulties, and systematic behaviours by health professionals (Adamson et al 2003).

Work in Kent

A handful of studies provide information that would be useful for health needs assessment in Kent (Pahl & Vaile 1988, Watson 2006, Jones 2009).

Pahl & Vaile (1988) used health visitors to interview 263 mothers. They found poor levels of general health, perinatal mortality, immunisation and preventive care, and described 'horrifyingly poor environmental conditions' at some traveller sites. In a small area health needs assessment that focused on pockets of deprivation (Watson 2006), travellers took part in a focus group and four family interviews. The problems found included 'an ignorance led racism', complex health needs, a lack of confidence in accessing health (and other) services, and communication problems.

Members of a local gypsy support group carried out a survey of sexual health and family planning (Jones 2009). Fifty Gypsies and Travellers took part, and the studied produced recommendations about raising staff awareness of cultural issues, training community members to act as peer educators or community experts, enhanced services to include outreach and mobile services.

In 2006 and 2007 the government introduced new rules requiring all local authorities to allocate sufficient legal stopping places for Gypsies and Travellers (GOSE 2008). Information from interviews is combined with the caravan count data to identify how much space is needed in terms of pitches and sites. Accommodation assessments have been made for East Kent, North Kent and West Kent (Richardson et al 2007, DCA 2006a, DCA 2006b).

3.1.2 Specific actions and interventions

There are not many examples of specific work to address the health and health needs of the Gypsy Traveller population and it has been noted elsewhere that most of the evidence for effective interventions is based on expert and respected views (Grade C). Aspinall (2005), found Grade C evidence supporting the use of community health workers in a variety of ways, also for hand-held records, specialist health visitors, mobile outreach units and clinics, having traveller representation and liaison, culturally appropriate health promotion materials, and combinations of these to address a specific problem like cardiovascular disease. Only one well-conducted study was found in Ireland/UK which provided evidence of some benefits from a community mothers' programme (Fitzpatrick et al 1997).

One GP practice in Leicestershire has set up an enhanced GP service for Travellers (Market Harborough 2008) which is cited in the national primary care service framework for Gypsy and Traveller communities. The practice drew up a 13-point list of changes to practice policy in dealing with travellers and a recognition of the costs, with the result that they saw a range of positive outcomes.

A community project embarking on joint training to build trust and mutual understanding between travellers and health service providers reported two-way learning and some clarity about health conditions that could deteriorate rapidly without treatment (Charikar 2008).

Another district level approach in the East Midlands built up working relationships between traveller groups and health visitors, to the extent that travellers have been part of multi-agency groups, actively involved in planning and carrying out a needs assessment, preparing a subsequent action plan and monitoring it (Patel 2005). This group was also involved in educational packages to reduce social prejudice and provide health education sessions.

Participation and engagement of traveller women was the main thread of a project in Sussex aiming to get traveller participation in health promotion through providing skills and encouraging dialogue among women (Friends, Families and Travellers 2006). The report described the initial aims, and a series of approaches and set-backs in achieving them, which seem to suggest that to be successful, such projects need to be flexible and opportunistic in finding ways to engage and involve travellers, for example willing to spend time to build group dynamics, and setting up activities that would increase women's self-confidence and self-esteem.

A knowledge transfer project is currently under way in Swale, involving a training programme to qualify members of the traveller population to manage primary and secondary prevention of disease within their communities (SECC 2008 personal communication).

Other initiatives may have been carried out by voluntary organisations and PCTs, but would not be found if there was little documentation or publicity. For this review, several websites for travellers were searched, for example Romany Roots at BBC Kent

(http://www.bbc.co.uk/kent/romany_roots/). Some of these were more concerned with health, for example Pavee Point in Galway (www.paveepoint.ie) and the Gypsy Roma Traveller Leeds website (http://www.grtleeds.co.uk/Health/index.html), which gives brief details of the 'Health Bus' providing a mobile drop-in clinic.

3.1.3 Suggestions and recommendations for general improvements

Race relations legislation in 2000 gave public authorities a statutory general duty to promote race equality and to have 'due regard' to the need to eliminate unlawful racial discrimination. As a result policies and strategies have been emerging from national government that address the specific health needs of Gypsies and Travellers. In England there is a NHS Primary Care Service Framework for Gypsy & Traveller communities (NHS 2009), which puts considerable emphasis on information needs, and calls for services to be much more flexible and sensitive to user needs. The extent to which NHS commissioners use this service framework is not known.

Wales recently put out a draft Gypsy Traveller Strategy for consultation (Welsh Assembly Government 2009). The objectives relating to health cover the inclusion and involvement of travellers when developing policy, making services more accessible and establishing reliable databases. The strategy lacks some of the details recommended by the Equal Opportunities Committee in Wales (NAW 2004), in particular by not addressing the infrastructure and resourcing that the committee had thought would be needed to deliver change,

An all Ireland strategy established for 2002-2005 was based on similar core principles of social inclusion, and in Ireland, paid particular attention to the essential organisational and management structure, such as designated responsibilities and funding, that must be in place if the strategy's aims are to be achieved (Department of Health and Children 2002).

As well as the national policies and strategies just mentioned, the literature contained many possible solutions and recommendations to improve travellers' access to health services – Tavares (2001) provides a good example of these. There is a lack of high grade evidence based on trials or well-conducted studies, and recommendations are based on the authors' research and reviews of the topic. Recommendations fell into the following broad areas:

- addressing the lack of health needs information,
- what service providers can do to reduce barriers to access,
- involving travellers,
- addressing deprivation among the traveller population,
- the nature of interventions required to improve access.

Two recommendations stood out as they occurred most often. First, the wide-spread support for training health service staff in cultural awareness, racism and discrimination. Second, that travellers must be involved in efforts to improve access to services – for example as coordinators, providing liaison between their community and service providers, and by engaging in discussions.

Many of the suggestions focused on making changes to the way service providers work, in order to reduce the barriers that travellers experience. For example, to work in partnership with other services when addressing the needs of travellers (inter-agency working), and to use trusted and dedicated staff. It was also generally felt that needs of this group should be embedded in mainstream planning, but at the same time considering better models of care to improve access, more outreach/ traveller specific/ drop-in services, and more culturally appropriate materials/ health information. Other actions included carrying out equity audits/ 'equity proofing', acceptance and prioritisation of the problem, allocating clear responsibilities with funding, and more actively promoting health education, for example with specialist health visitors. The need for positive discrimination was also mentioned as were the need to avoid specialist staff becoming isolated and meeting travellers requests for gender specific staff, although these were less often mentioned in the literature.

As for Travellers, it is recommended that they play an active role, with high levels of participation. The literature also identified the benefits of members of the traveller community acting as peer educators or role models for their community. However, some see ethical dilemmas (Doyal et al 2002) when involving travellers in service planning if travellers are unwilling participants and being brought in to discussions is seen as eroding their independence and identity.

Regarding the necessary information resources for addressing health needs, the suggestions for improvement focused on:

- building better databases of traveller health,

- recording ethnicity,
- monitoring traveller health.

A few suggested the use of hand-held records and recording other relevant information, eg travellers' experiences of accessing services.

Improving the wider determinants of health for traveller communities was also put forward as a solution. One way was to improve conditions on traveller sites to a good standard of cleanliness and basic amenities and reduce the chance of accidents. Another was to work across government departments to address inequality more generally, for example to make improvements in travellers' education, housing and employment.

The literature contained suggestions about future interventions, saying there should be more research to provide a sound basis for formulating interventions, that they should receive longer-term funding, and that there should be more evaluation. Matthews (2008) pointed out that the most successful actions have been bottom-up, involved travellers, and provided support to travellers to participate, but have stopped after short-term funding ran out.

To some extent the needs of Gypsy Travellers are similar to those of other ethnic minority groups. Aspinall & Jacobson's (2004) review of evidence and best practice in addressing ethnic disparities in health and health needs found that for all ethnic minority groups there was a need to build databases, adopt an integrated approach, use specialist/ trained staff, create appropriate materials, acknowledge trust and fear issues, adapt to local sensitivities, involve the community, and understand patients' needs.

3.2 Analysis of available data

A health needs assessment requires hard data such as the size of traveller population, their health status, the incidence and prevalence of disease, or at least socio-demographic profiles that would enable these to be estimated. For traveller communities this information is in very short supply.

Gypsies and Travellers are not counted in the Census (although this will change in the 2011 Census), and that this group of people is rarely included in studies of ethnicity and health. The government department Communities and Local Government requires a bi-annual count of caravans, but this

does not count the number of people in them, or count the Travellers living in houses. Local authorities have also to supply the CLG with details of the number of sites they provide, and in 2006 were required to carry out Gypsy Traveller Accommodation Assessments (GTAAs). In the field of education, the national schools census (PLASC) is an unusual dataset as its ethnicity coding includes travellers, allowing pupils to identify themselves as 'Gypsy/Roma' or 'Traveller of Irish Heritage'. Beyond these limited data sources there are no systematic data collections on the Gypsy Traveller population.

Kent County Council currently estimates the Gypsy Traveller population in Kent to be 10,000-15,000, or I in 100 (http://www.kent.gov.uk/community_and_living/gypsies_and_travellers.aspx). A select committee report to KCC in 2006 estimated it to be lower (9,600), and local views suggest it could be much higher, for example in the Swale area Gypsies and Travellers have said they make up half the population.

Nationally, CLG figures showed a count of 17,437 caravans on authorised and unauthorised sites in July 2009, of which 3,471 were in the South East region and 1,101 in Kent (CLG 2009a and see Table I). Around a quarter of these (261) were on local authority run sites, and most of the rest on privately rented sites with planning permission. It seems that there were no vacant pitches at this time, as CLG figures on local authority run sites in Kent showed there was space for 259 caravans on 16 sites (CLG 2009b and Table 2). If there are approximately 3 people per caravan, CLG figures would indicate a population of 3,300 living in caravans in Kent.

Combining this figure with KCC's current estimate, it could be that three quarters (9,200) of the Gypsy Traveller population in Kent live in bricks or mortar.

Figure 1 shows the location of sites provided by local authorities.

This study made innovative use of schools census data (PLASC) to count and map Gypsies and Travellers in Kent. It does not appear that PLASC data has been used as a means of enumerating the Gypsy/Traveller population, and as a result little is known about the quality and completeness of recording this ethnic group, so PLASC may only give a rough estimate of the number of travellers on school rolls. There were 1,264 school pupils recorded of Gypsy/Roma or Traveller of Irish Heritage in Kent in September 2009. Assuming the traveller population has the same proportion aged 5-17 as Kent as a whole, this suggests a total population of 7,700, somewhat lower than other estimates. Undercounting is likely when people of Gypsy/Traveller heritage do not wish to identify themselves or there is reluctance to record them as such, and it is possible that a few Traveller children do not go to school at all.

The school census data showed the number of Gypsy Travellers for each year group. Numbers started to fall away after Year 8, and after age 16 only about 5% of this group remained at school (Fig 2). The pupil census also showed the geographical spread of these children (Fig 3), which is reasonably consistent with other counts and estimates as only a small proportion of travellers live on local authority sites. According to PLASC data, the population is most dense in Swanley, Gravesend, Margate, Dover, and Folkestone. There are also pockets around Maidstone, Sittingbourne, Ashford and Canterbury, with the remainder scattered across the Weald of Kent. See Roberts & Maunder (personal communication 2010) for more detail.

Another source of information on the population is the assessments of accommodation needs (GTAAs by Richardson et al 2007, DCA 2006a, DCA 2006b), which looked at existing provision and future demands for permanent sites and transit pitches between 2007-2012. Assessments have been made for North, West and East Kent and will be used at regional level to plan appropriate pitch provision. The assessments were based on interviews with large samples of the Gypsy Traveller population, including some of the housed population. Some of the environmental characteristics found in GTAAs may be of help when assessing traveller health and access to health services. The most useful figures from GTAAs for enumerating the population were the average household size, although they varied between 3.1-3.3 in North Kent and 2.0-2.1 in West Kent. It is also worth noting the big increases in demand that the GTAAs envisaged - West Kent and East Kent requiring nearly 30% more pitches by 2012, and North Kent an additional 69%, although the latter was partly due to an existing backlog of problems with planning permission and over-crowding. London is also considering a big expansion in traveller sites (Times Online 2010).

Gypsies and Travellers were identified in KCC's Supporting People strategy as one of the groups and people with multiple/complex needs (Kent Supporting People Team 2008), and health was the most important area after housing where support was needed. Due to the lack of ethnic coding, this group has not been separately identified in Joint Strategic Needs Assessments (JSNA) in Kent. Some documents refer to the Kent County Council Select Committee Report on Gypsies and Travellers in 2006, but this has not been obtained.

A search of local authority websites for information on Gypsies and Travellers yielded no hard data. Travellers were mentioned on some websites under the banner of education or diversity in an informative and positive manner (KCC, Medway), and some authorities provided information on the availability of caravan pitches (Canterbury, Dover, Tunbridge Wells). Some local authorities did not seem to mention this group at all, or created a rather negative image by giving advice for reporting unauthorized encampments or rubbish dumping.

3.3 Taking local views

Three of the interviews took place on local authority-run traveller sites and one in a house. Introductions were made through site managers or members of KCC's Children, Families & Education department who were asked to identify people with a with a range of ages, family circumstances and health needs. Those approached by the interviewer (LJ) all agreed to take part, giving a sample of five married women in the age range 25 to 60, and two men between 55 and 65 years old. One of the interviews was with a middle-aged woman, one with an older man, one with three younger women, and the fourth with an older married couple and their site manager. Interviews took place in people's caravans, homes or outdoors. The visits lasted between 40 minutes and $1\frac{3}{4}$ hours, with between 30 and 65 minutes recorded on tape.

Those taking part were friendly, quite open in what they said and willing to give their time. Having more than one person to interview was not always planned, but happened because others were around at the time, or possibly because they gave the interviewees greater support and confidence when speaking to a stranger. The interviewees described their health and how they responded to illness, but did not really accept that traveller health was worse than average. They described their experiences with the NHS, which gave some insight as to why uptake was low and what improvements would benefit them.

Travellers described their independent lifestyle, especially in the past, which included being out in all weathers, physical work and living off the land. Fresh air was seen as healthy as was their typical meal of meat and vegetables. In general, those interviewed on traveller sites did not agree that traveller health was poorer than average. Even though they related what seemed a surprisingly large number of incidents of illness among their family, they did not see this as worse than anyone else experienced. However, the housed family was different, in suffering from extremely high levels of serious illness and disability, and in needing help. This family's life was dominated by illness and disability and lacked the social support of family and neighbours that had been seen on sites. Little was said about substance misuse, and it may be that a single interview is insufficient to find out about drug and alcohol problems and attitudes to these.

There was a range of responses to illness, as some seemed quite comfortable with accessing primary care services, had been in hospital on a number of occasions, or were in regular contact with the health services. Where travellers had built up a good relationship with a GP or practice they valued

this and would continue using them even if they had moved away. One was able to get appointments lasting an hour. Most of the women and children got invited for immunisation and screening, whereas the men were less likely to be invited for any anything. All were registered with a GP, but very few with a dentist, even though they needed dental treatment.

A common reaction to illness was to feel you had to keep going, especially if you had to look after children or could not afford not to work. A whole range of traditional remedies for earache, headache, etc. were mentioned as well as the role of religion in healing. There were also conflicting messages on how ill you had to be to go to the doctor. Often hospital A&E has been the first port of call, and then only if you 'were dying'. There are now generational differences and changes in behaviour, that are narrowing the gap between traveller and settled cultures. Some see changing attitudes among younger travellers, who engage more readily with health services and have higher expectations of getting illness treated. Older generations would 'not look after themselves', meaning they delayed going to the doctor. They were proud of both past and future generations.

Problems were often encountered in trying to access NHS services. There were difficulties getting registered with a GP, with some saying that when the practice realised they were from a traveller site it was suddenly full up. Most felt discriminated against in various ways. One expressed it that society was graded, that travellers were at the bottom, and this status was reflected in the amount of money that health care providers were willing to spend. They also disliked the overt prejudice shown to them from other service users. Other problems were the risk of catching illness in the waiting area, not really wanting surgery where there were risks of poor outcomes, or prescribed drugs for psychiatric symptoms.

A significant problem was with communication, for example lacking confidence in explaining the symptoms, feeling they were not being listened to, trouble expressing themselves and understanding the doctor, and some difficulties with literacy.

It was clear that stress featured in people's lives from a variety of sources, and that this was exacerbated by multiple health problems. The travellers interviewed described much more severe and chronic illnesses and earlier loss of life in their immediate family than one would normally expect. Being heard and getting health problems taken seriously, along with prejudice against them in other areas of their life, added to the day-to-day levels of stress.

4. Conclusions and options for further work

The literature on Gypsies and travellers is part of a wider literature on inequalities, which demonstrates there are persistent problems and argues that these are unacceptable in a fair and just society. In the case of the Gypsy and Traveller community many of the factors associated with poor health and low life expectancy are present. When racism and prejudice are added to the mix of cultural, environmental and economic factors then it also becomes difficult for this group to get effective health care.

Rather than dwell on the causes of illness, this study has focused more on what has been done or what can be done. A number of possible actions to improve travellers' access to health services have emerged from the literature, mainly based on expert and respected opinions. There are very few reports of specific interventions whose effects have been evaluated, and only one well-conducted study was found in UK/Ireland. Nevertheless there is considerable consensus on recommendations: to improve data and information about Gypsy and Traveller communities; to develop more culturally sensitive and appropriate services; to engage travellers in making and monitoring these improvements; and to improve living conditions for travellers.

Information on traveller health is clearly needed in order to monitor and evaluate future actions. Only a minority live on authorised sites run by local authorities or registered landlords and get included in official counts. For a population that has historically been mobile and independent the scale of under-enumeration is uncertain. In addition, the cultural gap has manifested itself in negative ways such as a mutual lack of trust between travellers and others, poor experiences with authority and persistent racism, all of which making Gypsy/Travellers unwilling to be labelled as such.

Collaborations with other services (for example, Children, Families and Education) and creative use of other datasets (PLASC) have shown it is possible to share knowledge and resources effectively. Bringing together data from a number of different sources can help to show where there are consistencies and establish greater confidence in the data.

There has been good participation by travellers in this study, following introductions through site managers and family liaison officers. The people taking part in this study were very willing to give their views and experiences.

The travellers interviewed described much more severe and chronic illnesses and earlier loss of life in their immediate family than one would normally expect, yet did not generally feel traveller health was any worse than the settled community. The descriptions of response to illness and uptake of services were quite complex. They included reluctance to seek help outside their community, difficulty getting seen, feeling unwelcome, lacking confidence, and having some problems with communication and literacy.

In summary, this study found that cultural and communication gaps create huge barriers to travellers having satisfactory encounters with health services, and it is clear that changes in attitudes and awareness are needed. This is a challenge that may well fall most on the providers of health services if appropriate and culturally sensitive health services are to be developed. But Travellers also have a role to play. There is a balance to be achieved between protecting culture and traditions, and avoiding the damaging aspects of becoming marginalized and excluded. Travellers are aware that change is taking place, and that there is a shift from the attitude of older generations who would only going to see a doctor 'when you were dying', to the younger generations who have higher expectations of medical care and greater confidence in asking for it.

There is now a need for further work to expand on what has been done in this preparatory study. This will need discussion and focus, but might include some of the following:

Literature and document searches

- do more,
- widen the geographical focus,
- make greater use of information from the voluntary sector and on websites,
- search local authority and NHS reports, minutes, etc.
- find out more about current work which has not yet been reported, for example in Sittingbourne.

Data

- use site managers or site representatives to get population profiles,
- survey local authorities and NHS to find who has responsibility for Gypsy Traveller health, and ask for numbers, sites, policies, etc.
- use existing records to identify use of health services (can be done for those on sites with distinct postcodes hospital episodes, prevention/screening, GP registration, GP visits, prescriptions, A&E),
- gather data on the wider determinants of health, eg environment, housing,
- survey travellers on their health and need for services.

Views

- carry out a more detailed analysis of the interviews carried out in this study,
- run Focus Groups to develop themes from the interviews,
- refine interview topics and themes and speak to more Gypsy Travellers,
- speak to more traveller support organisations those at the 'Travellers' access to GPs: Kent & E Sussex' meeting hosted by the KCC Gypsy and Traveller Unit in March 2009.

Issues for future work

- incorporate the views and experiences of local players,
- make more use of existing skills, structures and resources in the NHS and local government,
- work with other agencies and Traveller representatives to get appropriate access to a small and potentially over-researched population,
- address the under representativeness in this study of travellers on private/ unauthorised/ temporary sites and the housed population,
- consider the effect of biases in traveller participation, eg who has been asked (selection bias), who refused (non-response bias), and how open the responses were (response bias),
- create a forum for longer-term participation of NHS and gypsy/traveller representatives.

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South East Regional Assembly – accommodation needs factsheet http://www.southeast-ra.gov.uk/documents/consultations/5/G&T%20factsheet%20(Feb09).pdf

South East Plan has no mention of Gypsies and Travellers http://www.southeast-ra.gov.uk/sep_gtts.html

BBC Kent website for travellers. http://www.bbc.co.uk/kent/romany roots/

KCC – good background information, including health http://www.kent.gov.uk/community and living/gypsies and travellers.aspx

East Kent GTAA – accommodation needs assessment (also referenced as Richardson 2007) http://www.canterbury.gov.uk/assets/housing/eastkentgtaafinalreport17july07.pdf

North Kent GTAA - accommodation needs assessment (also referenced as DCA 2006a) http://www.dartford.gov.uk/planningpolicy/documents/NorthKentGTFinalforMedway3.pdf

West Kent GTAA - accommodation needs assessment (also referenced as DCA 2006b) http://www.maidstone.gov.uk/pdf/080414%20GTAA%20Final%20Report%20.pdf

Ashford - http://www.ashford.gov.uk/community_and_living/gypsies_and_travellers.aspx

Canterbury – site information http://www.canterbury.gov.uk/main.cfm?objectid=1781&type=SISTRGY

Dartford - found nothing

Dover - site information

http://www.dover.gov.uk/council__democracy/equality__access_to_services/gypsy_and_traveller_informatio.aspx

Gravesham – Gravesham Local Development Framework for Gypsies and Travellers http://www.gravesham.gov.uk/media/pdf/2/b/3a_Gypsies.pdf

Maidstone – relating to planning http://www.maidstone.gov.uk/pdf/081016 regen gypsytoolkit.pdf

Medway - good information

http://www.medway.gov.uk/index/learning/schoolinfo/38557/37417/56018/56024.htm

Sevenoaks - found nothing

Shepway – very little

Swale - found nothing

Thanet - broken link for Gypsy & Traveller Liaison

Tonbridge – very little

Tunbridge Wells – site information http://www2.tunbridgewells.gov.uk/Default.aspx?page=755

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	Jul 2008	0	0	0	0	0	0	
	Jan 2008	0	0	0	0	0	0	
	Jul 2007	0	0	0	0	0	0	
		_						
Swale	Jul 2009	21	78	29	3	11	0	14
	Jan 2009	27	59	34	3	13	0	13
	Jul 2008	29	65	33	2	0	26	15
	Jan 2008	26	76 55	39	2	0	18	10
	Jul 2007	28	55	19	14	3	7	12
Then:	het occer	_	•	_	^	_	^	
Thanet	Jul 2009	0	0	0	0	0	0	
	Jan 2009	0	0	0	0	0	0	
	Jul 2008	0	0	0	0	0	0	
	Jan 2008	0	0	0	0	0	0	
	Jul 2007	0	0	0	0	0	0	
Tambaidee	N. II. COCC	0-	6	_	40		6	_
Tonbridge and		25	8	2	10	11	0	5
	Jan 2009	25	7	2	7	10	0	5
	Jul 2008	30	9	2	6	10	0	5
	Jan 2008	26	5	2	10	10	0	
	Jul 2007	26	5	2	6	10	0	4
mental and the						_	_	
Tunbridge We		10	38	1	13	0	0	(
	Jan 2009	13	41	1	13	0	0	•
	Jul 2008	19	32	4	10	0	0	•
	Jan 2008	13	38	1	10	0	0	•
	Jul 2007	19	32	4	10	0	0	
edway Towns U		16	11	5	3	0	0	;
	Jan 2009	0	0	0	0	0	0	
	Jul 2008	20	10	0	6	0	0	3
	Jan 2008	10	7	0	10	0	0	2

Table 2

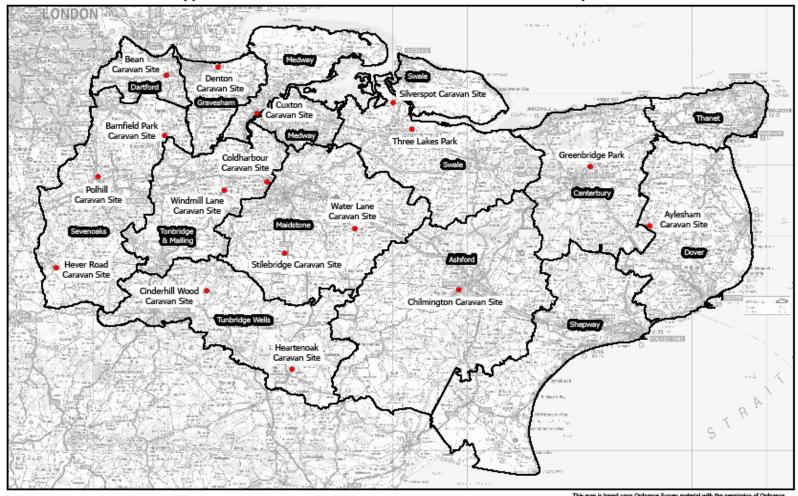
Table 2 (continued)	Gypsy sites provided by Local Authorities and Registered Social Landlords in England											
	16tl	n July 2009										
South East		Total number		of which are:	Caravan	Date site	Date of last					
Unitary/ County		of pitches	Residential	Transit		opened	site changes					
Site		or pricries	Residential	Halisit	capacity	Орепец	site changes					
Total for South East		1020	989	31	1408							
Kent CC		207	199	8	259							
Ashford (Chilmington Chart Road, Ashford) 1	Y	16	16	0	16	1970	n/l					
Canterbury (Greenbridge Park Vauxhall Road Canterbury) 1	Y	18	18	0	26	1976	1999					
Dartford (Claywood Lane Claywood Lane Dartford Kent)	Y	12	12	0	12	1964	n/l					
Dover (Snowdown Caravan Site Aylesham Road Ayelsham Nr Canterbury Kent)	Y	14	14	0	28	1985	n/l					
Gravesham (Denton Caravan Site Dering Way)	Y	16	8	8	16	1973	n/l					
Maidstone (Stilebridge Lane Caravan Site Stilebridge Lane MardenTonbridge TN12 9BJ)	Y	18	18	0	18	1964	2000					
Maidstone (Water Lane Caravan Site Water Lane Ulcombe Maidstone Kent ME17 1DE)	Y	14	14	0	14	1964	1998					
Sevenoaks (Hever Road Caravan Site Hever Road Edenbridge Kent TN8 5DJ)	Y	12	12	0	24	1960	200					
Sevenoaks (Polhill Caravan site)	Y	9	9	0	9	1996	n/					
Sevenoaks (Barnfield Park Caravan site Ash Road Ash)	Y	35	35	0	35	1999	n/l					
Swale (Three Lakes Park Church Road Murston Sittingbourne Kent ME10 3NL)	Y	14	14	0	22	1989						
Swale (Silverspot Iwade)	Y	1	1	0	3	1991	n/l					
Tonbridge and Malling (Windmill Lane Gypsy Site Teston Road West Malling Kent ME19 6PQ)	Y	14	14	0	14	1969						
Tonbridge and Malling (Coldharbour Caravan Site Coldharbour Lane Aylesford Kent)	Y	8	8	0	16	1982						
Tunbridge Wells (Cinderhill Cinderhill Matfield Nr Tunbridge Wells)	Y	6	6	0	6	1991	n/l					
Medway Towns U A		11	11	0	12							
Medway UA (Cuxton Caravan Site Sundridge Hill Cuxton Rochester Kent ME2 1LD)	Y	11	11	0	12	1967	1999					
Notes												
n/k - not known												

^{1.} July 2009 count data estimated using July 2008 count data. Data not received from the following local authorities:

Ashford, Basingstoke & Deane, Bexley, Boston, Camden, Canterbury, Crawley, East Lindsey, Elmbridge, Fareham, Fenland, Fylde,
Gloucester, Greenwich, Hackney, Isle of Wight, Kensington & Chelsea, Lambeth, Malvern Hills, New Forest, Newham, Poole,
Sheffield, Southampton, Spelthorne, Surrey Heath, Thurrock, Waltham Forest and Winchester

Fig I Local authority run sites

Gypsies and travellers - Sites in Kent and Medway



Management Information Unit - CFE Commissioning and Partnerships Group, KCC

ArcMap 9.3.1 - GH - 29/03/2010

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Fig 2 Map of PLASC pupils of Gypsy/Roma or Traveller of Irish Heritage ethnicity in Kent schools, September 2009

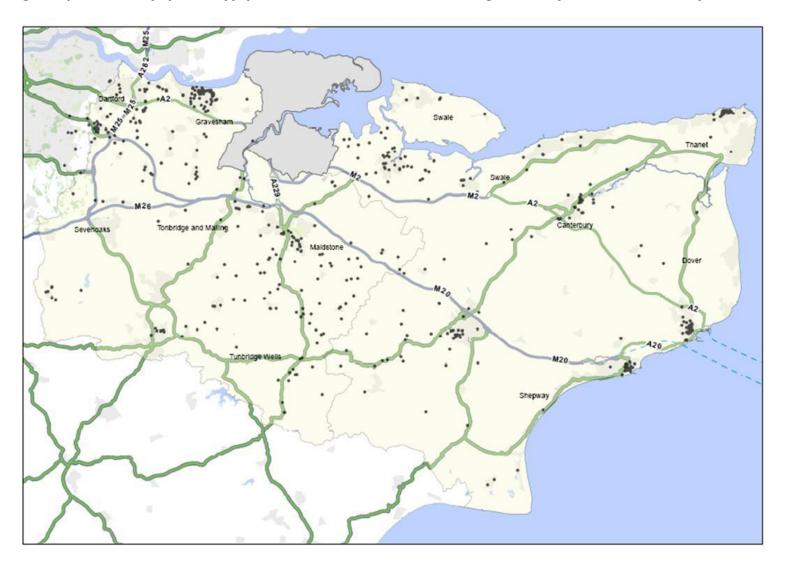
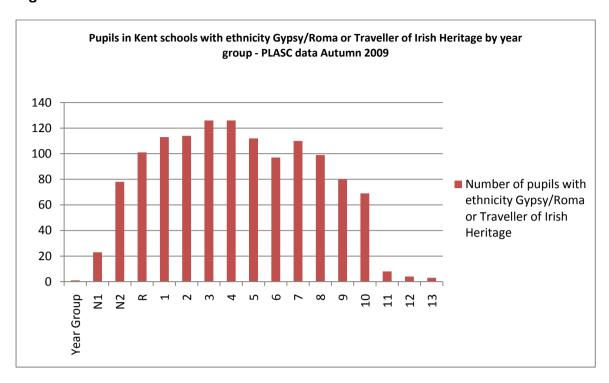


Fig 3



Key Stage	Year Group	No Pupils with Ethnicity of Traveller Of Irish Heritage	
Nursery Age	N1	0	1
	N2	4	19
Foundation Stage Profile	R	5	73
Key Stage 1	1	12	89
	2	8	105
Key Stage 2	3	15	99
	4	10	116
	5	8	118
	6	11	101
Key Stage 3	7	3	94
	8	3	107
	9	0	99
Key Stage 4 & GCSE	10	5	75
	11	2	67
Post 16	12	0	8
	13	0	4
	14	0	3
Total		86	1178

Data taken from the Autumn 2009 Schools' Census

APPENDIX A INFORMATION SHEET



February/March 2010

Do Gypsy and Traveller Communities get the health care they need?

My name is Linda Jenkins and I work at the University of Kent in Canterbury. I have been asked to find out more about this topic. Would you be willing to take part by giving me your views? Can you tell me about the times you or your family have needed to see a doctor, dentist, health visitor, or wanted to get advice from a health professional. I'd like to know what happens, how easy it is to get seen, and if services are suitable for your needs. It would be a great help to spend half an hour with you and listen to your views and experiences.

Why am I doing this?

Three departments at Kent County Council (KCC) - the Public Health Department (whose job is to promote health of people in Kent), the Gypsy and Traveller Unit, and the Children, Family and Education Unit - all want this work to be carried out, to help them understand local people's views better.

Should you take part?

Taking part is voluntary and I would like to reassure you that any information about you will be kept strictly confidential. You will not be identifiable in any feedback to KCC or written reports.

This work has been approved to go-ahead by the university ethics committee.

It is entirely up to you whether or not you take part, and you are free to change your mind and stop at any time. If you do decide to take part, will you please sign the attached consent form. Thank you, I am grateful for your time.

Yours sincerely

Linda Jenkins
Centre for Health Services Studies, University of Kent,
Canterbury, Kent, CT2 2NF.
Tel: 01227 827641. e-mail: l.m.jenkins@kent.ac.uk

APPENDIX B CONSENT FORM



Consent Form

Preparatory study of Gypsy and Traveller health needs.

If you are happy to help us try and improve the provision of health care for Gypsy and Traveller communities, please fill in Parts A and B below.

Part A	Please tick for 'yes'		
	d and understand the information letter search and have had the chance to ask		
	cand that taking part is voluntary. If can stop and don't have to give a rea	•	
3. I agree to	take part in the project		
4. I am not to	aking part in any other projects		
	ase give your name in capitals and sig your address or telephone number so we		
(N ame)	(Signature)	(Date)	
Address			
Talanhana	Number		

APPENDIX C INTERVIEW SCHEDULE

Introductions – who I am, and that meeting was arranged through *name* (KCC Gypsy and Traveller Unit/site manager or KCC Children, Families and Education Unit). Explain project, provide information sheet. Ask for consent and permission to use audio recorder.

How's your own health?

- Do you get ill from time to time?

What generally happens when you are not well?

- Do you take time off to get better?
- Is it OK with your family or work to have time off?
- Do you generally expect to get better?

How do you treat the illness?

- Don't do anything
- Why?
- Treat yourself
- Ask advice from family or friends
- Call for help (ask GP or someone else to visit you at home)
- Use telephone advice lines
- Go straight to GP or hospital
- Make an appointment

Are there changes you would like to see in the local health service and the people who provide it?

Can you tell me about the last time you or your family needed to see a doctor, dentist, health visitor, or get advice from a health professional (someone providing health care)?

What happened?

- How did you decide who to ask?
- how easy was it to make contact?
- how easy was it to get seen/appointment?
- was the service OK?
- would you like it to have been different in any way?
- It has been said that Gypsies and Travellers are some of the people most likely to have poor health and illness do you think this is **true**?
- It's also been said that Gypsies and Travellers are the least likely to use health services and the NHS why do you think this is?

Is there anything you would like to add about local health services, such as those for:

- Older people
- Children
- Pregnancy/childbirth
- Mental health, stress, anxiety, depression
- Drugs and alcohol

Please circle the answer that applies to you:

Are you:	Male		Female		
	Married/living as co	uple	Single		Separated/widowed/divorced
Age:	16-24	25-44	45-64		65+
Are you r	egistered with a GP:	Yes		No	
	et invited to your GP health checks	for: - flu jabs	-	other v	raccinations/immunisations
- :	screening for cancer	- adv	vice on sm	oking, d	diet, etc
- (anything else?	- don't get ir	nvited for a	anything	g
Are you r	egistered with a dent	ist: Ye	s	No	
If 'yes', is	the dentist:	NHS	private		
Do you ge	et reminders to visit t	he dentist:	Yes		No
Have you	been seen at home b	y: - GP			- health visitor
		- distr	rict nurse	- any o	other NHS person?
		- nobe	ody from I	NHS	