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Gypsies/Travellers and health: risk categorisation versus being 'at risk'.

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**Short title: Gypsy/Travellers and risk categorisation**

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### **Abstract**

Risk categorisation provides a routine and necessary contribution to the way people make sense of and impute predictability in a complex human world of which their knowledge is limited. It is a precursor to the development of risk management strategies. Risk categorisation schemes can vary depending on the underlying perspective and knowledge used in their construction. There are estimated to be between 120,000 and 300,000 Gypsies and Travellers in the UK. They have been categorised on the one hand as a group that is 'at risk' suffering wide ranging inequalities and on the other they can be seen as the archetypical 'other' posing risks to normative stability. Public policies to manage their health risks have been limited in contrast to policies to address their 'otherness' status which have aimed to exclude, relocate and forcibly remove them from public space. Little is understood about the way in which Gypsies and Travellers categorise and manage the risks to their health within the context of adverse public policies. In-depth qualitative interviews were undertaken during 2010 and 2011 with 39 Gypsies and Travellers aged between 18 and 66 comprising 20 females and 19 males living in an area of South-East England. Respondents framed risk in terms of threats to

their health, culture and traditional way of life and issues of trust were central to this. They sought to devise risk management strategies that would maintain boundaries between their community and outsiders who were perceived to be the source of risks to their health. A consequence of their risk management strategies was the potential perpetuation of threats to their health and wellbeing.

**Key words:** risk management, risk, risk categorisation ✳, uncertainty, gypsy, travellers

## **Introduction**

There are estimated to be between 120,000 and 300,000 Gypsies and Travellers in the UK including English Romani Gypsies and Travellers, Welsh Gypsies, Scottish Gypsy-Travellers and Irish Travellers (Commission for Racial Equality, 2006, Cremlyn and Clark, 2005). In addition there are an increasing number of Roma, Travelling Show people and New Travellers (Van Cleemput 2010). These groups have been identified or have identified themselves as having different languages, beliefs and certain different cultural traditions but also many common features of lifestyle and culture that unite them collectively as distinct from the rest of UK society (Van Cleemput, 2010). Gypsies and Travellers have been defined as persons of nomadic habit of life, whatever their race or origin, (ODPM 2006) including such persons who have ceased to travel temporarily or permanently in order to access public services (Shelter 2008). Thus, although nomadism features in their cultural heritage many now live in houses, or on authorised or non-authorised caravan sites (Van Cleemput et al, 2007). Nevertheless, Law (2010) has suggested that Gypsies and Travellers are socially and ethnically identifiable in terms of their shared history, unique cultural tradition, family and social customs and the marginalised position they occupy within British society (Powell, 2008, Mason and Broughton, 2007). Gypsies and Travellers have been defined or classified on the one hand as a group that is 'at risk' and that suffers wide ranging inequalities (Parry et al, 2004) and on the other as the archetypical 'other' posing risks to normative stability (Wild, 2005). Little is known about how Gypsies and Travellers frame, categorise and respond to risk within this context and this paper explores their accounts.

## **Risk Categorisation**

Categorisation provides a routine and necessary contribution to the way people make sense of and impute predictability to a complex human world of which their knowledge is limited (Powell 2008, Skolbekken et al., 2012). Categories provide the means by which individuals routinely, albeit largely unconsciously, observe and classify events (Sarangi and Candlin, 2003). Comparing and ranking large numbers of risks systematically is not feasible, especially for non-experts, therefore, risks must be

grouped into a manageable number of categories. Additionally, because risk is a multi-attribute concept it is necessary to choose a set of risk attributes against which to evaluate each category and then develop conceptual descriptions of each category of risk in terms of these attributes (Granger Morgan et al, 2000). Heyman et al (2012) described risk categorisation as a conjoint societal process of contingency selection, differentiation and homogenisation of intra-category variation.

Categorisation manufactures risks as identical, distinctive entities that can be counted so that probabilities can be inductively estimated prior to the development of risk management strategies (Heyman et al. 2012). However, there is no unique categorisation of risks that will suit all contingencies and that different categorisations will best serve different objectives (Granger Morgan, 2000). Categories can change as a certain set of criteria, which make up the categories, are redefined in order to accommodate uncertainty and ambiguity (Sarangi and Candlin 2003) and/or social contexts (Scamell and Alaszewski, 2012, Pryor, 2001). Thus, risk categories take on meaning only because of an underlying set of knowledge and beliefs and a category is only meaningful in a particular decision context that clearly defines the actor's goals for categorisation (Desmond et al, 2012). Given this, risk categorisation schemes can vary greatly depending on the underlying perspective and knowledge used in their construction. Additionally, because different people and organisations have different concerns about risk, there can be no entirely value free ways to classify risky phenomena (Ciata-Zuffery, 2012).

Gypsies and Travellers –categorised as 'at risk'

Rational approaches have underpinned the categorisation of populations or individuals into high risk or low risk groups. This categorisation is then often used as the basis for deciding upon and offering treatment or service options. Studies that have sought to determine or measure the health status, health inequalities or health needs amongst Gypsies and Travellers have utilised an a priori selection of categorising variables or attributes that are based on objective epidemiological data of risk factors that have been shown to be associated with disease and ill health in the general population (Parry et al, 2004, Greenfields and Home, 2006, Braveman et al, 2000, Graham and Kelly, 2004). The selected variables have included lifestyle behaviours, age, gender, educational level, income, employment and

housing etc. For example, Parry et al (2007) in their study of Gypsies and Travellers in Sheffield used a brief generic health status measure, the EQ-5D (a standardised instrument used as a measure of health outcome) to identify health status.

These studies have shown that Gypsy and Traveller communities are the most 'at risk' group in terms of health in the UK and that there are marked health inequalities on standardised measures between the Gypsy and Traveller population and their non-Gypsy/Traveller counterparts (Parry et al, 2007). For example, their average life expectancy is 10 to 12 years less than that of the general population. Forty two per cent of Gypsies and Travellers have long term illness compared with 18 per cent of the general population. Their infant mortality rate is 3 to 10 times greater than in the general population with 18 per cent of Gypsy and Traveller mothers having experienced the death of a child compared with one per cent in the general population (Parry et al, 2004). Additionally, smoking prevalence, angina rates and accident rates are also higher than in the general population. They are much more likely to suffer anxiety and depression and there is a growing substance misuse problem amongst Gypsies and Travellers (Parry et al, 2004, Greenfields and Home, 2006).

However, in spite of being categorised as a 'high risk' population, efforts to treat or manage these risks by health and other professionals appear to have been limited. For example, Parry et al (2004) reported that fewer than half of the Primary Care Trusts and Strategic Health Authorities in the UK had knowledge of the numbers of Gypsies and Travellers in their populations and only a fifth had any specific service provision. Hester (2000) argued that the categorisation of risks on the basis of what is known about the general population has resulted in mainstream services being designed on the assumption of sedentary lifestyles and as a consequence Gypsies and Travellers remain a 'high need' population that have experienced long term exclusion from health services that are appropriate to their needs (Hester, 2004, Cemlyn and Clark, 2005).

Gypsies and Travellers categorised as a 'risk' to society

Douglas (1966) noted that people need to classify others and objects in order to make sense of their world. Where classification is not possible anything which cannot be classified is viewed negatively –

as dirt, pollution and a threat to the collectivity creating uncertainty and a sense of danger. To protect itself the collectivity engages in a strategy of purification restoring boundaries and order by excluding threatening groups and individuals (Powell, 2008, Wild, 2005, Douglas, 1966). Thus when the stranger (such as a Gypsy or Traveller) enters strongly defined communal spaces he or she fractures the entrenched order that prevails within that community, threatens that order and thus becomes subject to ritual control (Wild, 2005). Gypsies and Travellers are attributed an 'otherness status', that is inextricably linked to notions of risk, by the categories and concepts used to describe them. Thus, the non-rational categorisation of Gypsies and Travellers as presenting a risk to mainstream society has prepared the ground for the imputation of stereotypes which are often exaggerated by the media through the amplification of the risk associated with them (Powell 2008). The recurring stereotypical description of Gypsies and Travellers have been based on negative and imagined images and include notions of a lack of morals, self-restraint, dirt, violence, deviance, laziness and illiteracy which are constructed in opposition to the values of 'respectable' society (Powell, 2007, Morris, 2000). These attributes have been used to justify discriminatory responses to the perceived risks posed by Gypsies and Travellers to the settled community.

In the 20<sup>th</sup> Century such responses to Gypsies and Travellers were enshrined in law and government policies that aimed to curb their nomadic lifestyle and largely enforce their settlement, for example, the closure of the commons in the 1968 Caravan Sites and Control of Development Act and the Criminal Justice and Public Order Act 1994 (James, 2007). The latter made it an offence for anyone to stop on any land that they did not own, or did not have planning permission to reside on and was followed by the Anti-social Behaviour Act 2003 which gave the police and local authorities powers to rapidly evict Gypsies and Travellers from land (James 2006).

The action taken in response to the perception of Gypsies and Travellers as a threat to society has been described by James et al (2006) as including guerrilla tactics of disruption and de-stabilisation to achieve spatial exclusion. Spatial exclusion through the bunding (protection) of land by local authorities and the physical blocking of areas by digging ditches or dumping hardcore or gravel at entrances to land or lay-bys is a common action taken by local authorities. Thus eviction is common

in the lives of Gypsies and Travellers particularly those who live on unauthorised sites and on the roadside. Additionally, official sites have been located in marginal, inhospitable spaces – often industrial locations or next to refuse tips. Thus policies which serve to segregate Gypsies and Travellers against their wishes and situate them within the marginal spaces play a role in the maintenance of the outsider status of gypsies.

Bancroft (2000) argued that such actions constitute policing beyond the normative limits that is disproportionate to any harm caused and Hawes (1997) noted that this combined with Gypsies and Travellers having to live at the margins, beyond the reach of service provision, has resulted in a reduction in their health status.

There have been a limited number of studies which have examined the health related beliefs and experiences of Gypsies and Travellers most of which have reported anecdotal data from practitioner accounts (Van Cleemput et al 2007). Van Cleemput et al (2007) in their study reported that coherent cultural beliefs and attitudes underpin health related behaviour amongst Gypsies and Travellers and that ill health is seen as normal and inevitable as a consequence of adverse social experiences.

However, little is understood about the way in which Gypsies and Travellers categorise risks to their health. Drawing on Gypsies and Travellers own accounts this article examines their framing, identification of and responses to perceived threats to their health.

## **Methods**

The overall purpose of the study on which this article is based was to examine Gypsies and Travellers understanding of factors that potentially put their health and wellbeing at risk in order to develop an intervention to mitigate these risks. The sampling strategy sought to recruit a range of people with varying socioeconomic and demographic characteristics and who were living in various forms of accommodation including conventional housing, council sites, private sites and the roadside. The sample was purposive in terms of covering these types of accommodation as evidence suggests explicit connections between type of accommodation and health status and experience (Clark, 2007).

A ‘snowball’ sampling method was employed in order to identify and gain access to this hard to reach



group. Fieldwork involved in-depth qualitative interviews with 39 Gypsies and Travellers aged between 18 and 66 comprising 20 females and 19 males living in an area of South-East England known for having a relatively large Gypsy/Traveller population. Interviews were conducted between September 2010 and April 2011. Fourteen participants were living in conventional housing, 11 on council sites, three on private sites and 11 on the roadside, however, all respondents had at one time or another experienced living in all forms of accommodation. Interviews continued until 'data saturation' was reached and where interviews yielded no new information or insights (Polit and Beck 2008). Interviews were conducted by one of the authors with each lasting between 45 minutes and two hours, took place in the participant's homes and were tape recorded.

The broad questions covered within the interview included;

- Gypsies and Travellers perceptions of common illnesses and health problems faced by their community and the causes of these illnesses;
- Which health risks they perceived to be the most important and the factors contributing to making them important;
- What they felt could be done to improve the health of the community;
- What advice they would give to health professionals about tackling health risks being faced by the community and
- What advice they would give their own community members about how to reduce health risks and keep themselves healthy.

All questions were explored in relation to the community as a whole, as well as, specifically in relation to those living on the roadside, on sites and those living in houses.

Data analysis

Interview data was transcribed verbatim and manually coded by one of the authors. Common themes and linguistic patterns were isolated and initial coding reflected the research questions but also

included identification of newly emerging themes which were then incorporated into the interview guide and addressed in further interviews. Thus, through 'constant comparative assessment' coding and analysis occurred simultaneously with categories added or modified as further data became available. Relations between themes and categories emerged through analysis of the transcripts and became increasingly refined through the interplay of data collection and analysis. Final analysis involved double blind coding with each transcript being read and re-read by both authors. Both authors then discussed and refined categories by comparing one category with one another to identify similarities and differences and to ensure that concepts and relations between variables could be confirmed or modified if necessary. Similar concepts were then collapsed to enhance generalisability. Categories not supported by the data were then discarded (Maycut and Morehouse, 1994).

## **Findings**

Respondents were asked to describe the main illnesses and diseases that Gypsies and Travellers experienced. Their responses showed a high degree of consistency with lung, breast and bowel cancers, heart disease, diabetes and kidney and liver failure being identified as most prevalent. Life threatening co-morbidities were reported as almost endemic within families. For example, fifty one year old Sara, who lived on a council site, described cardiovascular problems affecting most members of her family:

Heart problems, diabetes, erm, epilepsy that's what most of my family have got. Most people I know have always got heart problems, in my family just everyone is the same with their heart.

Whilst John, aged fifty who had lived on the roadside most of his life, described his grandparents dying of cancer:

Yeah, me grandfather died of cancer, all me, me granny died of cancer, half of 'em died of cancer, not natural causes, do you know what I mean. Yeah, most of it was all cancer.

Living in housing triggered depression and was the source of mental health problems. For example, Jim, who was fifty eight and living in a house described how he had seen an increase in mental health problems amongst those who were moved into housing:

In the houses it's mental problems coz they don't want to be there, they're segregated from their family, because we're so family orientated and once you're segregated outside the family then they suffer very badly with er, mental illness, drug addiction.

Gypsies and Travellers drew upon their routine observation of illness and death in their community when identifying common health problems. These matched those identified in studies into Gypsy and Traveller health and were not dissimilar to the types of long term conditions also found amongst the local general population.

We invited our respondents to describe the risks they felt they were exposed to in their everyday lives and to suggest ways in which risks contributed death and illness in their community. Perceptions of risk express an evaluative activity and disclose a host of subtle evaluations of and responses to the social and physical world, a way of responding to variable levels of social order and control and a sense of unease in an unpredictable environment (Jackson et al, 2006). Our respondents reflected upon their everyday experiences when recounting causes of illness within their community. Four broad, interrelated risk categories could be derived from analysis of their responses: experiencing spatial control; living in stigmatised/dangerous spaces; having limited access to appropriate health care; and engaging in unhealthy lifestyle and help-seeking behaviours.

Category one –experiencing spatial control

Most respondents articulated an idealised, traditional way of life which they associated with the freedom to move from place to place, living outdoors in the fresh air, working close to nature and eating healthy food. This nomadic way of life was portrayed as healthy compared with their sedentary or settled way of life which was ascribed health damaging properties. Sadie, a sixty six year old elder of the community, who lived on a council site, illustrated this by contrasting the health benefits of the

traditional, outdoor way of life with the health risks associated with living in an artificial, indoor, atmosphere:

In the travelling days travellers were healthy people. They stayed outdoors which was good for the skin no spots and rashes like those in houses with all allergies. There's natural warmth from the sun and fire outside. Central heating dries the air and is dangerous for health – lungs and heart. Living indoors breathing bad air in an artificial environment erm, most gorgers [non-gypsy/travellers] look ill pale and weak and travellers in housing are now starting to look the same living in an artificial atmosphere with chemicals and breathing it when they sleep. Living under electric light is bad for your eyes and gives a headache.

However, this traditional, healthy way of life was considered to be in jeopardy from aggressive, menacing sedentarisation. The enforcers of sedentary policies were officialdom who were labelled by respondents as 'they' - an amorphous or ill-defined group of officials such as the police, housing officers, local authority personnel. 'They' were accused of enforcing spatial control practices, in particular dispersion and containment, which were threatening Gypsy and Travellers health.

Dispersion, involved curbing Gypsies and Travellers use of public spaces by restricting the time roadsiders could stay in any one place and then forcibly moving them on. It was perceived by respondents to be a device to destroy Gypsy and Traveller culture which respondents believed was associated in officialdoms' mind with risk and criminality. This perspective was illustrated by Jilly, a forty year old roadsider, who reported how she and her family used to be allowed to stay on the roadside for six weeks at a time but that now they were lucky to have a week in any one place:

I'm getting a lot of stress now because once upon a time you'd get six weeks anywhere, but six weeks was enough, you were happy with six weeks. Now the way they're pushing and pushing is ..it's coz they want to kill your culture innit? They give us a week around here now because they know us around here..we're not thieves, we're not murderers, we're not rapists, we're nothing like that, we're just a straight, quiet family.

The stress triggered by constantly being relocated was blamed for ill health and death amongst roadsiders. For example, John, a fifty year old roadsider talked about how the stress of being moved on was resulting in roadsiders dying younger than in the past:

Lots are dying, dying younger with heart attacks and things and it's all down to stress, stress that comes because they won't leave us alone, won't give us a bit of peace. My mum's 87 years old, in her generation they lived that, they used to live that long but now the young travellers, like my age [53] they're dying off with stress and torment.

Containment in contrast to dispersion involved coercing Gypsies and Travellers to move into official caravan sites or social housing - the purpose being to control their movement and remove them from the roadside and mainstream society. Containment was also depicted by respondents as a threat to Gypsies and Travellers health, their freedom and their cultural integrity. For example, Josie, a forty eight year old roadsider, complained that they were often unfairly housed with the low life or scum of society:

They'll put us in where the low life and scum live...either the druggies and paedophiles and murderers and rapists and then call us stinky, dirty, rotten Gypsies!

May, a fifty four year old who was living on a site, also explained how enforced containment evoked feelings of imprisonment which were affecting her mental wellbeing:

It is like you're in a concentration camp, iron gates with the little spikes on the top of the fence and you're all fenced in it affects you mentally.

Jill, who was forty three and was living in a house, concurred with the view that the implementation of containment policies led to a range of health problems:

Those in housing that don't want to be there do have a hard time. A lot go in and get depressed and start drinking or go on depression pills... Travellers get ill when they first go in houses because the air and light's different it's artificial not fresh air and takes getting used to - a lot of breathing and lung problems start then.

Thus respondents narratives depicted spatial control practices negatively and conceptually linked them with the loss of freedom, the demise of Gypsy and Traveller traditional way of life, the experience of physical and mental illness and the classification of Gypsies and Travellers as criminals and low life.

Category two- living in stigmatised/dangerous spaces

Linked to and stemming from the imposition of spatial control practices was the resultant re-location of Gypsies and Travellers into stigmatised or dangerous places/environments. James et al (2006) described how official sites were often located in marginal, inhospitable places and how safe lay-bys, fields and common ground were no longer accessible leaving roadsiders to stay in dangerous areas. This was echoed by our respondents who also characterised the roadside, council sites and housing as dangerous and containing health damaging features.

For example, fifty three year old Mike, who had moved into housing following a life on the road, illustrated the dangers of living on the roadside now:

Living on the road is dangerous. You're on the road and in and among the traffic all day and many a traveller is killed in road accidents or hit by cars, else their kiddies are out playing by the roadside because there's nowhere safe to pull in anymore.

John, a, fifty two year old roadsider, and Sue, who was twenty five and lived on a site, branded council sites and houses as dangerous, marginalised spaces which exposed Gypsies and Travellers to health risks. John described these places as unfit for human habitation:

They'll put the travellers on the worst sites that's either on a tip, been, been made on a tip.. They'll make them where they won't make houses ..next to or on an old sewerage, or on the side of a railway with one standpipe to service about thirty families. I know only a year ago they built another site on top of a tip and they've been eat alive for the last twelve months with flies and rats.

Whilst Sue described the dangers of council site in the following way: A lot of council sites are too crowded with poor facilities and they're put where nobody else would live. You're fenced in. You live somewhere like that and it'll give you health problems then there's the chance of it all going up in a fire because the trailers are crammed in too close and that's on your mind. I've lived on sites like that and it makes people ill with depression.

George, who was fifty nine and lived in a house attributed the risk of turning to criminality to mental health problems caused by being housed alongside criminals:

Well they put them in sub-standard housing. They put them in sub-standard areas because they think that that's what we are sub-standard, you know, they don't put them in decent areas. It's only a criminal element that will talk to them, that have anything to do with them. The only house dwellers that mix with travellers are the villains. And then they (travellers) get into criminality. It's all to do with mental illness.

Respondents' narratives painted a picture of a community that was stigmatised, singled out by authority and classified as 'sub-standard'. The dominant theme that emerged was that as a consequence of being subject to spatial control practices Gypsies and Travellers were now being exposed to an increasing range of risks to their health that had to be assessed and managed on a daily basis. However, the narratives of a small number of respondents (9 respondents) contained evidence that suggested dangers and risks to health also featured in Gypsies and Travellers traditional life on the road and had potentially contributed to the illnesses now prevalent amongst older Gypsies and Travellers. Hazards emanated from the environment roadsiders lived and worked in, as well as, the nature of their traditional work. For example, George, who was fifty nine and had lived and worked on the road for most of his life before moving into housing, illustrated how his traditional lifestyle had placed him at risk of developing lung disease:

Bronchitis, lung disease. A lot of it's to do with open fires and it's all to do with damp and it's to do with outside living, outside working conditions, farm work or whatever they're doing –

bending over, burning scrap, breathing toxic fumes, burning rubber, bloody big fires, black, thick black smoke. Yeah, burning out motors, burning the tyres off the metal rims. I used to have lines of 'em and I'd set 'em alight at one end and they'd just burn all night long.

Nick, a sixty four year old roadsider concurred with George's view that their old way of life was dangerous and also suggested that living in damp conditions had contributed to his health problems:

Um, er my lungs are nearly finished and that's because of scrap and things like that in the past, maybe it might be through asbestos and things I don't know. I've got arthritis at the base of the spine..you're constantly living in the damp, you're constantly living outside working with pesticides on farms.

Whilst Bernie, who was forty one and had lived on the roadside for years described how risks in the environment had meant that she nearly lost her daughter:

I think the biggest problem is er lack of water, lack of healthcare, er lack of toilet facilities. I mean I had a daughter that had Weils disease and nearly died – its rats, you know, the child goes out does her toilet and puts her hands on the ground and wipes them and ends up with Weils disease.

Most respondents' assessments of risk were coloured or influenced by harmful experiences of spatial control policies, perceived loss of an idealised traditional way of life and an emotional response to feeling stigmatised rather than any objective assessment of the differences between their traditional and modern ways of life. Risk and the traditional, nomadic way of life were abstractly disconnected in respondents' narratives. Their traditional way of life had become an idealised vision of security and good health and their modern way of life a source of adversity and risk.

Category three –having limited access to appropriate healthcare

Bernard et al (2007) have argued that health inequalities are determined to a significant extent by the resources to which individuals have access. Our respondents suggested that restricted access to appropriate healthcare posed a significant risk to their health. Two themes emerged in their



discourses: access problems created by their itinerant life and encountering sub-standard care from health professionals and the health service.

Obtaining appropriate access to the National Health Service (NHS) was viewed as problematic for all Gypsies and Travellers, however, roadsiders, in particular, were considered to experience the greatest access problems. Roadsiders' nomadic lifestyle meant that they had no fixed address and therefore could not register with a doctor. Forty three year old Barry, who was living in a house, described the problems facing roadsiders:

Roadsiders are not there long enough so they can't get a permanent doctor, so their health papers [patient notes] can't follow them anywhere so every time they see a doctor in a different town they're being treated for something different.

Linked to this was the fact that roadsiders generally also had poor levels of literacy and could not read their appointment letter thereby missing appointments. Twenty eight year old Bill who lived in housing discussed literacy problems:

Coz they can't read or write, tell the time, and they're 5 – 10 minutes late – 'Oh erm, I'll book you another appointment for another couple of weeks time' and has just missed a second appointment because he can't read or write.

Access to healthcare was considered to be slightly less challenging for those living in houses or on official sites. Nevertheless, respondents' expressed limited confidence that the NHS would treat them fairly. This view was based on perceptions and experiences of prejudicial actions by health professionals. For example, thirty year old Shaun, who was living on the roadside, illustrated how Gypsies and Travellers could be turned away by doctors:

Some doctors will turn you away if they know that you are a Traveller. They know you're a Gypsy and they won't, they won't have nothing to do with you.

Although within the NHS most Accident and Emergency (A&E) departments have long waiting times and general practitioners no longer routinely make home visits, fifty three year old Mike (currently

housed), and sixty five year old Smithy (currently living on a site), felt that Gypsies and Travellers were singled out and expected to wait longer than other people to receive care:

We know that when we go to the doctor we ain't going to get that care, like other people do.

We get pushed to one side. Coz I know you ring the doctor, they could take a day or two to come out. You go up to the hospital and they push you to one side anyway. (Mike)

We have to wait for hours and hours and hours (in A&E), you could be dead and gone before they come to see you. (Smithy)

There is a general policy within the NHS of only prescribing antibiotics when they are really necessary, nevertheless, Annie, a twenty nine year old mum who lived on the roadside described feeling as though she was going to be forcibly removed from the doctors surgery when she disagreed with the doctor over the prescription of antibiotics:

I took my little boy to the doctor, he couldn't breathe. Now I've already told them he has got bad lungs and was in hospital a long time..She (doctor) said 'I'm not giving you antibiotics'. She said 'All you are is a Gypsy and all you Gypsies like is antibiotics for your children. There's nothing wrong with him.' I said 'Yes there is.' I said 'He can't breathe'. I said 'Ring an ambulance for him.' She said 'No'. And she picked up the phone like she was going to call the police. I said 'Whatever do you keep picking up the phone for?' I said 'I haven't done nothing to scare you or holler [shout] at you.' ..... I left and went from there to A&E he was on a breathing machine all night and the next morning they let him out with antibiotics. If that would have been like a person from a house she would believe 'em.

Respondents drew upon their everyday experiences of their contact with the NHS to express their belief that access to health care was restricted and how this exacerbated the risk they felt they were exposed to. They blamed doctors for labelling them and treating them as problematic and their accounts of being denied services and of receiving lower levels of care underpinned their mistrust and lack of confidence in the NHS.

#### Category four- engaging in unhealthy lifestyle and help-seeking behaviours

Throughout their narratives respondents described a way of life in which individuals engaged in a range of unhealthy, lifestyle behaviours. Respondents indicated that smoking, poor diet, drinking alcohol in excess and drug taking which were commonplace amongst parts of the Gypsy and Traveller population. For example, Andy a housed, forty four year old reported that smoking and drug taking tended to run in families:

Erm smoking, big heavy smokers in the family side of things er, obviously sort of on the drugs side of things.

The adoption of unhealthy lifestyle behaviours were considered by respondents to be increasing as Gypsies and Travellers responded to living with adversity on a daily basis. For example, Sara, aged fifty one described how being constantly moved on was causing Gypsies and Travellers to adopt compensatory unhealthy behaviours:

There's constant hassle and being moved on is the biggest health problem it creates a lot of worry and stress in the parents that's why heart problems, bad nerves, bad nerves makes people not take care of themselves, drink and smoke too much and that rubs off on the kids and carries down the generations.

And, twenty five year old Sue, who also lived on a site, described how containment was limiting opportunities for Gypsies and Travellers and as a consequence they were taking drugs, smoking and drinking:

Council sites ..they're substandard accommodation, it's very limited, er lack of education, training and employment and they go the same way - drug taking, smoking, drinking. They might have a community but they have no future - it's a place they put us to die. It's like Colditz only one way in and one way out. They've got a big fence around you so you know what I mean. Barbed wire on the fence to keep you in the only thing that is missing is the watchtower and the guard on the gate.

At the same time respondents indicated that the adoption of compensatory unhealthy behaviours was compounded by the loss of health protecting aspects of their traditional way of life. For example, Smithy, who was sixty five and lived on a site, talked about being housed and accessing welfare benefits influenced risk behaviours which were no longer moderated by physical activity at work. As a result they were putting on weight:

My generation smoked and didn't know different so a lot of people got heart diseases, bronchitis and cancer now less people are smoking but more are fat so they're dying of that instead. Now most travellers are in houses so it's hard to tell Gorjers (non Gypsy/Travellers) from Travellers and they're getting ill for the same reasons: there's no work for lads now so they're not burning off the calories. We'd be in the fields from dawn up ladders, carrying baskets, lifting, picking we were always outside and active. You didn't see a fat traveller when I was a boy.

Fifty nine year old Joe, who also lived on a site, also reflected on the demise of Gypsies and Travellers old way of life which was active and therefore helped to mitigate unhealthy behaviours:

Heart disease – smoking, drinking, a lot of the old work that kept us fit has gone. Field work, constructions going now, jobs are going to the Poles and we're less active, welfare systems made people lazy and you can't go calling for work anymore. No work so sitting about smoking coz they're so bored, eating too much getting fat and dying of heart disease.

In addition to health risks associated with the adoption and maintenance of unhealthy lifestyle behaviours respondents suggested that Gypsies and Travellers' health seeking behaviours were also potentially damaging to their health. For example, they described seeking health advice from relatives or other community members, whom they trusted, rather than the medical profession, as a routine practice for all health problems other than real emergencies requiring immediate hospitalisation. For example Jim a fifty eight and living in a house noted that 'You'd trust your granny, you'd trust your father more than you would your doctor'.

Although, help seeking from community members was commonplace the potential risks associated with seeking support from non-experts was acknowledged and tolerated. Brian, aged forty two and sixty, six year old Sadie both of whom lived on a site explained the risks and benefits of confiding in relatives:

You trust your family, you can confide in your family and they've been there so you know it's almost tried and tested somebody's gonna have had what you've got. But if they don't go to the NHS first, that could be lethal. It could be something that is really untoward and really nasty – it could mean potential death. (Brian)

We just stick together and sort our own problems out. We talk to each first, yeah, we all listen to each other and take advice from each other. It's a risk coz they've not had the education and been through doctors themselves. You don't really know what you're talking about. (Sadie)

Another potentially dangerous help seeking behaviour identified by respondents was delay in seeking help for potentially serious problems and symptoms. This was considered to be a systemic problem which was particularly marked amongst male Gypsies and Travellers. Sixty year old Stephen who lived in a house, commented:

You won't go to a doctor or a hospital until you drop down and so that's the risk isn't it. You might get pain in your chest for a week but the next thing you know you've had a heart attack because you haven't gone to a doctor, you'll just put up with the pain in your chest.

Respondents noted that using medication or treatment prescribed for others was widespread and acceptable. Judy who lived on a site and was forty years old described this process:

Well they'll go to their own first, you know, er – I've got this, I've got that and someone will around and say 'Well I had that and it was this' and you're all, everyone's wrongly diagnosing and 'Oh they put me on these pills, I've still got some, here you are, try them'.

Risky self treatment practices was accepted practice and thirty five year old Mary who lived on a site noted:

Well the last time I went to the doctors I had a lump, they worked out it was only a cyst but I ain't been back since but the lump still keeps coming back, so me mum bursted it and squeezed all the blood out of it. It keeps coming back and we use a pin, we boil it first and we stab it loads and we burst it – its only like water and blood in it, it's not manky [infected].

Respondents displayed a general lack of confidence or trust in health professional and were reluctant to seek their help. In contrast they reported having confidence in their own families and communities to provide them with support, even though they acknowledged the risks associated with this form of help seeking behaviour. They routinely engaged in self management or treatment based on advice from community members.

#### Strategies for managing risk

Overall in their assessments of factors that were endangering their health and wellbeing respondents demonstrated an understanding of the complex interplay between social, economic, environmental and behavioural risks created by exclusionary and assimilatory practices, their physical environment and their own behaviour. However, when they were asked to suggest ways in these risks could be managed they focused almost exclusively one aspect - that of managing behavioural risks.

Respondents singled out the ways they moderated unhealthy lifestyle behaviours and promoted the adoption of appropriate help seeking behaviours as the main ways in which they managed health risks. Nineteen year old Laura and forty four year old Mark both of whom lived in housing suggested that the imperative was to persuade and support Gypsies and Travellers to reduce or avoid the classic unhealthy lifestyle behaviours of smoking, drinking, drug taking and lack of exercise:

Eating better, I would say stop the drinking, sort of thing, or even ease down on drinking, smoking and get some exercise. (Laura)

Educate the youngsters so they've got a future and don't need to take drugs. Drugs are destroying the community round here for everyone that's a top priority. (Mark)

Sue, who was twenty five and living on a site added the need to support Gypsies and Travellers to adopt appropriate help seeking behaviours and practices:

Well they've got to get themselves the medicine and take it and keep themselves fit and healthy.

However, respondents stated that any if any risk management strategies were to be successful they would need to be controlled and delivered by members of their own community. Fifty nine year old George, who lived in housing, summed up why this would be necessary:

The biggest problem we face, I think and Gypsy and Traveller people actually face is that we're on the periphery of society – forgotten. Nobody comes into the community, everybody expects the community (Gypsies and Travellers) to come to them and that's where people are wrong. We don't go to anybody because we don't want to be a burden and we don't trust outsiders... We're frightened to move outside our community – there's fear of each other, that's the biggest problem

Mistrust and fear, which appeared to be pervasive and corrosive, permeated respondents' perceptions and experiences of contact with outsiders and their likelihood of engaging with them. Sadie, a sixty six year old, elder of the community who lived on a site emphasised the importance of trusting and of looking to their own community to provide support and guidance, stressing: 'Our own community, other Gypsies and Travellers coz that's who we trust'.

Whilst, fifty year old John who was living on the roadside echoed this sentiment and suggested that Gypsies and Travellers would probably not listen to outsiders:

I think it's gotta be like sort of from one traveler to another. I don't think there's no point in a nurse coming in, cause I think they wouldn't listen, but or even, somebody in their family that had like experienced it. So say sort of my sister said 'Oh look I've got diabetes, I haven't ever

looked after it, this is what has happened to me'. Then she makes a video and shows it to me and says 'look this is what will happen to you.' I think maybe they would sit back and watch.

Respondents felt that their own community members could be entrusted with improving the health of Gypsies and Travellers despite their limited health related knowledge and skills.

Respondents acknowledged the risks of engaging in unhealthy lifestyle behaviours recognising risky lifestyle behaviours and the need to address these in order to reduce illness and death in their communities. They lived with illness on a daily basis and made the link between risky behaviours and unhealthy outcome. However, the strategies they promoted to manage these risks potentially placed them at even greater risk for two reasons. They failed to access healthcare in response to symptoms and they relied on their own community members to diagnose, provide advice and treat health problems. Managing risks in this way had the potential to perpetuate ill health rather than prevent or ameliorate it. Gypsies and Travellers effectively became agents in the creation and continuance of risky behaviours and ill health. However, in promoting these risk management strategies they could be seen to act to preserve their cultural integrity and reduce the risks associated with contact with outsiders, whom they did not trust.

## **Discussion**

The dominant method of risk categorisation used within public health is based on a rational approach and is evident in the identification, prevention and management of disease. Statistical risk models, based on prior categorisation of risks, are used to differentiate those who are diseased from those who are not and to identify disease free, but 'at risk' populations (Hann and Peckham, 2010, Holmberg and Parascandola, 2010, Heyman et al., 2012). There is evidence that Gypsies and Travellers experience an excess burden of ill health, including lifestyle related diseases, which exceeds that seen in other ethnic minorities and socially disadvantaged groups (Parry et al, 2007). Our respondents also reported chronic, long term diseases such as heart disease, diabetes and cancers as being endemic within their communities. Epidemiological evidence indicates that risky lifestyle behaviours linked to a range of socio-economic characteristics such as deprivation constitute the main determinants of such diseases.



Therefore risk management strategies underpinned by rationality should be grounded in a two pronged approach to risk management - one focusing on tackling adverse environmental, economic and social constraints the other on individual behaviour change.

However, Zinn (2008) argued that most individuals do not generally interpret risk as an objective category which is measured and controlled but will live with risk using their culture, available symbols and their sense of aesthetics to make judgements about what risks to take and avoid. Non-rational judgements use prior knowledge and experience and include the use of emotion, trust and intuition. Risk categorisations vary depending on the underlying perspective and knowledge used in their construction and different underlying approaches used to assess and categorise risk would be expected to have important consequences for actions taken to identify and manage risks (Granger Morgan, 2000). Gypsies and Travellers in our study utilised different sources of information and perspectives for their assessment of risk and risk management strategies.

When identifying the risks faced by their community respondents relied on prior knowledge and experience. They drew on their experience of being subject to spatial control measures and prejudice to classify the physical and emotional risks they faced. In this context prior knowledge and emotion were utilised to construct an image of an idealised traditional way of life which was now under threat. They accorded their traditional way of life health protecting characteristics and contrasted it with their modern sedentary way of life which they portrayed as health damaging. Risk categories are only meaningful in the context that clearly defines the actor's goals for categorisation (Desmond et al, 2012) The underlying purpose of respondents assessment of risk appeared to be to articulate a community and culture under threat. They perceived the loss of their traditional way of life as threatening not only to health, both directly and as a result of the adoption of compensatory health damaging behaviours, but also as the loss Gypsy and Traveller culture and values.

In determining a risk management strategy to address risks facing their community respondents singled out changing individual lifestyle and help seeking behaviours as a means of managing the risks to health. Their goal was to improve the health of individual members of their community. In

doing this they ignored the threats posed by spatial control measures that they had identified as posing a risk to health. It is feasible that their limited responses to the risk they perceived they faced were due to incomplete cognition. Jones (1999) argued that when rationality fails there is a mismatch between the decision-making environment and the choices of the decision maker – this represents a form of bounded rationality. Bounded rationality assumes that the actors are goal orientated but takes into account the cognitive limitations of decision makers and the complexity of the decision environment in attempting to achieve those goals. Certainly the decision making environment facing respondents was complex – the risks resulting from spatial control measures were diffuse and created by an amorphous, faceless officialdom potentially making it difficult to take action to manage these diverse risks. Whereas the focussing on individual behaviour of members of their community the decision context was less complex as they had observed the effects of risky lifestyle behaviours and inappropriate access to healthcare on health outcomes on a daily basis within their communities. The individual Gypsies and Travellers who engaged in health damaging practices were the creators of risk and could be readily identified.

However, respondent's insistence that any advice and support for changing individual behaviour should be provided by members of their own community, whom they acknowledged lacked the required medical skills and knowledge and were already putting the community at risk, suggests that imperfect cognition does not fully explain respondents rationale for their decisions.

Brown (2008) has argued that trust is a response to uncertainty and is only required when there is an absence of appropriate knowledge and hence where one is required to make an ontological leap in spite of limited cognition. Thus trust transcends knowledge, is a mechanism for dealing with anxiety and is only required if an adverse outcome could result in serious harm. Thus failure is an explicit possibility of trust (Brown, 2008). Respondent's narratives contained clear references to their implicit trust in their own community members and their distrust of outsiders, in particular the medical profession. Thus trust appeared to act as a short cut for risk decision making (Rhodes et al, 2008, Zinn, 2008). In choosing to exclude the possibility of help from outsiders they were prepared to accept the potential failure of their objectives to improve the health of Gypsies and Travellers.

Cultural theorists suggest that notions of risk would be shared within communities rather than being the product of individual knowledge and perception and risk judgements would be shaped through shared understandings and anxieties about phenomena (Tulloch and Lupton, 2003). Gypsies and Travellers in our study shared common concerns about threats to their health and used their cultural bias – that only Gypsies and Travellers could be trusted – as a protective function for their community. Jaeger et al. (2006) suggest that cultural bias is blind to some things and sensitive to others.

Thus, people select certain risks for attention to defend their preferred way of life and as forensic resource to place blame on other groups – when people feel at risk they focus on external sources and blame them, rather than concentrate on the dangers afforded to their community by their own members (Gabe 1995). Our respondents blamed others – the faceless, officialdom, the medical profession – for the risks to health that Gypsies and Travellers faced and sought to ensure their cultural survival by minimising contact with these outsiders (Jaeger et al, 2006, Douglas 1966). Although they acknowledged the risks associated with the health seeking behaviours of their own community members they were prepared to take the risk associated with relying on their own community members providing advice and support. Jaeger et al (2006) suggests acceptable risks would be those that do not pose a cultural threat whilst unacceptable risks threaten culture by undermining vital cultural presuppositions. Cultural biases and their focus on specific risks at the expense of others form a shield that provides ontological security. The covert aim or goal of our respondent's risk management strategy was in fact to protect their culture and the risk associated with relying on their own community to provide support would be an acceptable risk in these circumstances.

The findings of this study echo some of those found in the literature on endangered or deprived cultures and communities. For example, Gjenes (2008) in her study of Sami Reindeer herders reported that in response to perceived threats to their ethnic identities herders acted to protect parts of their culture but also expressed ambivalence and resistance towards major changes towards their lifestyle. Whilst Ruston (2009) noted that responses to risk within an inner city deprived community were

based on mistrust and resulted in increasing the negative effect of isolation which was in turn perceived to be putting the community's health and risk.

## **Conclusion**

Gypsies and Travellers are generally regarded as a high risk, hard to reach population by those charged with improving the health of ethnic populations and they have experienced long term exclusion from health services. This paper explored how this marginalised, stigmatised population framed and managed risks to their health in an extremely uncertain environment. In the face of globalised threats from a nebulous or amorphous officialdom trust was invoked as a short cut for decision making and they mobilised themselves to manage the threats, albeit in a way that was likely to pose further risks to their health. This paper adds to our growing understanding of how the risk management goals of marginalised communities are potentially thwarted by their distrust of outsiders and their desire to preserve their cultural integrity.

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