**Humber & North Yorkshire Health Equity Fellowship**

***Develop an understanding of the range of beliefs and behaviours towards cancer prevention, screening and treatment within the GRT community.***

Introduction

This project was inspired by the need to develop an approach to engaging with inclusion health groups about cancer preventative behaviours and experience of care in the Humber and North Yorkshire (HNY) region for the HNY Cancer Alliance. In my role as Lead for Health Inequalities, I was tasked with steering the Alliance's Core20PLUS strategy to develop culturally sensitive and effective approaches to reducing the incidence of late-stage cancer diagnoses in inclusion health groups and areas of deprivation. The HNY region has a number of GRT camps and communities across its geography, and at the stage of the project development, there had been very few attempts to engage with them. Early research in the work had identified the work of Professor Louise Condon at Swansea University in exploring the health needs and service use of Gypsy, Roma and Travellers, which was inspirational is shaping the focus of the project.

Members of Gypsy, Roma and Traveller (GRT) communities have the worst outcomes of any ethnic group in education, health, employment, criminal justice and hate crime in the UK (Condon Knowledge) Their outcomes in health are significantly poorer than for other members of the population, both in the UK and across Europe, with average life expectancy considerably shorter, around 10 years, less than their peers. There are around 6 million Roma people living in the European Union, making them the largest ethnic minority in Europe. The 2021 census showed approximately 100,000 Roma people living in the UK, although the actual figure is likely to be higher than this due to under-declaration and poor engagement with the survey.

There are many factors that contribute to poorer health outcomes for members of the GRT community. They have experienced longstanding exclusion and prejudice that has impacted their ability to find safe housing, access to amenities, employment, health services and education. As a result, families experience high levels of social and geographical isolation, poverty, low levels of literacy and poor access to information and digital services. Cancer, cardiovascular disease and suicide are major causes of early death in these communities.

A qualitative study by the Office for National Statistics exploring the lived experience of Gypsy and Traveller communities relating to health issues found behaviours in delaying seeking health care and perceived barriers to healthcare. It described challenges to registering with a GP surgery without a fixed address, particularly those who lived roadside, and not being able to receive postal communications to site locations. It also described perceived discrimination and derogatory attitudes of healthcare providers; superstition that mentioning ill health or seeking healthcare could worsen the condition and community members only really accessing help when they were unwell rather than take any preventative measures. Literacy barriers were also identified, acting as a barrier to engaging with health services as well as the increasing use of computer and online services for those without access to the internet.

Historically, GRT communities have had a rich tradition of folklore that has passed stories and beliefs verbally through the generations of the community, and this has included guidance around health and disease. Traditionally, there have been strong cultural beliefs within the community about ill health, especially cancer, which is regarded as a taboo subject, with a refusal to name the disease or even talk about it in case the discussion brought bad luck. It is known variously as 'the bad thing' or 'kuva'.

There has been little in-depth study into the GRT community's knowledge of cancer preventative behaviour or their views and engagement with cancer screening programmes, such as the Cervical Screening programme. There is also very little insight into their experiences of cancer care. More recently, and particularly after the COVID-19 pandemic highlighted the huge disparity in health outcomes for inclusion health groups, there have been more studies to understand health beliefs and behaviours of the GRT community. These have identified multiple phenomena that could affect health outcomes, including a lack of trust in health professionals, a level of fatalism in regard to disease, a lack of understanding of medical terminology, feelings of shame and embarrassment and a tendency to seek health advice and guidance from community elders, thus allowing the continuation of harmful beliefs.

A study into the health beliefs and experiences of Gypsies and Travellers undertaken in 2006 by Patrice Van Cleemput found an exceptionally strong and specific aversion to discussing cancer, describing a focus group that showed a reduction in participation when cancer was mentioned, a group that became 'uneasily silent'. Beliefs about cancer in the group were fatalistic, with low expectations of health, and a tendency to self-reliance in ill-health to stay in control. The study identified that fears around death and dying were strongly associated with a dread of a diagnosis of cancer, which was seen as an inevitable death sentence, by most respondents, so people avoided the possibility of hearing that diagnosis.

However, more recent research by Professor Louise Condon’s team at Swansea University into cancer beliefs and behaviour in the South Wales Gypsy and Traveller communities has found a significant shift in cultural beliefs and understanding of the disease. The team found that women and men in the community were aware of lifestyle factors that contributed to a reduced cancer risk, such as a healthy diet, stopping smoking and drinking less alcohol. In addition, they identified members of the community demonstrating an understanding that if the disease is diagnosed early it can be treated effectively; a shift in the fatalistic view of cancer as a death sentence and a recognition that some cultural beliefs were old-fashioned and out of date.

Condon's work further identified that younger people might be more likely to attend cancer screening, with almost all the women in one study having accessed cervical screening and some breast screening. Research by Jackson et al also reported changing attitudes among younger Travellers who have had more contact with health professionals in their lives.

Current work by the national Gypsy/Traveller charity, Friends, Families and Travellers also suggests a shift in the of view of cancer in some parts of the community. The charity undertook a series of focus groups and interviews within the community to develop a series of new information guides for health professionals and peers that are culturally sensitive and give clear insight into the barriers the community has identified in accessing services. These include fear, prioritising others' health needs before their own, access to primary care, literacy and digital literacy, and the practicalities of screenings, such as whether it would be done by a man.

The desk research for this project also identified that attitudes and beliefs around cancer, and the barriers to participation differed between Roma and Gypsy/Traveller groups, and within smaller communities in each group. Roma people from Eastern Europe are familiar with health-screening programmes, are more likely to have participated in them in their country of origin, and are more likely to return there for screening, rather than engaging in programmes in the UK, which are confusing and considered to be less comprehensive and effective.

Methodology

As there had been little engagement between the GRT community and the HNY Cancer Alliance prior to this project, little was known about how and where members of the community lived; their liaison with the wider community including health services and the local authority. As the desk research had identified a distrust of people the community regarded as 'official' and an unwillingness to engage with those unknown and untrusted, I was aware that my approach to this needed to be sensitive and careful in order to be seen as a trusted and reliable resource.

My initial plan for this project was to access GRT communities via existing trusted routes that were yet to be determined, and to undertake a series of informal discussions directly with the community about cancer and uptake of cancer screening. I began working with my stakeholder network to scope those who had experience of liaison with GRT communities. My Population Health Fellowship mentor was able to direct me to a current large-scale study by North Yorkshire Council into the GRT community within its geography and I joined the working group for this.

Shortly after the commencement of the project, the HNY Cancer Alliance commissioned the University of York St John and Healthwatch to jointly undertake a large-scale region-wide cancer awareness measure survey focusing on areas of deprivation and inclusion health groups. This work was to include surveying members of the GRT community. In addition, at around the same time, the HNY Cancer Alliance Innovation Grant scheme awarded the Herriot Hospice in Thirsk funding to run specific cancer clinics aimed at the Gypsy/Traveller community in North Yorkshire.

I was sensitive to overloading the GRT community with an increased scrutiny and inspection of their cancer beliefs and was conscious that the Cancer Alliance was at the beginning stage of developing a relationship that needed to be sustainable, useful and trusted. At the same time, early entreaties within the Roma community had identified a reluctance to engage with health professionals who asked for a lot of information about the community, but gave little back to them in terms of support and help. To avoid impacting the outcome of the larger cancer awareness survey, I reviewed my approach to the project to reduce my activity in attempting to directly contacting the gypsy and traveller communities and to utilise the network of trusted liaison workers and link in to work that was already underway in local areas.This confined the work of the project to three areas: East Riding, York and North Yorkshire.

Initial work on the project had identified how separate and unconnected the Roma community was from the Gypsy and Traveller communities within the region and this necessitated developing a separate plan to engage with this group.

**Outcomes**

The Roma Community

Engagement with this community was accessed through the Roma liaison service with York City Council, which covers large areas of Yorkshire, beyond the York city boundary, and includes hundreds of members of the Roma community. The majority of Roma people live in permanent brick homes in settled small communities across the region. Traditionally they have a strong religious faith and maintain their community connection through church. The outreach scheme run by York City Council holds several small support groups and larger celebratory events that are attended by members of the community from all across North, West and South Yorkshire.

On my initial contact with the outreach service, there was a degree of hesitancy to engage, which was explained as a response to previous attempts to engage with the community by various different health organisations and 'feeling used' to access information, tick boxes and not have any reciprocal benefit for use of their time or opinion.

Following reassurances that this was the beginning of a long-term reciprocal and supportive relationship to promote health understanding and behaviour in the community, engagement took place through discussion with two separate groups. Conversation was unstructured, and covered themes such as access to GPs, trust in the NHS, cancer screening programmes, knowledge of cancer signs and symptoms, comparison to healthcare systems in country of origin and preference of choice.

The discussions with the Roma groups identified the following:

* Despite the early hesitancy, there was a willingness to engage openly in the discussion about health, GPs and hospital care by all present.
* A willingness to discuss cancer openly. There were no signs of suspicion or reluctance to engage
* A recognition by the community of a shared history of poor discussion of all health matters including cancer within their culture and that this was no longer the case, with modern Roma community members taking a more pro-active approach to their health
* Some confusion and mis-beliefs about the causes of cancer, such as microwave ovens, with a recognition that this had been caused by a lack of reliable information and open discussion in their early life, and the impact of the strong controlling political culture in their country of origin that managed the dissemination of information
* A general lack of knowledge on the signs and symptoms of common cancers
* A lack of faith in the NHS in general compounded by a lack of information about the NHS and specifically the cancer screening programmes,
* A belief that the NHS screening programmes provided a poorer service than that offered in their country of origin, due to the age restrictions and regularity of screening of the NHS system compared to that at home. There was a strong preference in the groups to return to Europe for what was perceived to be a more thorough screening programme that was also available to people at a younger age.

The findings from these discussions demonstrated a modern and open approach by the community towards pro-active healthcare, and a need for access to reliable and trusted information sources to make informed decisions. My findings reflected some of those identified in the work by Michal Kozubik which compared health beliefs within the modern day Roma community to those from an historic study which identified changes in attitudes to illness, and finding that the main factor for those changes was the interaction between the Roma community and the majority population.

Gypsy and Traveller Communities

The large-scale study by North Yorkshire Council focused on gypsy and traveller communities and used trusted partners, including camp site managers in the North Yorkshire area to have general conversations with members of the community which they then analysed for themes. The geography of North Yorkshire is vast, with gypsy/traveller sites based on the coast around Scarborough, and around smaller market towns such as Malton, Thirsk, Northallerton and Selby. The findings from this mirror some of the themes that had already been identified through the desk research such as difficulty in accessing GPs, the cultural and family norms that influenced behaviour, and a strong preference for known and trusted clinicians.

However, there was some evidence from the study that there had been a shift from the old cultural mores around attitudes to healthcare to a more modern approach. Discussion with the communities suggested that poorer health outcomes were created from issues in accessing health care services rather than a specific decision not to engage with them. On some sites, long-term residents were registered with GPs and had engaged in preventative vaccination around COVID. The study found that access to information and contact with members of the community was compounded by digital access issues. Most mobile phones were not smart phones, which limited internet access, and limited transport access meant that often women were left without transport on remote sites during the day making attending healthcare appointments difficult.

Whilst the Cancer Awareness Measure survey is still evaluating its findings, the Healthwatch team who undertook the field survey were able to feed back to me about their engagement with Gypsy and Traveller camps. They had focused their research into this community in the North Lincolnshire area, which is part of the HNY geography and visited sites personally to hold general conversations to gauge understanding about signs and symptoms of common cancers. Despite being known by the communities and having previous engagement with them, the Healthwatch team reported difficulty in engaging with the community to discuss cancer. On one site in North Lincolnshire a member of the community had successfully recovered from breast cancer and the team found a more open discussion here around attendance at screening programmes, and an open discussion, about cancer, particularly from the survivor.

The clinic established by Herriot Hospice was specifically for members of the Gypsy and Traveller community with a cancer diagnosis to support breathlessness, which can be a common and distressing symptom of the disease. The hospice team were aware that there were members of the community with a diagnosis in their area who were experiencing discomfort and their aim was to provide relief, reassurance and guidance in managing and coping with the symptoms. However, to date, they have been unable to recruit members to attend the clinic at the hospice, and the team are now working with site managers on how to provide the support in a way that is more acceptable to the community.

Engagement with York City Council GRT liaison service took place early in the project, which successfully led to the Roma outreach service and also to the Gypsy/Traveller site liaison support team. Early advice from the team was that relations between the council and the community could be complex at that time and access to the community should be made through the York Travellers Trust. An approach was made to the leader of the Trust for advice on how to approach the subject with the community. I was given strong advice from the leader of the community that discussions on the subject of cancer would not be possible, that the disease was still viewed as a taboo by many in the community and it would cause distress and upset. Further discussions with the leader of the community have continued through the course of this project to look at ways that access to screening services could be promoted, but to date there is no further progress to access the community in the York area through this route.

An additional, more informal, attempt was made to access members of the Gypsy/Traveller community in York through a known and respected boxing gym, that is heavily used by men and women from the community. The owner of the gym, who is known and respected by the community, and who is also a trained trauma counsellor, approached a community leader who was a friend to gauge their opinion about how to approach opening up discussion about cancer. He was advised that the disease is still a taboo subject that is not openly discussed and no progress would be made. No further progress has been made to understand the York community's beliefs around cancer.

Progress in understanding the view of the Gypsy and Traveller communities in East Riding changed significantly on the return to work of a local authority key worker from extended sick leave. This key worker had a significant number of years of experience working with the three traveller sites in East Yorkshire and had a wealth of knowledge and experience about the different communities. The initial advice was that each community was culturally very different, due to the state of settlement on each site, the living conditions and relationships with local health system, and that a separate plan to engage with each site was necessary.

The two sites based at Cottingham were fairly settled, with the same families having stayed there for a number of years. They were registered with a GP, attended hospital and screening appointments and were open to and interested in discussions around health and wellbeing. Members of the community had cancer diagnoses in the past, and a current member was undergoing treatment for breast cancer. As the lung health screening team were keen to include the community in the screening in the locality, it was arranged for them to visit the site to gauge interest and undertake initial engagement about the screening process. Plans are in place for dialogue about cancer screening with the communities in Cottingham, a roll-out to the Bridlington site and partnership with the East Riding public health vehicle that visits the sites on a monthly basis.

Recommendations

The experience of undertaking the project was equally challenging and rewarding. The significant findings were that there was such a broad range of views within the GRT community towards cancer.

The views of the Roma community were, on the whole, more modern and realistic, and poor engagement was more likely to be around accessibility and lack of faith in the service rather than a refusal to engage. The need for this community seemed to be more information about services, more information about risk factors and proactive health actions to reduce the risks.

The range of views within the Gypsy/Traveller community was most surprising to me and originates from my lack of understanding of the different communities, and their interactions across the region. The strong advice from the East Riding liaison team to view each community as a separate entity, that has been shaped by the people who live there and the environment they live in was particularly useful and will be adopted into the HNY CA Health Inequalities strategy moving forward.

The original aim of the project was to develop an understanding of the range of beliefs and behaviours towards cancer prevention, screening and treatment within the GRT community to help devise a strategy to improving cancer knowledge, uptake of screening, and ultimately, early cancer diagnosis rates. Despite the challenges of accessing the community, the project work has identified that there is a huge variation in the range of beliefs and that a culturally sensitive and tailored approach is required to engage with this community across the region. The development of the strategy will include factors that have been identified through the work of the project, namely:

* Continued engagement with the Roma community to provide information about cancer signs and symptoms and NHS Screening Programmes
* Provide cultural competence training for NHS cancer colleagues to enhance empathy by raising awareness of various GRT groups and their diverse history.
* Provide information to the communities for them to manage their own health needs
* Co-produce accessible information, such as short videos, featuring trusted members of the community or step-by-step guides
* Develop and nurture ongoing relationships with trusted liaison officers within local authorities
* Promote a Making Every Contact Count approach for the HNY CA programmes of work, and with key stakeholders in the health system, such as the NHS Screening Programmes
* Develop an individual approach to each separate community based on its cultural beliefs, behaviours and health literacy needs
* Allow for time and effort to develop relationships

J Walker

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