

JenniBerlin,David Smith ,Paul Newton

“It's because it's cancer, not because you're a Traveller”-exploring lay understanding of cancer in English Romany Gypsy and Irish Traveller communities

## Abstract

### Purpose

The lay understanding of cancer among English Romany Gypsies and Irish Travellers, has not been studied in depth before. Lay understandings of cancer, and illness in general, varies between different ethnic groups suggesting that procedures that work for one community may not work for another. Therefore, the measures that are in place in the UK to educate and treat people with cancer may not work for the - often hard to reach - Gypsy and Traveller communities. This study explores Gypsies and Travellers lay perceptions of cancer.

### Method

In collaboration with community interviewers, 18 Gypsies and Travellers were recruited to take part in this study. Data comes from four semi-structured focus groups that were transcribed and thematically analysed using data-driven coding.

### Results

A lack of trust of the wider society has contributed to some Gypsies and Travellers' health related practices as has the persistence of old customs that negatively influence their health. As a reticence towards seeking outside help often exists, information about cancer is sought from family members. When engaged with cancer services however, Gypsies and Travellers generally feel them to be non-discriminative.

### Conclusions

Health professionals need to develop a better understanding of Gypsy and Travellers' health beliefs and practices in order to successfully interact with them. Information about cancer has to be delivered in an understandable form and to places where it reaches these communities. Because of historical societal discrimination, including by some health services, engaging with Gypsies and Travellers may require considerably more time and effort.

**Keywords:** Gypsy; Irish Traveller; cancer; lay perception; culture; information; trust; stigma; discrimination; qualitative

## **1. Introduction**

Research indicates that knowledge of lay understandings of health and illness is important when designing effective and appropriate health care and support services for different communities. Different ethnic groups have their own systems of beliefs, perceptions and ideas about health and illness that influences the experiences of illness and health seeking behaviour (e.g. Helman, 2007; Dein, 2004.) In fact, it has been argued that “understanding cultural responses to cancer are as important to healthcare professionals as knowledge of statistical trends” (Dein, 2004:119).

Lay understandings of illness are based on personal experience of what happens or has happened to the individual, their family and/or closest friends (Prior, 2008:179). Hearsay and word-to-mouth have been recognised as an important source of health information among Gypsy and Traveller communities (Ipsos MORI, 2009). A number of studies have highlighted a taboo surrounding discussion of cancer in those communities with many community members associating cancer diagnosis with certain death (Parry, 2004; Van Cleemput, 2007). Parry et al. (2004) also found that there is a consensus that family members with cancer should not be told that they had the illness. In terms of lay understanding, Jesper et al. (2008) found that some Gypsies and Travellers described the nature of cancer not in relation to the physiological body but as a distinctly gendered disease, particularly in terms of who may be prone to it. Other studies identify a belief that the disease is contagious (Twiselton and Huntington, 2009), -while others report a belief that discussing cancer can make one more susceptible to it (Ruston and Smith, 2013). Some Gypsies and Travellers also believe that a bad diagnosis from a health professional can actually harm the patient’s overall resilience (Welsh Government, 2015). While the above studies highlighted some of the lay beliefs and perceptions of cancer none of them focused specifically on either cancer, or on Gypsies and Travellers’ lay understandings of cancer or health in general. Capturing lay understandings of health and illness are an important component of providing tailored health promotion, advice and communication training for health care professionals, and therefore, this study explores Gypsy and Traveller communities lay understandings of cancer.

## **2. Methods**

This article presents the findings of exploratory focus group research which used a critical constructivist approach (Crossley, 2005) to look into English Romany Gypsies and Irish Travellers' lay perceptions of cancer. The research takes the stance that much of our reality, and the categories and frames we use to explain and interpret everyday life, are socially constructed, and that human knowledge is constantly being constructed by the surrounding cultures, structures and people (ibid.). As Gypsies and Travellers can be considered as extremely close-knit and segregated communities suspicious of the outside world and its institutions (Berlin, 2015), we argue that their perceptions of cancer are mainly (although not exclusively) constructed by their own social norms, culture and people. This exploratory study increases knowledge of these segregated communities and their perceptions of, and practices surrounding cancer.

The research was conducted by organising four focus group interviews. These were conducted in 2016 with adult members (18+ years) of English Romany Gypsy and Irish Traveller communities in two locations one in the South East and the other in the East of England. 18 participants took part (two men, 16 women). Thirteen of the interviewees were English Gypsies and five were Irish Travellers, see Table 1.

**Table 1**  
Focus Groups

Focus group 1	Focus group 2	Focus group 3	Focus group 4
1 English Gypsy woman	3 English Gypsy women	3 English Gypsy women	4 English Gypsy women
5 Irish Traveller women	1 English Gypsy man	1 English Gypsy man	

As Gypsies and Travellers can be considered as extremely 'hard to reach' communities, the participants were recruited with the help of community interviewers known to the researchers. All participants were given a Participant Information Sheet prior to interview, and were asked to sign a Consent Form if they decided to take part. The interviews were audio recorded with participants' permission, and transcribed verbatim using a professional transcribing company.

To explore lay perceptions of cancer within Gypsy and Traveller communities, a semi-structured topic guide was designed to gather information about issues identified from

previous research and the literature review, see Table 2. Probing questions were used to gather more information on issues the participants' brought up themselves. This assured that the participants' perspectives and concerns about the research topic were not overlooked. Using a data-driven approach of thematic analysis and treating the four focus groups as subsamples, we identified and then compared themes within the focus groups and between them (Boyatzis, 1998: 41). This led to the creation of five codes, the main themes of our research, which will be introduced in the results. The identified themes were discussed and agreed upon with the research team and community interviewers.

**Table 2**

Topic guide for focus groups

---

<p><b>Topic 1: Explore your experiences beliefs and practices surrounding cancer.</b></p> <ul style="list-style-type: none"> <li>• Health workers and researchers who work with Gypsies and Travellers often say it's hard to get them to discuss cancer – is this true in your experience and if so why?</li> <li>• What do you consider to be the major causes of cancer?</li> <li>• Where does your knowledge and information about the disease come from? (E.g. public health information, media, friends/family).</li> <li>• Do you feel you have enough (or too much) information about the disease?</li> <li>• Should someone diagnosed with cancer be told about it? If so why/ why not?</li> <li>• How would someone be treated if they were diagnosed with cancer (E.g. would people feel uncomfortable/ avoid/ visit/ offer help/ care)?</li> </ul> <p><b>Topic 2: Investigate the experiences of yourself and/or your family members surrounding palliative and end of life care in formal healthcare settings.</b></p> <ul style="list-style-type: none"> <li>• If anybody had a loved one/ friend become ill with cancer how do you consider the quality of treatment they received from healthcare/ medical staff – was it appropriate to their needs?</li> <li>• How do you consider the attitudes of healthcare and medical staff towards (the sick person/ your relative/friend) and their level of understanding towards people from Gypsy and Traveller backgrounds?</li> <li>• In your experience, how did the medical/ nursing staff relate to the family and visitors who came to the hospital/ hospice?</li> </ul> <p><b>Topic 3: Examine any unmet needs or obstacles in relation to effective cancer care that you/ your family or friends may have experienced.</b></p> <ul style="list-style-type: none"> <li>• Were there any aspects of care or of their time in hospital which could have been better?</li> <li>• Do you consider there were aspects of your culture and the way you treat cancer that the doctors and nurses didn't understand?</li> </ul> <p><b>Topic 4: Consider how cancer care could be organised to better suit the needs of you and other Gypsies and Travellers.</b></p> <ul style="list-style-type: none"> <li>• How could cancer services be improved so they better met the needs of Gypsies and Travellers?</li> <li>• What training on this issue would benefit medical staff? What would you want them to know/ understand?</li> </ul>
---

---

This article introduces the findings by using illustrative quotations from the focus groups. The focus groups are coded with numbers 1-4. '(F)' means that the respondent is female

and '(M)' that they are male, e.g. '(F3)' is a female participant from focus group 3. When displaying parts of discussion, the interviewer is marked with '(Int)'.

### 3. Results

This chapter analyses the following five themes that were identified from the data:

- Gypsies' and Travellers' beliefs about cancer
- Fear and stigma surrounding cancer
- The role of gender and gender based care for those with cancer.
- How Gypsies and Travellers look for and would like to receive information about cancer
- Perceptions and experiences of cancer treatment and medical professionals

#### *Gypsies' and Travellers' beliefs about cancer*

Many Gypsies and Travellers will not talk about cancer because they see this as invoking bad luck; as bringing forth painful memories of family members who have suffered or died from the disease and as causing their families too much worry. Because of a widely held belief among Travellers that there is no cure for cancer, it might be ignored entirely, with people carrying on with their lives as normal: *'I think that's because they'll never find a cure for it, all the research and that they do, they're never going to find a cure for it and I think that's why it's so, people don't like to talk about it because there's hundreds and hundreds of different types of cancer and they haven't found a cure for any one of them yet ...'* (F3).

Cancer was referred to by our interviewees as 'that old cover', 'that old thing', 'that disease', 'the C word', or 'the bad complaint': *'What my daughter will say is, "that old cover" or "that disease", I think I try not to say the word "cancer" but at some point, I'm forced to and part of that is because my mother dying of it, I think it's almost for me, it's like it brings back her to me straightaway soon as I mention it ... so I think I don't mention cancer unless I have to because then it brings back how she was'* (F3).

For Gypsies and Travellers treating cancer, as well as other illnesses, is still strongly influenced by customs, beliefs and their history of being discriminated against in the UK. The interviewees discuss how their culture of 'not running to doctors' because doctors have not always been willing to help Gypsies and Travellers, can still affect people's health behaviour and therefore many illnesses are still treated at home: *'It's not in our culture to keep running to the doctor's, we don't want the doctors. That's because years ago when we used to try and go to the doctor's they wouldn't see you. Then your parents got you to not go to the doctor's. A lot of it is dealt in home. My daddy used to hold my foot, if you had a sore foot, in a dish of water with salt in it. They'll do that rather than you go to the doctor's, they'll try and fix it themselves, which isn't always a bad thing.'* (F4).

During the focus groups we discovered that some Irish Travellers visit traditional 'curing men' in Ireland (and England) as well as accessing conventional treatment. The interviewees told us that different 'curing men' specialise in different illnesses and that there are also specialised 'curing men' for cancer. The cancer 'curing men' will not treat a patient if a professional surgeon has 'cut into' the cancer (performed surgery). When asked whether the respondents prefer to see a doctor or a 'curing man', they replied that they would visit both. Most importantly, they will first ask their family's opinion of what to do: *'Would you go to a curing man or would you go to the doctor?' (F4), 'I'd go to both would you?' (F4), 'What if the curing man wouldn't touch you if the doctor's cut the thing? So if the doctor says it has to be cut out ... What we would do then is go in-house, back into the family and ask about the curing man, because you're left with no scars or nothing with the curing man' (F4).* Furthermore, as many Irish Travellers are Roman Catholics prayer and penance is commonly used as a way to deal with illness and this may well reduce the willingness and / or need to seek conventional oncological treatment: *'But Travellers are strong believers in prayer... Some people might say, "Well I'm going to do this," or they'll apply something or do something, they do it as penance. So in the Traveller communities penance is a big thing' (F4).*

Our interviewees mentioned several different ways they believed a person can get cancer. For example, there is a belief that some families have the 'cancer gene': *'You've got a cousin who's had the cancer and then one of the ladies, her daughter had her breasts scooped out, was it, so she doesn't get the cancer?' (F4), 'Yeah she had the gene, but her*

*mother's dead now. The mother and a load of her sisters died, they all had the gene'* (F4). This knowledge of a genetic predisposition is reinforced through the nature of Gypsy and Travellers' extended family and kinship networks, which ensures a good knowledge of individual and family health histories: *'In our community you can see how it spreads because we're such a close knit community a lot of cancer runs in families'* (F4). Many also believe that if cancer is 'cut into' (if someone has surgery) it will spread to different parts of the body and give the person cancers in other parts of the body: *'... so hers [cancer] was in her pancreas and then it became secondary because it spread to, I don't know, organs, then it spread somewhere else. ... So the more places it spread means you've got third, fourth cancer, depending where it's spread'* (F3).

Travellers' lifestyle choices were acknowledged as potential causes of cancer by our participants, although they were unaware of some potential causes, like alcohol: *'I don't think Travellers would think that alcohol causes cancer at all'* (F4). The interviewees consider skin cancer to be common among Gypsy and Traveller communities and they acknowledge that an excessive use of sun beds may be its cause. Regardless, the participants reported that it is more important to look beautiful and therefore have no intention in stopping using them: *'And I've got a lot of skin cancer in my family, but I still have sun beds'* (F4), *'So it doesn't matter to you? (Int), I've got to be beautiful'* (F4), *'Yeah I don't feel afraid of having sun beds'* (F4). In fact, the respondents acknowledge that on average people die younger in their own community when compared to other communities, because they do not take care of themselves as well as they think they should. However fear and lack of trust of the outside world makes them want to segregate more: *'Well Travellers die younger than most people'* (F4), *'Why do you think that is then?' (Int), 'Because we don't look after ourselves properly'* (F4), *'But is it because you don't want to or you're not used to doing it?' (Int), 'It's because it's just our culture it's the way it is. We don't run to ... it's like going out of the community again isn't it. Outside there's always a chance ... If you see a pack of animals and you're threatened, you'll stick together and you'll huddle together. Outside of our community there's always a threat'* (F4).

#### *Fear and stigma surrounding cancer*

Although there are vast amounts of information available, diagnosis of cancer is still associated with fear and stigma. Cancer is regarded as something more serious and

treated with more reverence than other potentially life threatening diseases: *'I am petrified of cancer, petrified of getting it, petrified of having it because I have cancer equals death, I don't have sugar diabetes equals death, I don't have heart attack equals death but cancer equals death in my world ...'* (F3), and *'Everyone's got diabetes. When I was told I'd got sugar diabetes, I was neither here nor there. I really didn't bat an eyelid'* (F2).

Our interviewees recognised the 'cancer equals death' equation, and in fact two focus group conversations ended as conversations about death. Cancer was discussed as something long term and that breaks down the whole person, not just their physical health: *'If you've got cancer and it's the wrong, well there's not much you can do is there?'* (M1), and *'When you've got that [cancer], well that's it then, it's over'* (F1), and *'It's more or less a death sentence isn't it?'* (M2).

Feeling embarrassed or ashamed about cancer may deter people from seeking medical treatment, information or any kind of emotional support. Gypsies and Travellers can be discouraged from seeking medical treatment for cancer partly because the illness is often considered as weakness: *'I think Travellers, they think if they've got illness, it's a weakness'* (F1). However, as the following discussion demonstrates, our interviewees deny that someone with cancer would be stigmatised within the community. In this respect, people with cancer are treated the same way as people with other illnesses: *'Do you think people in your community if someone has cancer and tells people, do they get treated differently after that? Is there a stigma?'* (Int), *'No'* (F4), *'No'* (F4), *'No, people don't do that?'* (Int), *'Not at all'* (F4), *'Never'* (F4), *'The opposite way, if someone has cancer everybody tends to come, everybody goes and visits'* (F4).

#### *The role of gender and gender based care for those with cancer*

Gypsy and Traveller women are more willing to look for medical help and support than men. Men usually have to be forced and badgered by their wives, mothers and sisters before they will go and see a doctor. When they finally agree to go, the women often have to accompany them: *'... how do you get your husband or brother or dad or whatever, how do you get them to go to the doctor?'* (Int), *'Badger them all the time, "You have to go, you have to go, you have to go"'* (F4), *'You have to go with them, don't you?'* (F4), *'Yeah'* (F4).

Being cared for by family was important to all our focus group participants, and they stated that most Gypsies and Travellers wanted to be cared for by their immediate family at home. There were only a few incidents when participants reported that it would be better for a Gypsy or Traveller to go into a care home or hospice, for example if someone is disabled and it is impractical to care for them at home, or if the person does not have same gender family support at home: *'... my mother had grown up daughters so we did the personal care for her, showering her, bathing her, changing her clothes, didn't bother us and when my dad become ill, we said to our brothers: "right, your job is to do his personal care whether you want to or not, you've got to take it in turns, we'll cook for him, we'll clean the trailer, make the bed but to help him in the shower and help him with his personal care is your job" and they did it'* (F3).

Personal care services by health professionals were criticised for sending male nurses to care for female relatives: *'But the last resort ever was when they sent that male nurse out ... I said "Oh no, we're Travellers, we don't have men in there, washing my mum ... so out", he said "I'll sit in the car", I said "you do that"'* (F1).

#### *How Gypsies and Travellers look for and would like to receive information about cancer*

Our interviewees reported that as illiteracy is still relatively common within Gypsy and Traveller communities, information about cancer should more often be in audio form, e.g. a phone help line they could call or a clinic where they could talk with someone. The participants feel that information leaflets about cancer are often hard to understand even for the literate. When feeling emotionally frail, as often is the case when a person is dealing with cancer within their family, reading too much information about cancer can be overwhelming: *'I can read and write but sometimes when you're really emotionally hurt, you can't read 'cause you read it but you don't take it in'* (F3).

The interviewees stated a preference for someone to explain everything to them in common everyday terms, without using jargon and complicated medical terms. They felt that this information should come from someone who "speaks the same way" they do: *'We just want the basic information so that we know and also the way it's spoken. You know*

*if we go in-house in our own community then we can understand it because we're talking to someone who speaks the same way we speak' (F4), and 'Really and truthfully the best thing would be to have people coming around and talking to people about it and discussing it, someone that they knew that they could go to, really a Traveller' (F4).*

Information about cancer on television is said to be too medical and hard to understand, and participants also felt there was too much cancer-related information and campaigning on television. They believe campaigns and programmes about cancer can be harmful because they can raise people's hopes as well as create anxiety and hypochondria: *'What do you think of these adverts, Cancer Research etc.?' (Int), 'I don't think they should do that because it's getting hopes up for them people that can't beat it. ... I think on telly it's too much' (F3).*

Participants described how the majority of information about cancer was gleaned from family members and other people from the community who had had cancer, and acknowledged that this information had previously turned out to be inaccurate. Furthermore, those interviewees who had searched for information about cancer from the internet and / or social media said they had often found the wrong information (e.g. information about lung cancer when someone has breast cancer) which, in turn, frightened them: *'... sometimes when you seek information, if you haven't got the correct information, you can cause just as much harm trying to find it. ... I mean I did know it [brother's cancer] was kidney cancer but some of my family were just reading up, "cancer", they didn't hear about the kidney ... and they reading up signs to have chemotherapy, which he didn't, it was contained so he didn't need that. But they was saying, "he's going to lose his hair, this is going to happen" ...' (F3).*

#### *Perceptions and experiences of cancer treatment and medical professionals*

The main reason Gypsies and Travellers prefer to get information about cancer from someone from their own community is their deep mistrust of outside society. This same mistrust and avoidance of outside help is, according to some of the interviewees, the biggest issue negatively affecting Gypsy and Traveller health. In the following, two interviewees elaborate on what they perceive to be the main reasons for the high burden of illness and poor health within their communities': *'... It's not the outside community*

[who is to blame for Gypsies and Travellers health problems], *the problem it's within'* (F4), *'How do you think that can be changed, or can it? Can it not?'* (Int), *'The only way to change it is to educate people, someone in the Travelling community and let them have a job of doing it or talking to people. That's the only way you could do that because it's hard to go out of home'* (F4).

Interestingly, despite the lack of trust and the fear of outsiders, the participants told us that the cancer treatment and care they or their families had received has always been excellent and that doctors and nurses in cancer clinics had always treated them well. There was a sentiment that those living with cancer, got treated the same as other patients in general hospitals and GP practices: *'... everybody I've spoken to who's had cancer I've never heard one person complain about it. In general the cancer hospitals in England are very good'* (F4), and *'... they [health professionals in cancer care] do seem like they're there to help and they're trying, which I think is all we can ask really'* (F2).

Based on these reports, it seems that Gypsies and Travellers accessing health professionals treating patients with cancer do not experience discrimination. We cannot determine without further research whether this has something to do with the specific nature of cancer and how health professionals perceive it as an illness in comparison to other illnesses. This explanation however, seems to be how our respondents see it: *'I think they're [health professionals] very sensitive towards it, it's because it's cancer it's not because you're a Traveller'* (F4).

#### **4. Discussion**

Robert Putnam's concepts of bonding and bridging social capital (1995) can be used to theorise health behaviour and lay perceptions of cancer within Gypsy and Traveller communities in the UK. Bonding social capital describes the strong connections between people who already know each other such as family and friends, whereas bridging social capital consists of looser relationships between individuals from different social, age or ethnic groups for example. Berkman and Glass (2000, 184) argue that strong bridging social capital can influence individual health in three ways. First by influencing health related behaviour by exerting social control over deviant health behaviour, secondly by

increasing access to services and amenities e.g. by encouraging people to unite against inequalities, and thirdly by affecting psychosocial processes e.g. enhancing mutual trust, respect and self-esteem.

Gypsies and Travellers' social capital can be characterised as bonding social capital partly because they are segregated communities with low levels of institutional trust (Berlin, 2015). Our results support this argument: ill-health and non-compliant health behaviours are often normalised, and there is a widespread lack of trust towards outside society and its institutions such as health services. Also Van Cleemput et al. (2007) have argued that the familiarity with ill-health, premature deaths of family members, and minimal close contact with the wider society explains the normalisation of ill-health among Gypsy and Traveller communities. However, our results also show that trust, and therefore bridging social capital has begun to increase between Gypsies and Travellers and the specialist cancer services

It is important to acknowledge that fear, guilt, disbelief and lack of awareness about cancer appear to be reasons for a lower uptake of cancer services among *all* ethnic groups (Elkan et al., 2006). However, there is evidence of lower awareness of cancer symptoms among people from the most socioeconomically deprived groups and some ethnic minority communities. Moreover some studies have shown that BME groups are less likely to understand their diagnosis than their white majority counterparts (Marmot, 2006.) In fact, misconceptions and misunderstandings about cancer and cancer services are easily reinforced in close-knit social networks (Marmot, 2006; Niksic et al., 2014). This was evident among our focus group participants; even if family and friends had previously provided incorrect information about cancer, they were still the first place to go for information.

Although the experience of cancer has changed in recent years and it is increasingly considered as a long-term illness not least because of its improving survival rates (Corner, 2008; Macmillan Cancer Support, 2015), the 'cancer equals death' equation was found to be pervasive among people without cancer diagnosis (Balmer et al., 2014). This was not different among our focus group participants; many still believe that cancer still equals death. However, given the high burden of chronic health issues in Gypsy and Traveller communities (Parry, et al. 2004) our focus groups demonstrated a surprising degree of

normalisation of, and blaseness towards, some other health conditions such as diabetes and heart disease which could be addressed using a health promotion focussed on the common risk factors approach.

Studies among Gypsy and Traveller communities have demonstrated that women are more willing to look for help and support whereas men are more prone to stoicism and avoidance of medical professionals (Parry et al., 2004; Van Cleemput et al., 2007; IPSOS MORI, 2009). Sanctioning from family, friends and the media has been found to be an important push factor for men seeking medical help and in reducing their fears surrounding cancer consultations (Smith et al., 2005; Scanlon et al., 2006). Although the key role of women in families' health related issues within Gypsy and Traveller communities (e.g. Ipsos MORI, 2009) should be recognised by health professionals, our study shows it is also important that men are targeted with health information. This is partly because some Gypsy and Traveller women will not speak about health issues with men as it can be regarded as culturally inappropriate (Welsh Government, 2015).

Previous research has shown that the preferred sources of cancer related information for all communities are family, friends, public figures diagnosed with cancer, television, internet, books and newspapers. Surprisingly, information provided by health professionals is said to cause misunderstandings and to be unreliable and inconsistent (Balmer et al., 2014.), a finding reflected in the present study. The need for better understanding of lay perception is especially relevant when dealing with life threatening illnesses such as cancer where more knowledge does not always prompt behaviour change in people (Lipworth et al., 2010).

'Hard to reach' communities such as Gypsies and Travellers are more likely to adopt behaviours that can increase cancer rates (Marmot, 2006). For example, in our findings participants reported excessive use of sun beds, high levels of smoking and low awareness of the health risks of alcohol, indicating that more community specific education about factors contributing to cancer risk was needed. As lack of conviction in the meaning or purpose of preventative health measures, like cancer screening, is common among Gypsy and Traveller communities (Parry et al., 2004), the need for more community specific cancer (and health) information is even more pressing. In fact,

variable cultural beliefs about cancer and lower levels of knowledge about the purpose of preventative cancer services have acted as barriers when accessing cancer-related health services (Marmot, 2006; Niksic et al., 2014). Conversely targeted health information about cancer has increased ethnic minorities' uptake of those services (Thomas et al., 2005; Marmot, 2006).

Lower levels of literacy in Gypsy and Traveller communities means that online information can be misinterpreted, e.g. reading about lung cancer when someone has cancer of the pancreas. However, if designed appropriately, social media can be utilised in informing Gypsies and Travellers about cancer and health in general. In fact, organisations working with Gypsies and Travellers have lately started utilising this method of engagement (Traveller Movement, 2017a).

Although little evidence exists about the effect of perceived discrimination in cancer patients on their adherence to medical professionals' recommendations, there are studies that support this hypothesis (e.g. Ngo-Metzger et al., 2006). This would suggest that Gypsy and Traveller communities' extensive mistrust of, and historically negative experiences with, health professionals, whether perceived or enacted, makes them more sceptical towards physicians' advice about cancer. In fact, one study has shown that fear, low expectations and lack of knowledge reduce the likelihood that Gypsies and Travellers will seek early treatment for cancer (Van Cleemput et al., 2007). In addition, if the verbal and non-verbal communication styles and the explanatory models of illness and disease between the patient and the health professional diverge, the overall communication between the two can be negatively affected and therefore damage both the experience and the outcome (Ngo-Metzger et al., 2006). This was evidenced above, when our interviewees preferred to receive cancer related information from someone that "speaks the way" they do.

Our research suggests that Gypsies and Travellers feel specialised cancer services to be non-discriminative, and report their own (in some cases) and their family members' cancer treatment as overwhelmingly positive. This is a significant finding as according to a recent study a third of Gypsies and Travellers have experienced discrimination when accessing healthcare (Traveller Movement, 2017b). It also indicates that reluctance to access cancer screening programmes may relate more to the anticipation of

discrimination when accessing GPs or preventative interventions than oncology services. Therefore, the practises and methods used by health professionals in specialised cancer clinics etc. could be used as a model in order to make all health services more inclusive of Gypsy and Traveller patients.

This study should be viewed within the context of some limitations. Due to a small sample size, saturation of data could not be reached. However, as this is an exploratory study about communities where no official NHS data exists, hence its results are important in understanding the health needs of Gypsies and Travellers.

This study's results are limited on men's experience, with the exception of two male participants. The unwillingness of Gypsy and Traveller men to take part in studies about their communities is well acknowledged among academics and third sector actors in the UK.

## **5. Conclusion**

Our research shows that historical discrimination against Gypsies and Travellers (and therefore their lack of trust of the outside society) has led to a culture of 'not running to the doctors'. This in turn has contributed to some Gypsies and Travellers unhealthy habits and the persistence of customs and practices that negatively influence their use of preventative and primary healthcare services. These habits and customs also affect how Gypsies and Travellers deal with cancer. As outside help may be considered with suspicion, information about cancer is often sought from family members. Many feel that information about cancer should be oral (phone helplines and walk in clinics) and/or come from someone who speaks in a manner they can understand. There is also a strong sentiment within these Gypsy and Traveller participants that information about cancer should not be forced upon them.

Our interviewees did have positive experiences of health professionals treating cancer. They felt that when someone has cancer it overweighed that person's ethnicity and background. They felt that cultural awareness training is needed among health professionals mostly about gender-related issues. Some of our interviewees considered

the biggest issue negatively affecting Gypsies and Travellers health to be their distrust of, and therefore avoidance of, outside help.

Arguably partly because of their segregated position in the UK, Irish Travellers have preserved traditional 'curing men' a role in treating illness. 'Curing men', prayer and penance are important parts of Irish Travellers' health behaviour, sometimes to a degree that a person may refuse to have a cancer operation because a cancer 'curing man' will not treat them if they have the operation. To our best knowledge, no one has yet studied this aspect of the Traveller communities' holistic health behaviour. This would be extremely important if we are to improve the health of these communities.

Communication between the health provider and the patient is crucial when planning care and therefore shared decision making between professionals, patients and families when planning care is highly important (Ngo-Metzger et al., 2006). As Dein (2004) suggests, it is not the patient's responsibility to change their beliefs in response to biomedical culture. Health professionals should not blame the patients for their beliefs but instead modify their practices to be more culturally appropriate.

## **Acknowledgement**

Thank you to the community interviewers, whom conducted some of the focus group interviews, and therefore, were both a crucial part of making this study possible.

## **References**

Balmer, C.E., Griffiths, F. and Dunn, J. A. 2014. A qualitative systematic review exploring lay understanding of cancer by adults without cancer diagnosis. *Journal of Advanced Nursing*, 70(8), 1688–1701.

Berkman, L., Glass, T. 2000. Social integration, social networks, social support and health, in: Berkman, L., Kawachi, I. (Eds.), *Social Epidemiology*. Oxford University Press, Oxford.

Berlin, J., 2015. *Assimilated Individuals and Segregated Communities. A comparative study of housing and living related well-being of Finnish Roma and housed Gypsies and Travellers in England*. Publications of the University of Eastern Finland, Kuopio.

Boyatzis, R., 1998. *Transforming qualitative information: thematic analysis and code development*. SAGE Publications Ltd., California.

Corner, J., 2008. The changing picture of cancer. *European Journal of Oncology Nursing* 12, 281-282.

Crossley, N., 2005. *Key Concepts in Critical Social Theory*. SAGE Publications Ltd., London.

Dein, S., 2004. Explanatory models of attitudes towards cancer in different cultures. *The Lancet Oncology*. 5(2), 119-124.

Elkan, R., Avis, K., Cox, K., Wilson, E., Patel, S., Miller, S., Deepak, N., Edwards, C., Staniszewska, S. and Kai, J., 2006. The reported views and experiences of cancer service users from minority ethnic groups: a critical review of the literature. *European Journal of Cancer Care*, 16(2), 109-121.

Helman, C. G., 2007. *Culture, Health and Illness*, fifth ed. Hodder Arnold, London.

Ipsos MORI, 2009. Research to achieve actionable insight and intervention recommendations for Gypsy and Travelling communities. NHS Mid Essex. Available from: [http://essexpartnership.org/data/download\\_file/267e6da29661b4367cdcba1b6b0d1901bfc3deb26039129053ecc3df258eb566](http://essexpartnership.org/data/download_file/267e6da29661b4367cdcba1b6b0d1901bfc3deb26039129053ecc3df258eb566) [Accessed 22 August 2017]

Jesper, E., Griffiths, F. and Smith, L., 2008. A qualitative study of the health experience of Gypsy Travellers in the UK with a focus on terminal illness. *Primary Health Care Research & Development*. 9(2), 157-165.

Lipworth, W.L. Davey, H.M., Carter, S.M., Hooker, C. and Hu, W., 2010. Beliefs and beyond: what can we learn from qualitative studies of lay people's understanding of cancer risk? *Health Expectations* 13(2), 113-124.

Macmillan Cancer Support, 2015. Cancer survival in the UK and Europe, 1995-2009. Available from: [http://www.macmillan.org.uk/Aboutus/News/Latest\\_News/UKCANCERSURVIVALRATESSTUC KINTHE1990SSAYSCHARITY.aspx](http://www.macmillan.org.uk/Aboutus/News/Latest_News/UKCANCERSURVIVALRATESSTUC KINTHE1990SSAYSCHARITY.aspx) [Accessed 22 August 2017]

Marmot, M., 2006. Cancer and health inequalities: An introduction to current evidence. Cancer Research UK. Available from: [http://www.cancerresearchuk.org/prod\\_consump/groups/cr\\_common/@nre/@pol/documents/generalcontent/crukmig\\_1000ast-3344.pdf](http://www.cancerresearchuk.org/prod_consump/groups/cr_common/@nre/@pol/documents/generalcontent/crukmig_1000ast-3344.pdf) [Accessed 22 August 2017].

Ngo-Metzger, Q., Telfair, J., Sorkin, D.H., Weidmer, B., Weech-Maldonado, R., Hurtado, M. and Hays, R.D., 2006. Cultural competency and quality of care: obtaining the patient's perspective. The Commonwealth Fund. Available from: [http://www.commonwealthfund.org/usr\\_doc/Ngo-Metzger\\_cultcompqualitycareobtainpatientperspect\\_963.pdf](http://www.commonwealthfund.org/usr_doc/Ngo-Metzger_cultcompqualitycareobtainpatientperspect_963.pdf) [Accessed 22 August 2017].

Niksic, M., Forbes, L., Rachet, B., Wardle, J. and Ramirez, A., 2014. Awareness of cancer symptoms and barriers to symptomatic presentation among different ethnic groups in England. 2014 NCRI Cancer Conference, Liverpool.

Parry, G., Van Cleemput, P., Peters, J., Moore, J., Walters, S., Thomas, K. and Cooper, C., 2004. *The Health Status of Gypsies & Travellers in England*. Report of Department of Health Inequalities. The University of Sheffield, Sheffield.

Prior, L., 2008. Lay understandings of health and risk: a changing picture, in: Cooke, H. & Philpin, S. (Eds.), *Sociology in Nursing and Healthcare*. Elsevier Limited, Edinburgh.

Putnam, R., 1995. Bowling Alone: America's Declining Social Capital. *Journal of Democracy*, 95;6 (1), 65-78. Publisher's Version.

Richards, M., 1997. It runs in the family: Lay knowledge about inheritance, in: Clarke and Parsons (Eds.), *Culture, kinship and inheritance*. Macmillan, London, pp. 175–196.

Ruston, A. and Smith, D., 2013. Gypsies/Travellers and health: risk categorisation versus being at 'risk'. *Health, Risk & Society*, 15(2), 176-193.

Scanlon, K., Harding, S., Hunt, K., Petticrew, M., Rosato, M. and Williams, R., 2006. Potential Barriers to Prevention of Cancers and Early Cancer Detection among Irish People Living in Britain: A Qualitative Study. *Ethnicity and Health*, 11(3), 325-341.

Smith, D. and Ruston, M. (2013) 'If you feel that nobody wants you you'll withdraw into your own' Gypsy/Travellers, networks and health care utilisation' *Sociology of Health and Illness*, 35, 8, 1196-1210

Smith, L.K., Pope, C., Botha, J.L., 2005. Patients' help-seeking experiences and delay in cancer presentation: A qualitative synthesis. *Lancet* 366, 825-831.

Thomas, V. N., Saleem, T. and Abraham, R., 2005. Barriers to effective uptake of cancer screening among black and minority ethnic groups. *International Journal of Palliative Nursing*, 11(11).

Traveller Movement, 2017a. Information Guides. Available from: <http://travellermovement.org.uk/informationguides/> [Accessed 6 February 2018]

Traveller Movement, 2017b. The last acceptable form of racism? The pervasive discrimination and prejudice experienced by Gypsy, Roma and Traveller communities. Available from: <http://travellermovement.org.uk/wp-content/uploads/TMreportFinalWeb1.pdf> [Accessed 26 September 2017]

Twiselton I. and Huntington F., 2009. Health Needs Assessment: Cumbria Gypsy Travellers. NHS, Cumbria [online] Available from: <http://www.cumbria.gov.uk/eLibrary/Content/Internet/536/671/4674/5359/5360/40723111743.pdf> [Accessed 22 August 2017]

Van Cleemput, P., Parry, G., Thomas, K., Peters, J. and Cooper, C., 2007. Health-related beliefs and experiences of Gypsies and Travellers: a qualitative study. *Journal of Epidemiology and Community Health*. 61, 205–210.

Weiss, M., 1997. Signifying the pandemics: metaphors of AIDS, cancer, and heart disease. *Med. Anthropol. Q. (New Series)* 11, 456-76.

Welsh Government, 2015. Travelling to Better Health. Policy Implementation Guidance for Healthcare Practitioners on working effectively with Gypsies and Travellers. Available from: <http://gov.wales/docs/dhss/publications/150730guidanceen.pdf> [Accessed 22 August 2017].

