Service Mapping for Communicable Disease Inclusion Health Programme: Gypsy and Traveller Communities in Wales

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Executive Summary

Gypsy, Roma and Traveller communities experience some of the poorest health outcomes and severe health inequalities among any population in the UK. This mapping exercise considered the existing services available to these communities in regard to communicable disease transmission. It also explored the healthcare experiences of these communities in order to inform service development and optimisation moving forward.

Mapping consisted of two activities: i) Gypsies and Travellers Wales (GTW) consulted with organisational advisors and other relevant networks to generate a map of services currently used by Gypsy and Traveller communities in South Wales ii) a brief scoping review of the evidence-base was conducted to establish the potential effectiveness of services, proposed examples of best practice, and barriers and facilitators to service delivery and receipt.

Consultation identified a significant lack of services tailored specific to the needs of Gypsy and Traveller communities in Wales. The most commonly used healthcare provider is General Practitioners (GPs). Both the consultation and review identified a range of barriers to the uptake of services. These included: the stigma related to negative stereotypes among health professionals; variable access to services, notably where communities may travel for prolonged periods of time; lack of suitability of language and literacy, especially given that they may be a tradition of oral communication; insufficient cultural humility, such as lack of recognition that some health areas may not be open for discussion; and inadequate resources. There are useful suggestions from the evidence-base on what types of approaches may be help in engaging these communities. These can include offering trusted individuals, hand-held personal health records, professionals trained in cultural humility and multi-agency working.

In terms of the development and optimisation of future service provision, four recommendations were identified. First, there is a paucity of healthcare data for Gypsy, Roma and Traveller communities in Wales, and this needs to be strengthened to

support understanding of the health needs, risk profiles and outcomes in this population in Wales. Second, communities identify GPs as the preferred healthcare provider and they may be further supported in meeting culturally specified needs. Third, newly tailored services do need to be developed, and these should be co-produced with the communities they intend to engage. Fourth, Welsh Government and Public Health Wales should consistently and systematically attend to the needs of Gypsy, Roma and Traveller communities across all health areas. This includes addressing the systematic drivers of poor health, such as housing, and ensuring that appropriate services are being delivered.

1. Gypsy and Traveller Communities in Wales

1.1. Definition of Gypsy and Traveller Communities

Gypsy, Roma and Traveller communities are defined by the Department for Levelling Up, Housing and Communities (previously Department for Communities and Local Government) as:

> *Persons of nomadic habit of life whatever their race or origin, including such persons who on grounds only of their own or their family's or dependants' educational or health needs or old age have ceased to travel temporarily, but excluding members of an organised group of travelling show people or circus people travelling together as such (Department for Communities and Local Government, 2015).*

They encompass diverse ethnic groups. In the UK, this can include:

- Gypsies (including English Gypsies, Scottish Gypsies or Travellers, Welsh Gypsies and other Romany people);
- Irish Travellers, who have specific Irish roots;
- Roma (Race Disparity Unit, 2022).

While Gypsy and Traveller communities are distinct from the Roma population, with the latter being more recent migrants from Central and Eastern Europe, they are occasionally classified in the same ethnic category by government data collection, policy and practice. This is often due to shared experiences of social, educational, health and economic disadvantage.

The 2011 Census for England and Wales included 'Gypsy or Irish Traveller' as an ethnic group option for the first time, while those who identified as Roma were allocated to the White Other category. In 2021 the Census included a 'Gypsy or Irish Traveller' category and a new 'Roma' category. Meanwhile, data from the UK Department of Education has tended to combine data from the Gypsy and Irish Traveller category and the Roma category (Race Disparity Unit, 2022).

1.2. Size and Socio-demographic Profile of Gypsy and Traveller Communities in Wales

While analysis of the 2021 Census data is still in progress by the Office for National Statistics, the first phase of data has been released, with the remaining two phases expected to be published by mid 2023.

In 2021, 67,768 (0.1% of population) of Census respondents identified as Gypsy and Traveller in England and Wales, increasing from 57,680 in 2011 (0.1% of population) (Office for National Statistics, 2022). A total of 100,981 (0.2%) identified as Roma, with no data availability for 2011 (Office for National Statistics, 2022). Additional detailed analysis by, and within country, is provided by write-in responses from the 2011 census. In total 52,333 individuals identified as Gypsy or Irish Traveller in England. In Wales this figure stood at 2,629. Further categories for Wales were: Traveller (n=42); Irish Traveller (n=3); Gypsy/Romany (n=111); and Roma (n=182) (Office for National Statistics, 2018).

Data on age profiles from the 2011 Census indicated that people under the age of 18 years made up over a third (36%) of the Gypsy and Traveller population in England and Wales, which is higher than the national average of 21%. Meanwhile, 18% are aged 50 years and older, which is lower than the national average of 35% (Race Disparity Unit, 2022).

1.3. Location of Gypsy and Traveller Communities in Wales

The 2021 Census reports the geographical spread of Gypsy, Roma and Traveller communities across Wales. The highest proportion of Gypsy and Travellers is in Pembrokeshire, where they account for 0.4% of the population. This is followed by: Torfaen (0.3%); Blaenau Gwent (0.2%); Carmarthenshire (0.2%); and Cardiff (0.2%) (Office for National Statistics, 2022). In contrast, Roma communities tend to be primarily located in Cardiff (0.2%) and Newport (0.2%) (Office for National Statistics, 2022).

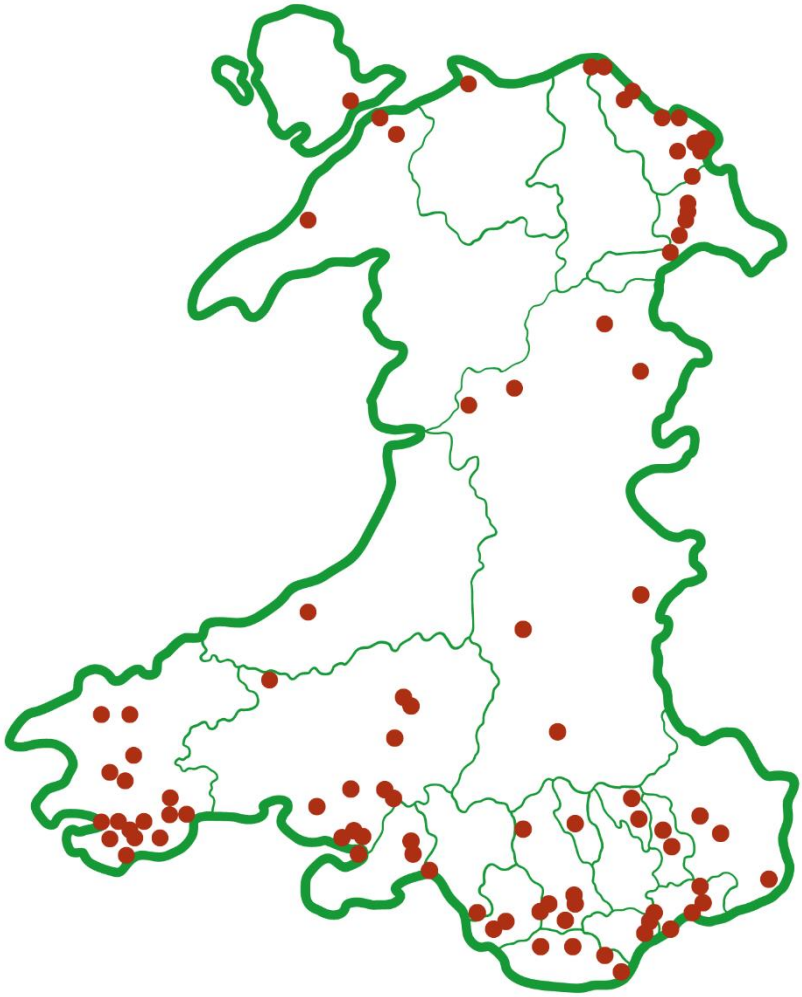
The Welsh Government conducts an annual Caravan Count in Wales to identify the number of Gypsy and Traveller caravans and sites (Welsh Government, 2022). On 21 July 2022, there were 1,166 Gypsy and Traveller caravans and 168 sites reported in

Wales. Between July 2021 and July 2022, the total number of Gypsy and Traveller caravans increased by 6% (71 caravans) and the total number of sites (both authorised and unauthorised) increased by 17% (25 sites).

In 2022 there were 912 caravans on authorised sites with planning permission, which accounted for 78% of all caravans. Of these, 598 (66%) were on socially rented sites and 314 (34%) were on privately funded sites. The highest number of caravans were in Cardiff, Flintshire, Pembrokeshire and Neath Port Talbot. There were 87 caravans (7%) on unauthorised sites on land owned by Gypsies and Travellers. There were 167 caravans (14%) on unauthorised sites on land not owned by Gypsies and Travellers. Newport had the highest number of caravans on unauthorised sites, while Denbighshire saw the largest increase in caravans on unauthorised sites since 2021.

There was a total of 409 pitches on Gypsy and Traveller sites provided by Local Authorities in Wales in 2022. Cardiff, Pembrokeshire and Neath Port Talbot had the highest number of pitches provided by Local Authorities, accounting for more than half of the total number (54%). At the time of reporting, 97% of residential pitches were occupied. A map indicating the location of sites is presented in Figure 1 (Gypsy & Traveller Wales, 2019).

Figure 1. Distribution and Location of Gypsy and Traveller Sites in Wales (Gypsy & Traveller Wales, 2019)



2. Health Profile and Needs of Gypsy and Traveller Communities in Wales

2.1. Health Profile of Gypsy and Traveller Communities

Gypsy, Roma and Traveller communities experience some of the poorest health outcomes and severe health inequalities among any population in the UK (House of Commons & Equalities, 2019). Data from the 2011 Census found that in England and Wales, Gypsies and Irish Travellers had the lowest proportion of respondents rating their general health as ‘good’ or ‘very good’ (70%) compared to the overall population (81%) (Cook et al., 2013; Office for National Statistics, 2014). These communities live between five and 25 years less than the wider UK population, and experience up to six less Quality Adjusted Life Years (i.e. years lived in good health) (European Commission, 2019; Parry et al., 2007).

Adverse health outcomes in these populations tend to cluster around non-communicable diseases and mental health. These include chest pain, respiratory problems, arthritis, anxiety and depression, and miscarriage (Parry et al., 2007). Evidence for the Roma community between 2005 and 2012 found that 60% had poor physical health including cancer, diabetes, epilepsy, hepatitis B, cardiovascular and respiratory alignments, and multiple sclerosis. Meanwhile 43% were suffering from mental health problems including depression, personality disorders, learning disabilities, suicidal tendencies, self-abuse, dependency/misuse of drugs (European Commission, 2019). However, Wales-based data shows no elevated risk of self-harm or common mental disorders (Rees et al., 2023).

There is more limited data in relation to communicable diseases. Indeed, evidence tends to centre on the experience of health provision in relation to vaccination programmes. A small number of mainly qualitative studies have considered vaccine hesitancy (notably for the COVID-19 vaccination) and low levels of uptake among these communities (Sides et al., 2022). This may increase the risk of disease contraction, but this is currently insufficient evidence to support this assertion in the UK context.

2.2. Determinants of Health among Gypsy and Traveller Communities

The adoption of compensatory unhealthy behaviours in the Gypsy, Roma and Traveller communities, and the prevalence of poor health, has often been explained by the loss of the health protecting features of traditional ways of life and the experience of living with daily hardship (Peter & et al., 2020; Ruston & Smith, 2013). There challenges are situated within a wider system of social, cultural and economic health determinants (Marley, 2016).

2.2.1. Housing

Official (and unauthorised) sites for Gypsy and Travellers are often reported to be in marginalised, inhospitable places, that are frequently unsafe, unsanitary and polluted (Greenfields & Brindley, 2016; Millan & Smith, 2019; Peter & et al., 2020; Ruston & Smith, 2013). While inadequate provision may be a risk for adults, it is also a key issue for children. According to the 2011 Census, Gypsy or Traveller households are more likely to be made up of lone parents with dependent children (20.4%) compared to the national average for England and Wales (7.2%). In total, 44.9% of Gypsy or Traveller households have dependent children (Race Disparity Unit, 2022).

A central issue for these communities is the tension between nomadic and sedentary lifestyles. There is suggestion that the sendentarisation of living is not health promoting (Ruston & Smith, 2013), as it can cause feelings of isolation, claustrophobia, depression and other adverse impacts on mental health (Greenfields & Brindley, 2016; Millan & Smith, 2019). This can be a particular issue for disabled people who are Gypsy, Roma or Traveller (Peter et al., 2020). Equally, it can lead to the dilution of cultural networks and the dissolution of social capital (Smith & Ruston, 2013). In contrast, nomadic lifestyles can mean that individuals miss essential healthcare services (Millan & Smith, 2019).

2.2.2. Education

Gypsy, Roma and Traveller communities tend to experience the highest rates of educational disadvantage across the life course. In the 2018-2019 school year, 19% of White Gypsy or Roma pupils, and 26% of Irish Traveller pupils in England, met the

expect standard in Key Stage 2 reading, writing and maths for 7-11 year olds (Race Disparity Unit, 2022). This was the lowest recorded achievement level for all ethnic groups. In the 2019-2020 school year, 8.1% of White Gypsy or Roma pupils in England got a grade 5 or above in GCSE English and maths, which is the lowest percentage of all ethnic groups. This disadvantage tracks through to further education. Gypsy or Roma (58%) and Irish Traveller (59%) pupils were the least likely to stay in education after GCSEs (or equivalent qualifications) and were least likely to get 3 A grades at A-Level. In total 10.8% of Gypsy and Roma students and 20% of Traveller students achieved 3 A grade, compared to the national average of 28.9% (Race Disparity Unit, 2022). It should be noted that available data is primarily for England and grades were awarded according to the alternative assessment process during the COVID-19 pandemic, which saw higher attainment levels than what be expected in a typical year.

Both Gypsy or Roma pupils, and Irish Traveller pupils, have the highest rates of school suspension, permanent exclusion, overall absence and persistent absence (Race Disparity Unit, 2022).

2.2.3. Employment

According to the 2011 Census, Gypsies and Irish Travellers are reported to have the lowest employment rates and highest levels of economic inactivity. They are also the group most likely to be self-employed, although it is stated that Government legislation has made it difficult for community members to follow ‘traditional’ trades (European Commission, 2019). Meanwhile, the migrant Roma community are often low paid, in receipt of zero hours contracts, agency based and in factory-based environments. This means they often have inconsistent working hours and income, and are considered to be particularly vulnerable to modern day slavery (European Commission, 2019)

2.3. Data Availability of Health Profiles for Gypsy and Traveller Communities in Wales

Data availability for Gypsy, Roma and Traveller community health is limited in the UK, especially in Wales. Data for both countries is often combined, as with some Census data, or is only available for England. However, recently published data from Swansea University's SAIL Databank has indicated the potential for understanding the health profile and needs of this population in Wales (Rees et al., 2023). The study used Welsh Government provided Traveller site postcodes included in the Caravan Counts between 2012 and 2020. Using spatial filtering with data from the Adolescent Mental Health Data Platform (ADP) the study created a cohort of Traveller site residents aged 11–25 years old, 2010–2019. ADP algorithms described health service use, and estimated incidence and prevalence of common mental disorders (CMD) and self-harm. Data from young Gypsies and Travellers (n = 802) found no difference in rates of common mental health disorders (CMD) and self-harm when compared to the general population. However, there were higher rates of non-attendance for psychiatric outpatient follow-up appointments. There will also differences in emergency department attendance and prescribed CMB medication without follow-up, suggesting less well-managed care.

3. Policies: Communicable Diseases in Gypsy and Traveller Communities

3.1. UK Government Policies

While specific health and equalities policies acknowledge the inequalities faced by Gypsies and Travellers and make recommendations, there is no oversight or leadership responsible for implementing measurable and lasting change (House of Commons 2019). T

3.1.1. UK Government Policy Response During COVID-19 Pandemic

UK Government policy responses to the COVID-19 pandemic have been criticised for a lack of tailored support for Gypsy, Roma and Traveller communities. There were reported issues around appropriate communication and inadequate consideration that these groups are more likely to be digitally excluded (Public Services Committee, 2020; Stevens et al., 2021).

4. Map of Health Services Gypsy and Traveller Communities

4.1. Health Service Map Methodology

Gypsies and Travellers Wales (GTW) consulted with organisational advisors to generate a map of services currently used by Gypsy and Traveller communities in South Wales. Other contacts across Wales were consulted. GTW also consulted networked organisations across the UK, to build a picture of healthcare provision across the nations.

GTW decided not to directly consult with the Gypsy and Traveller communities to generate the map due to concerns about overburdening them. However, further work to optimise and develop new services could be done in close consultation with these communities.

4.2. Services for Gypsy and Traveller Communities in Wales: Communicable Diseases

No statutory or voluntary health services were found in Wales, with the purpose of providing targeted health care or resources to Gypsy and Traveller populations in relation to communicable diseases. Regarding health conditions such as tuberculosis, Gypsies and Travellers would usually attend their GP practice with presenting symptoms and would attend hospital if a referral was made and supported by appropriate acknowledgment of literacy and communication needs.

There are further complications around accessing services providing treatment and prevention of Sexually Transmitted Infections (STIs). Gypsies and Travellers have a cultural preference to speak to medical professionals of the same gender and often will not engage at all with medics of a different gender. Sexual Health is considered taboo, so discussion around these areas may be avoided and testing or screening may be neglected for the sake of privacy.

4.3. Services for Gypsy and Traveller Communities in Wales: General Healthcare Services

Welfare advisors working with Gypsy and Traveller communities in South Wales reported that the majority of their clients were accommodated on permanent sites and as such were registered with a General Practitioner (GP). Relationship-building seemed to be the most important element of continuity of care, so Gypsies and Travellers will build relationships of trust with doctors at GP practices and attend those practices for all medical concerns. Outside of this provision, the other medical professionals empowered to build such relationships are Health Visitors. These relationships develop over time, whereas generally Gypsies and Travellers are reluctant to approach unknown services and practitioners.

Before the Covid-19 pandemic, welfare advisors for Gypsies and Travellers would often accompany clients to GP appointments. This support was required in order to keep records of what was said in appointments and to have trusted advisors explain the complex medical language and extensive vocabulary of medical practitioners after each appointment. However, even since the relaxing of guidelines to prevent the spread of Covid-19, Gypsies and Travellers are less likely to be allowed to invite a third party to GP appointments. Therefore, advisors are no longer mediating medical appointments and many Gypsy and Traveller families are misinformed and may misunderstand or mistrust offered treatment and care.

Due to a lack of digital literacy and widespread preferences against mediated communication (including online and telephone appointments and email communications), Gypsies and Travellers tend to prefer face-to-face GP appointments, which have decreased in availability since the pandemic began. Therefore, Gypsy and Traveller families can struggle to obtain convenient appointments. Where this is the case, Gypsies and Travellers were found to attend their local accident and emergency (A&E) hospital department. It is reported that these communities have historically relied heavily on A&E services as a first port of call. This is especially the case for those who

live roadside, do not have a permanent address and may come to expect barriers to accessing GP services.

4.4. Services for Gypsy and Traveller Communities in Wales: Non-healthcare Services

Communities draw upon a range of services that are not explicitly healthcare, but can be used to support health. Roma communities tend to rely heavily on local traveller education services. In Newport, Gwent Education Minority Ethnic Service (GEMS) has become key to health, welfare, education and other advisory areas as they support learners from Roma families with bilingual teaching assistants. Therefore, where schools have interpreters speaking certain Romanian dialects, health facilities do not, so education support services can become the focus for wider issues in the Roma community.

4.5. Services for Gypsy and Traveller Communities in UK

Outside Wales, there is limited evidence for services targeting communicable diseases among Gypsy and Traveller populations. While research is being conducted in Inclusion Health categories generally, and with measures taken to investigate health care and health outcomes for Gypsies and Travellers under this umbrella, targeted service provision is minimal.

This is also the case for general healthcare provision. In areas where there are large populations of Gypsies and Travellers, the service provision doesn’t seem to improve, with GP surgeries and A&E departments continuing to be the primary resource for Gypsies and Travellers on permanent sites. Those living roadside across the UK are even more likely to attend the nearest A&E, because of perception or lived experience of barriers to GP services.

Some regional provision is highlighted by organisations working with Gypsies and Travellers. For example, Friends, Families, Travellers (FFT) is based in Sussex and as

such has commissioned reports, made suggestions and outlined best practice for provision of services to those communities it represents (see Atterbury 2010).

5. Evidence for Health Services for Gypsy and Traveller Communities

A brief scoping review of the evidence-base was conducted to establish the potential effectiveness of services, proposed examples of best practice, and barriers and facilitators to service delivery and receipt. Searches were conducted in four bibliographic databases from a range of disciplines: OVID Medline in Progress; PsycInfo; Scopus; and Social Policy and Practice. They were undertaken January-February 2023. Search terms were tailored to the functionality of each database, with a combination of: population (gyps* OR travel*er OR roma); intervention (interven* OR polic* OR provision OR program* OR service*); and outcome (health). No restriction was placed on language, but a filter was included to retrieve studies published since 2013. The inclusion criteria were set to include primary studies conducted in the UK and systematic reviews of the international evidence-base that included studies from the UK or were relevant to the UK. Eligible evidence included both a focus on communicable diseases and general health-based studies (e.g., barriers to accessing General Practitioner (GP) surgeries), with the latter offering wider learning.

A total of 1373 study reports were retrieved, and following de-duplication, 1039 study reports were considered for inclusion. The title and abstract of each report were screened, followed by the screening of full text where relevant (RE). Thirty-two eligible studies reported primary data from the UK context or were relevant reviews. Key findings from the studies are narratively summarised below.

5.1. Barriers to Delivery and Receipt of Services

There were a number of reported barriers to delivering and receiving healthcare provision. Studies tended to report on generic health services. Where they focused on communicable diseases, this is specified.

5.1.1. Access

One of the most commonly reported barriers was the challenge of registering with health services, particularly primary care (Jackson et al., 2016; McFadden et al., 2018;

Ruston & Smith, 2013; Sweeney & Stanbury, 2019). For those who were actively living a nomadic lifestyle, this was often a consequence of GP surgeries being unwilling to register new patients without proof of a fixed address or other necessary documentation to fulfil the legal conditions for service use (McFadden et al., 2018; Ruston & Smith, 2013; Sweeney & Stanbury, 2019). This was a notable issue for vaccine uptake (Wilder-Smith & Qureshi, 2020). Without a permanent doctor, health papers (or patient notes) often did not follow the individual, so they did not have continuity of care (Ruston & Smith, 2013). One study suggested that government legislation making unauthorized camping a criminal offence and allowing faster evictions had a detrimental impact on the ability to access immunization (Newton & Smith, 2017).

5.1.2. Health Literacy, Information and Communication

Gypsy, Roma and Traveller communities often do not receive the requisite knowledge to access and navigate health services, particularly in regard to dental, mental health, vaccinations, and sexual and reproductive health services (McFadden et al., 2018) (Jackson et al., 2016) . This was particularly true for a large measles outbreak in England (Bell, Saliba, Ramsay, et al., 2020). Where individuals had nomadic lifestyles, they often did not know where to locate local clinics, which could reduce the uptake of children's immunization (Newton & Smith, 2017; Wilder-Smith & Qureshi, 2020).

There are central issues around literacy and language. Some individuals reported not being able to read appointment letters and so missed appointments (Ruston & Smith, 2013). This was explained by predominantly oral traditions within the communities (Mytton et al., 2021). Digital literacy was a related concern, where the need to use information technology (such as making or checking-in for appointment) could be alienating and embarrassing (Stevens et al., 2021; Sweeney & Stanbury, 2019). There was a preference for in-person communication, as traditionally used through social networks (Smith & Ruston, 2013). Potentially as a consequence of these challenges, one study including Irish Travellers, found that leaflets and website addresses for additional information were not useful, and that personalised information would be preferable (Ryan et al., 2017).

Further barriers related to the medical jargon used by medical professionals (McFadden et al., 2018; Peter & et al., 2020), and in one UK based survey over one third of respondents reported that they found information from their GP difficult to understand (Sweeney & Stanbury, 2019). Medication instructions could also be difficult to follow (McFadden et al., 2018). Some individuals suggested a need for colour-coded medicines for those who did not read (Ryan et al., 2017).

A small number of studies addressed knowledge and information in relation to vaccinations. There was limited knowledge of some viral diseases, such as hepatitis B and C (Sweeney et al., 2015). In the context of the COVID-19 vaccination roll-out, there were concerns about the lack of information about vaccine safety and efficacy, which was combined with mistrust in government advice and recommendations (Sides et al., 2022). There were similar information issues around the MMR vaccine, where uptake was linked to understanding of the problem and risk. For example, some felt the risk was situational (e.g. contracted at annual events such as horse fairs) and would arrange child immunization accordingly (Newton & Smith, 2017). Equally, there were concerns of adverse risks such as autism (Mytton et al., 2021). Some individuals also felt it would be beneficial to take doses individually and when children were older (Ellis et al., 2020; Jackson et al., 2016; Newton & Smith, 2017). The density of social capital within these communities meant that negative perceptions could quickly be disseminated through community networks (Mytton et al., 2021; Smith & Ruston, 2013).

5.1.3. Stigma, Stereotypes and Discrimination

It is widely reported that Gypsy, Roma and Traveller communities feel that they are negatively perceived by health care practitioners, and are not treated fairly (Francis, 2013; Heaslip et al., 2016; Jackson et al., 2016; Marsh, 2017; McFadden et al., 2018; Mytton et al., 2021; Ruston & Smith, 2013; Sweeney & Stanbury, 2019). Discriminatory attitudes and practices, at both the individual and institutional level, were seen to be influenced by negative media stereotypes (Francis, 2013). Indeed, there was suggestion that anti-Gypsy prejudice in the UK is the last acceptable form of racism (The Traveller, 2017). Harmful beliefs about these communities include one that a nomadic lifestyle is a choice, and that communities could live a sedentary lifestyle that

would facilitate easier service access. However, qualitative research has clearly established that the ability to travel offers a sense of psychological and physical freedom, and is an integral part of the identity of being part of a Gypsy, Roma or Traveller (Heaslip et al., 2016). There were also concerns about the lack of healthcare choice available, and that treatment is withheld (e.g. antibiotics) (Ruston & Smith, 2013).

Such experiences could lead to a reticence to engage with services. This process has been termed 'usurpationary' social closure, which involves a social group's closure in response to their outsider status and collective experience of exclusion (Smith & Ruston, 2013). There were also a sense of powerlessness, where individuals felt they had no choice but to accept discriminatory health provision (Heaslip et al., 2016). However, it should be noted that not all Gypsy, Roma and Traveller communities felt they had been discriminated against (Millan & Smith, 2019).

5.1.4. Trusting Relationship with Health Provider

Studies centralised the importance of continued care pathways and having a trusting relationship with a health professional (Doughty et al., 2016). Irish Travellers maintained that seeing the same doctor could increase efficiency and inspire confidence as the doctor would know their medical history (Ryan et al., 2017). For the large part however, there was a lack of faith in the healthcare system, as a result of personal or vicarious previous poor experiences (Bell, Saliba, Ramsay, et al., 2020; Jackson et al., 2016; McFadden et al., 2018; Poppleton et al., 2022). There were also concerns that seeking help for children would lead to social service involvement (Marsh, 2017). However, it should be noted that local doctors were generally trusted and appreciated, with Romani and Traveller families expressing a preference to visit their GP among different healthcare professionals, even in emergency situations (Marsh, 2017). Despite this, there were narratives of surgery receptionists engaging in discriminatory gatekeeping.

Within the context of this mistrust, and linked to cultural norms, individuals often relied on family and community members for decision-making, even if they did not have the

requisite knowledge (Ruston & Smith, 2013; Smith & Ruston, 2013). This was reported for decisions around vaccine uptake (Newton & Smith, 2017).

5.1.5. Cultural Humility

Cultural humility, or what has previously been termed cultural competence, is a central barrier. It can intersect with issues around stigma and discrimination. Health professionals often lacked cultural understanding (Fournet et al., 2018; McFadden et al., 2018; Peter & et al., 2020). Key areas that caused tension included: the number of accompanying or visiting relatives at healthcare settings; the need for professionals to be of the same gender, especially in regard to sexual and reproductive healthcare; some topics being taboo (e.g. mental health and substance use); and specific belief systems around health, palliative care and death that necessitate certain care practices (e.g. cultural narratives of resilience or a sense of 'fatalism') (McFadden et al., 2018; Peter & et al., 2020). In regard to vaccination, there was hesitancy around the HPV vaccine, which vaccinates against sexually transmitted infections, as it could be interpreted as endorsing sexual activity before marriage. Equally, as cancer is rarely discussed within Traveller communities, there was reticent to discuss its role in protecting against cervical cancer (Mytton et al., 2021).

5.1.6. Lack of Resources

Individuals can often lack the financial resources to afford transport to access services or they may not have a phone or other relevant technology to make an appointment (McFadden et al., 2018; Wilder-Smith & Qureshi, 2020). Women in particular found it difficult to gain resources to access services (Newton & Smith, 2017; Wilder-Smith & Qureshi, 2020). There was also fear among some migrant Roma individuals that NHS care would incur a cost (Stevens et al., 2021).

5.2. Recommendations for Best Practice in Service Provision

There is a general lack of evaluations assessing the effectiveness of healthcare provision for Gypsy, Roma and Traveller communities in the UK. This is true for both general healthcare and services targeting communicable diseases. However, in

response to the barriers to delivery and receipt described above, combined with reported service needs, a number of studies and reviews have prescribed possible models for care.

5.2.1. Increase in Vaccination Uptake

Three study reports recommended a model to support Gypsy, Roma and Traveller engagement to improve immunisation uptake (Bell, Saliba, Evans, et al., 2020; Dyson et al., 2020; Jackson et al., 2016). One was developed from a large-scale survey of Gypsy and Travellers in the UK (Jackson et al., 2016)**.** Activities included: communication strategies to educate people on the relative risks of vaccination and not being vaccinated, and countering vaccination myths; cultural competence training for health care professionals; identifying communities in health vaccine records to provide tailored support; effective partnership working and community engagement; a named frontline person in GP surgeries to provide supportive and respectful practice; flexible and diverse systems for booking appointments; and protected funding for specialist health visitors (Bell, Saliba, Evans, et al., 2020; Dyson et al., 2020; Jackson et al., 2016).

5.2.2. Community-Health Partnership and Community Outreach Programmes

Studies reported more widely on models for engaging Gypsy, Roma and Traveller communities in healthcare. One realist review recommended a differentiated community outreach approach, depending on the type of engagement needed (Lhussier et al., 2016). It reported that where the aim is to encourage attendance at one-off events, or where the need has been articulated by the communities themselves, it may not be important to have outreach workers with long established relationship with the community. In contrast, where the aim is to change behaviour or develop social capital within the community, outreach workers will need to build explicit long established and trusting relationships.

Other approaches to commissioning and delivery include: evidence-based and needs based decision-making; provision responding to the risk profile of the problem; offering

‘trusted individuals’ that can engage in ‘bridge-building’; improvement of access; hand-held records for patients; multi-disciplinary agency work with professionals being educated in this approach from the beginning of clinical training; building capacity in the community; and delivering outreach work (McFadden et al., 2018; National Inclusion Health, 2014; Paramjit & et al., 2013).

6. Conclusions

6.1. Overview of Current Services

Currently there is a significant gap in provision, both for communicable diseases and general healthcare, for Traveller, Roma and Gypsy communities in Wales. Previous literature does provide recommendations for best practice in service provision, specific to vaccine uptake and community-based healthcare more broadly.

6.2. Strengths and Limitations of Current Services

The wider literature provides a comprehensive overview of barriers to healthcare provision, which can limit the potential reach and uptake of services. These include: lack of awareness of services, and limited accessibility; limited or inappropriate communication about health appointments and medication; the perpetuation of stigma and negative stereotypes; lack of cultural humility; and lack of resources. Key facilitators of provision include healthcare professionals building trusting relationships with community members. Moreover, Gypsy, Roma and Traveller communities tend to express a preference for GP service providers, and see them as the safest option for seeking treatment.

6.3. Recommendations

There are four key areas of recommendations that might support future planning and provision of healthcare, specifically communicable disease related healthcare, moving forward. These recommendations are based on Gypsies and Travellers Wales’ (GTW) consultation with organisational advisors and the rapid review of existing approaches to service provision

6.3.1. Data Availability

- There is a paucity of healthcare data for Gypsy, Roma and Traveller communities in Wales. Recent analysis of data from the SAIL databank offers important opportunities for understanding the health needs and outcomes of this population moving forward.
- Further epidemiological research is needed to understand the health needs, risk profiles and outcomes of this population in Wales.

6.3.2. Optimisation of Current Services

- While the scoping of services has identified a lack of tailored provision for Gypsy, Roma and Traveller communities in Wales, the scoping review identified key health providers that might optimise services to support their needs.
- GP are reported as the preferred healthcare provider and may be further supported in meeting the needs of these communities.

6.3.3. Co-production of New Services with Gypsy, Roma and Traveller Communities

- New services, or the tailoring of existing provision, needs to be done through meaningful co-production with the Gypsy, Roma and Traveller communities (Filakovska Bobakova, 2019).

6.3.4. Welsh Government and Public Health Wales Policies and Strategies

- There is a need for Welsh Government and Public Health Wales to consistently attend to the needs of Gypsy, Roma and Traveller communities across all health areas. One of the only research studies conducted in the Welsh context concluded that there is variable attention paid in policy and strategy documents on health inequalities in Wales, but that there is ‘punctuated reporting’ depending on the effectiveness of advocacy on specific issues at specific time points (Marsh, 2017).

- There are wider systemic issues that need to be attended to at the policy level in order to remove barriers to service access and uptake. This includes tackling stigma and discrimination.

6.4. Summary

The health of Gypsy, Roma and Traveller communities remains a significant public health concern. Currently there is a lack of culturally tailored provision to meet the needs of these communities. There are significant barriers to service uptake in regard to access and cultural humility. Future services would benefit from improved data availability to ensure provision is sensitive to the prevalence and distribution of communicable diseases across Wales. There is also a need to co-produce services with these communities, while ensuring that they are sufficiently supported at the level of the Welsh Government and Public Health Wales.

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