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# **Travelling to Better Health**

Policy Implementation Guidance for Healthcare Practitioners on working effectively with Gypsies and Travellers

# Policy Implementation Guidance for Healthcare Practitioners on working effectively with Gypsies and Travellers

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#### Policy Implementation Guidance for Healthcare Practitioners on working effectively with Gypsies and Travellers

#### Introduction

- 1. The policy position of the Welsh Government is that all of the people of Wales are entitled to the same high standards of healthcare and that there should be no lesser service for any individual with any of the protected characteristics. All of us wish to be treated with dignity and respect and Gypsies and Travellers have the same expectations.
- 2. The Equality Act 2010 places a due regard duty on public authorities, including Local Health Boards, to advance equality for those with the protected characteristics. Having due regard for advancing equality means:
  - Removing or minimising disadvantages suffered by people due to their protected characteristics; and
  - Taking steps to meet the needs of people from protected groups where these are different to other people.
- 3. Taking the above actions will be necessary to ensuring equity of access to health and healthcare for Gypsies and Travellers.
- 4. This guidance is designed to assist healthcare practitioners in working effectively with Gypsies and Travellers and in so doing, assist Local Health Boards in meeting their existing statutory duty to advance equality for them. 'Healthcare practitioners' are professional staff employed by Local Health Boards and NHS Trusts. They are also General Practitioners. They will be, for example, doctors, nurses, pharmacists, optometrists, dentists, occupational therapists and dieticians. Many other professions will fall under this description. The guidance also responds to the four Health Objectives contained within the Welsh Government's Gypsy and Traveller Framework for Action *Travelling to a Better Future*<sup>1</sup>.
- 5. The guidance also draws on the emerging Welsh Government principles of *Prudent* Healthcare<sup>2</sup>. Of particular relevance to this guidance is the shift towards coproduction in healthcare: that citizens and service users will take a greater role in deciding what is best for them in terms of their health.

#### Why do we need this guidance?

- 6. Romani Gypsies and Irish Travellers are recognised ethnic groups protected by the Equality Act 2010. They are not a homogenous group but they do share well evidenced experience of poor access to healthcare and poor health outcomes (see Bibliography). This guidance is needed for precisely these reasons: there is wide disparity between the experience of Gypsies and Travellers and the rest of the population of Wales in relation to health and this has been a consistent position over the long term.
- 7. A number of pieces of primary and secondary research have been carried out, both UK-wide and in Wales. These reveal much about the poor health outcomes

<sup>1</sup>http://wales.gov.uk/topics/people-and-

communities/communitycohesion/publications/travellingtoabetterfuture/?lang=en

http://emailimages.co.uk/phw prudent healthcare/index.html

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experienced by Gypsies and Travellers. In general, the research<sup>3</sup> tells us that when compared to the general population, Gypsies and Travellers:

- live shorter lives:
- suffer from chronic ill health such as cardio-vascular disease, cancers, diabetes asthma and other respiratory conditions. There are also higher rates of stroke;
- have poorer mental health, from mild to moderate to severe and enduring conditions;
- have poorer dental health;
- have higher rates of stillbirths, perinatal mortality and post-natal depression;
- have higher rates of hereditary conditions as a result of consanguineous marriages;
- have lower levels of childhood vaccinations/immunisations;
- smoke and drink more;
- have poorer diets;
- · have higher rates of accidents; and
- have higher rates of domestic violence

Evidence is also emerging of increased substance misuse. Paragraphs 62 to 68 say more about the health status of Gypsies and Travellers.

- 8. From a human rights perspective Gypsies and Travellers may experience inequality in healthcare in a range of ways. For those that travel, the lack of a permanent address that is considered by some primary care staff<sup>4</sup> as necessary for access to healthcare reinforces discriminatory access to health and healthcare. Even those that do not travel may lack an address, for example if a family is living on an unauthorised site they may not have an address to use. Some research<sup>5</sup> has also revealed instances of Gypsies and Travellers being denied registration because they are Gypsies and Travellers. Overall, it can be argued that discriminatory conditions in relation to healthcare undermine the right to life itself.
- While LHBs have a responsibility to ensure primary care access for the whole of their populations, ensuring that Gypsies and Travellers understand and can use that right easily, is essential.
- 10. This guidance is primarily intended to benefit the Gypsies and Travellers who, as a result of their ethnic status, are protected by the Equality Act 2010.

http://live.ehrc.precedenthost.co.uk/uploaded\_files/research/12inequalities\_experienced\_by\_gypsy\_and\_traveller\_communities\_a\_review.pdf; http://www.bristolmind.org.uk/files/docs/research/gypsy-traveller-research-summary.pdf; https://www.shef.ac.uk/scharr/research/publications/travellers; www.disability-equality.org.uk/.../cfa5ecd2a7e54517ab0e32233559eca5.pdf

http://kar.kent.ac.uk/24443/

<sup>&</sup>lt;sup>3</sup> Example research-

<sup>&</sup>lt;sup>4</sup> Example research - <a href="http://www.better-health.org.uk/resources/research/fair-access-all-gypsies-and-travellers-sussex-gp-surgeries-and-barriers-primary-h">http://www.better-health.org.uk/resources/research/fair-access-all-gypsies-and-travellers-sussex-gp-surgeries-and-barriers-primary-h</a>

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#### The Value of Joint Working - Who is this guidance for?

11. This guidance is for staff working in the statutory healthcare sector: for those that design, commission and provide services. It should also be a useful resource for staff working in other sectors, such as in Social Services and social care, other public services and in the Third sector. Providing effective information, advice and services to Gypsies and Travellers (and other) communities is often necessarily a joint task. Research and fieldwork has shown that where services have worked together locally and where relationships have developed, more effective and stable outcomes are achieved for people. Gypsies and Travellers together with the rest of the population often have a range of needs to be met. For example, in relation to healthcare, it can sometimes be the case that there are social care, housing and other needs to be met. This guidance therefore covers issues which have equal transferability beyond health settings, particularly the core sections on *Cultural Awareness* and *Practice which could encourage participation in health services*.

### What does this guidance do?

- 12. The guidance provides advice to healthcare practitioners on how to work effectively with Gypsies and Travellers and examples of practice which appear to work with them.
- 13. This guidance sets out the evidence base and provides the rationale for its publication. The Welsh Government's *Programme for Government* is clear about the need to improve access and patient experience, prevent poor health and reduce health inequalities for the whole of the Wales population, including Gypsies and Travellers. *Travelling to a Better Future* goes further by stating the importance of involving Gypsies and Travellers in the development of policies and practices that will have an impact on them and the need to establish and collect baseline information on the health status of these communities.
- 14. An extensive bibliography of research and evidence relating to Gypsy and Traveller healthcare and culture together with links to useful resources and contacts is also provided.
- 15. Annexes showing the Health Objectives of *Travelling to a Better Future*, an account of the process of work undertaken in the preparation of this guidance, the section of the General Medical Services contract setting out the requirements for registering patients, a sample health section for inclusion in a joint protocol for managing unauthorised encampments, a sample Health Needs Assessment form, a series of service development issues and questions and a series of Outcome Measures for LHBs and the Welsh Government are also provided.

### Outcomes from using this guidance

- 16. Some of the outcomes that are expected from using this guidance include:
  - Increased practitioner knowledge of Gypsy and Traveller culture and traditions;

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<sup>&</sup>lt;sup>6</sup> http://wales.gov.uk/about/programmeforgov/healthcare/?lang=en

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- Increased practitioner knowledge of the health status and health needs of Gypsies and Travellers; and
- Increased practitioner confidence in working effectively with Gypsies and Travellers.
- 17. Directly linked to improved practitioner knowledge and confidence is the expectation that there will be increased confidence among Gypsies and Travellers in understanding and communicating their own health needs and in using health services. Paragraph 27 sets out the Welsh Government position in relation to prudent healthcare and a core feature of this position is that of co-produced healthcare. Improved practitioner knowledge and confidence will greatly assist Gypsies and Travellers in feeling empowered to improve their own health and that of their families and communities.
- 18. Also linked to improved practitioner knowledge and confidence, it is expected that over time equality will be advanced as the current poor general health status of and health outcomes for Gypsies and Travellers will be improved. A scoping document prepared by Public Health Wales found that there are currently no examples of routine health indicators for Gypsies and Travellers in Wales. The way in which the improvement is identified and measured is therefore a key issue hence the inclusion of a sample Health Needs Assessment form (see Annex 5) as a means of gathering baseline health data.
- 19. This work will also contribute to the development of the Gypsies and Travellers section of the local *Homeless and Vulnerable Groups Health Action Plans*<sup>7</sup> required to be produced by every LHB; the implementation of section 14 of the Social Services and Well-being (Wales) Act 2014 which places a joint duty on LHBs and local authorities to undertake population needs assessments; and the development of Integrated Medium Term Plans by LHBs.
- 20. The need to establish the baseline of Gypsies and Travellers health needs and for that data to be collected onwards are also included as Outcome Measures for LHBs which are published alongside this guidance. It is also intended that the health needs data collected will be shared with both the Welsh Government and Public Health Wales in order that analysis to establish health improvement or otherwise among Gypsies and Travellers can be identified.

#### **Effective Practice in Service Design and Delivery**

21. This section provides advice on how to work effectively with Gypsies and Travellers.

Overcoming barriers to access and participation

GP and other Primary Care Services

22. There is evidence of instances where Gypsies and Travellers have been denied registration at GP surgeries because, for example, a permanent address cannot be provided. The site visits undertaken to prepare this guidance suggested this was an infrequent problem in Wales, especially in relation to those living on authorised sites.

<sup>&</sup>lt;sup>7</sup> http://wales.gov.uk/topics/health/nhswales/healthservice/homeless/?lang=en

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This issue therefore primarily relates to those that travel or live where they are likely to face eviction. Whether or not Gypsies and Travellers are living a nomadic life, prevention of access to GP services should not happen: the requirement in law to enable GP registration is one of UK residency. So, as with the general population, Gypsies and Travellers are entitled to access GP treatment as a permanent or temporary resident (See Annex 3). If a Gypsy or Traveller feels that they have been denied registration because they are a Gypsy or Traveller, the Equality Act 2010 provides an opportunity to challenge this. This can be done via an Equality Act 2010 questionnaire<sup>8</sup>.

- 23. GPs are responsible for training reception and other practice administrative staff. Whether or not a practice area is known to have a population of Gypsies and Travellers and whatever their accommodation status, it would be beneficial for the practice to ensure that all practice staff are aware of their obligations to register people. If the Gypsy or Traveller has poor literacy, staff should be sensitive to this and offer to assist in the completion of any required forms. If the Gypsy or Traveller is unable to provide any identification, then a level of flexibility needs to be shown. For example the electoral roll requires Gypsies and Travellers to declare that they have a local connection. Electors who are registered by a declaration of local connection have special provisions entitling them to register despite not meeting the resident requirement. A person applying to register to vote using a declaration of local connection signs to say that they commonly spend a substantial amount of time in an area. The term 'substantial' is not defined in electoral law and therefore there are no criteria as to what would constitute such a period of time.
- 24. In relation to appointments, the lower levels of literacy among some Gypsies and Travellers mean that written communications are not always appropriate. GP practices and other primary care services should establish ways of informing and reminding Gypsies and Travellers of appointments by text message and telephone. Leaving an answerphone or voicemail message or recording a verbal reminder on to a community member's mobile telephone voice recorder has also proven to be helpful. However, face to face communication will generally yield the most positive responses. It is worth developing a relationship with local support projects for Gypsies and Travellers (such as the Unity Project in Pembrokeshire, Carmarthenshire and Ceredigion and the Cardiff and Vale Gypsy and Traveller Project – see Useful Contacts) and with the managers of authorised sites. Both can and already do assist Gypsies and Travellers with health and other types of formal communications. In addition, work undertaken in the preparation of this guidance revealed that some local Race Equality Councils provide a postal address for Gypsies and Travellers that do not have one. These are used for health appointment letters and other correspondence and similar assistance to that outlined above is also provided.
- 25. Be flexible about the duration of appointments and the potential for longer or multiple appointments if more than one patient from the same family asks to be seen. Also be flexible about other family members substituting and asking to be seen in relation to their own needs in the event that the original appointment-maker cannot attend. It is also important as far as possible to specify whether community members will be

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https://www.gov.uk/government/publications/process-for-complaints-under-the-equality-act-2010

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seeing a male or female GP ahead of their appointment. The Market Harborough GP practice enhanced service model sets out ways in which access for Gypsies and Travellers has been improved and further information can be found in the Bibliography.

#### Health Improvement

- 26. Removing barriers to healthcare is not just about increasing registration with GPs and other primary care service providers. It is also about encouraging healthier lifestyles by making services of this type more accessible. Research<sup>9</sup> shows that within some Gypsy and Traveller communities for example, bigger children are viewed as healthy and that a poor appetite is seen as worrying. The quantity of food may be seen as more important than the nutritional quality of that food. This relates to the mind-set noted at paragraph 71 about living from day to day. Conversely, other research shows there is general wariness around 'unnatural' foods and additives although there are some differences depending on age. Visits undertaken in the course of developing this guidance have shown that many Gypsies and Travellers know they are overweight (there are, for example, high rates of diabetes particularly among men developed as a result of being overweight). They also know that exercise is beneficial, that smoking causes disease and death and that excessive drinking is also damaging. However, measures to combat these do not routinely exist in a way that communicates these harms effectively to Gypsies and Travellers and the Gypsies and Travellers spoken to during the course of the fieldwork had not been provided with any appropriate health improvement advice. Paragraph 23 and elsewhere points to the low levels of literacy among Gypsies and Travellers and this issue will need to be taken into account when developing health improvement communications. Examples of resources which are designed to assist people working with Gypsies and Travellers in relation to diabetes and smoking cessation can be found in the Bibliography.
- 27. Research shows that the uptake of screening programmes among Gypsies and Travellers is lower when compared with the general population. The sample Health Needs Assessment at Annex 5 covers many of the health issues which are covered by screening programmes. It also includes childhood vaccinations/immunisations, which is another area where research has shown there to be low take up among Gypsies and Travellers. Public Health Wales are currently undertaking work to improve the uptake of public health screening among Gypsies and Travellers.
- 28. As Gypsies and Travellers have a lower life expectancy than the general population, health organisations which provide screening programmes that are offered at a certain age are advised to offer these services to community members at an earlier age. In doing this, it will be important to assure community members of the value of screening for preventative purposes to overcome the kinds of fears that lead to screening being avoided<sup>10</sup>.

#### Prudent Healthcare

29. The policy position of the Welsh Government in relation to healthcare is shifting in focus away from remedy and towards prevention. While research and fieldwork have

<sup>&</sup>lt;sup>9</sup> https://www.shef.ac.uk/scharr/research/publications/travellers

<sup>10</sup> https://www.sheffield.ac.uk/scharr/research/publications/travellers

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shown that Gypsies and Travellers experience difficulties in accessing healthcare and thus do not make effective use of them, the principles of prudent healthcare apply to this group as they do the whole of the population of Wales. Investing in measures such as materials or communications accessible to Gypsies and Travellers which promote health improvement and which have been developed in partnership with them and organisations which work with them, would be an effective demonstration of the principles of prudent healthcare.

#### Unauthorised Encampments

30. The Welsh Government states that public authorities should ensure that a Welfare Assessment of encampment occupiers is undertaken before any eviction action is taken. Public authorities are required to act reasonably and proportionately when carrying out their functions, and undertaking an effective Welfare Assessment is a key part of demonstrating this. In some areas, Health Visiting or Primary Care nursing staff carry out Welfare Assessments on Gypsies and Travellers on behalf of local authorities. Should such assessments reveal a health need requiring immediate attention, any proposed eviction is unlikely to be granted by the Court. Further guidance on conducting Welfare Assessments can be found in the Welsh Government's *Guidance on Managing Unauthorised Camping*<sup>11</sup>

#### Training in Cultural Competency

- 31. The Equality Act 2010 places an obligation on public authorities to positively promote equality and not just avoid discrimination. The general equality duty states that healthcare organisations and their staff must have due regard to the need to:
  - Eliminate unlawful discrimination, harassment and victimisation and other conduct prohibited by the Act;
  - Advance equality of opportunity between people who share a protected characteristic and those who do not; and
  - Foster good relations between people who share a protected characteristic and those who do not.
- 32. In the context of providing healthcare, having due regard for advancing equality means:
  - Removing or minimising disadvantages suffered by people due to their protected characteristics; and
  - Taking steps to meet the needs of people from protected groups where these are different to other people.
- 33. One important way of demonstrating due regard is to train healthcare staff in cultural competency.
- 34. Equalities training should already be routinely and regularly provided in order to ensure the required compliance with the Equality Act 2010 by all public bodies and LHBs should ensure that staff have further opportunities to develop knowledge and expertise in cultural issues.

<sup>&</sup>lt;sup>11</sup> http://wales.gov.uk/topics/localgovernment/publications/guidecamping/?lang=en

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- 35. Gypsies and Travellers are the people with whom the general population is least likely to have contact. The effect of this is that Gypsy and Traveller culture and lifestyle stay unknown and that media reporting, usually unfavourable, remains the only source of information that the general population receive.
- 36. Cultural competency is a process which entails continuously developing and refining one's capacity to provide effective healthcare, taking into consideration people's cultural beliefs, behaviours and needs. Developing a good understanding of Gypsy and Traveller culture will improve communication by facilitating the flexibility and openness necessary for interaction between people from different backgrounds.
- 37. To develop an understanding of Gypsy and Traveller culture, it will be important to establish the existing levels of knowledge and attitudes of healthcare practitioners. Examples of ways in which this could be undertaken are described in research <sup>12</sup> <sup>13</sup> and any further training which is required would need to be developed with Gypsies and Travellers themselves.

#### Cultural Awareness

- 38. Gypsies and Travellers are keen to share their culture and beliefs and if you are unsure of anything, questions are always welcomed. Doing this shows respect and minimises the risk of something being done in the mistaken belief that it is culturally correct.
- 39. When visiting sites, it is also important that healthcare practitioners are clear about their reasons for visiting. Privacy is very important to Gypsies and Travellers and any intrusion in to what they consider to be their private concerns could lead to a rapid loss of trust with the practitioner concerned.
- 40. Set out below is advice which would demonstrate a basic level of cultural awareness about Gypsies and Travellers:

On entering someone's caravan or 'bricks and mortar' accommodation, ask if you need to remove your shoes. This relates to a core cultural tradition around cleanliness of the home.

Gypsies and Travellers use separate sinks for washing different items. If providing healthcare in someone's home, establish which facilities can be used for which activity.

Some older Gypsies and Travellers are referred to as Aunt or Uncle as a sign of respect by immediate and extended family members. It is worth establishing whether you doing this would be welcomed ahead of any verbal communication.

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<sup>&</sup>lt;sup>12</sup> Francis, 2013. Developing the Cultural Competence of Health Professionals Working with Gypsy Travellers

<sup>&</sup>lt;sup>13</sup> Nursing Times, October 2011. Attitudes towards Gypsy Travellers

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Try not to refuse an offer of hospitality, such as a tea or a coffee. Ask for water instead if you do not like hot drinks. Some Gypsies and Travellers may feel that a refusal of hospitality suggests that you want to spend as little time as possible in the caravan or house and can be seen as a lack of respect.

Cups or plates should not be put on the floor for any period of time as this is considered to be unclean. Likewise, bags should not be put on tables or anywhere that food or drink may be consumed, as they are likely to have spent some time on the floor.

Gypsies and Travellers have very clear hygiene rules and may not wish to share toilets with others. Bear this in mind and try to use any communal or site office toilets if they exist.

Some lone female practitioners may be reluctant to engage with community members in their caravans if they are male. It is advisable for mixed gender teams to visit sites or arrange communal events on site, where possible.

Certain subjects may be considered taboo to be discussed in front of the opposite sex. Practitioners should ensure that issues such as sexual health or feminine hygiene are discussed discreetly and not in front of male Gypsies and Travellers.

Some may be offended if site visitors pat a dog and then offer the same hand to shake a community member's hand. This can be seen as a lack of respect as dogs are considered unclean by some.

If you need to refer to Gypsies and Travellers' ethnicity for monitoring or reports it is better to politely ask what they would rather be called than to assume. Be clear about the reasons for requesting their ethnic identity.

Try to keep the number of site visitors to a minimum unless residents have previously stated that they are happy to receive large groups. Many non-Gypsies or Travellers have never visited a site and they can be keen to visit.

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Gypsy and Traveller women and girls are likely to have lots of experience looking after children so be careful not to patronise them. Ask them about their knowledge and experience and respect this. They may be unwilling to breast feed due to taboos about exposing breasts in public. Mentioning pregnancy in front of males can be seen as 'shameful'. Even acknowledging or congratulating in front of males could not be seen as appropriate. Unless the family is well known to you, best practice would be not to mention pregnancy in front of the men or boys when you don't know the family.

#### Practice which could encourage participation in health services

- 41. The most important factors in promoting access to healthcare for Gypsies and Travellers are **trust**, **communication**, **flexibility and time**. All of these factors are inter-related and if some or all of these factors are not properly considered then the likelihood of non-compliance with appointment attendance, the taking of medication or advice and so on, is decreased. A trusted health worker is highly valued by Gypsies and Travellers and efforts are made to maintain continuity with that person. Treating the person with respect and empathy are seen as the most important factors in a successful health service interaction. Anticipation of discrimination can lead to hostile and demanding behaviour from Gypsies and Travellers, which in turn can have the effect of no consultation taking place and no health service being provided. Communication difficulties with health staff are common. This is may be due to a lack of cultural understanding or time on the part of practitioners, or as a result of illiteracy or a lack of confidence in explaining one's symptoms on the part of Gypsies and Travellers. This may also be due to a lack of understanding on the part of Gypsies and Travellers about how the NHS works.
- 42. Set out below is advice which could assist Gypsies and Travellers take-up of health services. Key to the success of all of this advice is ensuring the involvement of Gypsies and Travellers themselves and any local agencies that work with them for example, the Unity Project which covers Carmarthenshire, Pembrokeshire and Ceredigion.

#### Communication

In recognition of the low levels of literacy, develop ways in which health information can be provided to Gypsies and Travellers in non-written formats, such as audio and DVD. The value of face to face communication and giving advice over the telephone also cannot be underestimated. As outlined in paragraph, communicating information and advice in these ways and via text messages, answerphone/voicemail messages or recording onto a mobile telephone or smartphone voice recorder are methods which are known to work.

While many Gypsies and Travellers have access to their own transport, it is worth noting that many authorised sites are located away from residential areas and away from public transport routes. It is also the case that some taxi firms will not attend sites. Consider developing drop-in healthcare sessions at locations where Gypsies and Travellers live, either

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using site facilities or offices or with agreement, a resident's home. For Gypsies and Travellers living in 'bricks and mortar' housing, the use of local community facilities and again with agreement, a resident's home, could be very helpful.

Make a point of checking the understanding of what has been said during a consultation. Use straightforward language and keep jargon to a minimum.

Develop accessible materials which explain how the NHS works including in relation to making and keeping appointments and how information is generally communicated.

Develop accessible materials and programmes which explain the benefits of healthy eating and exercise.

Develop accessible materials and programmes which explain the benefits of smoking cessation.

Develop accessible materials which explain the benefits of safe drinking levels.

Develop accessible materials which explain the benefits of health screening programmes.

#### **Trust**

Until trust is developed, visit sites accompanied by someone known to and trusted by residents. This could have the dual effect of encouraging community members to use services and minimise any anxiety healthcare professionals have in working with the communities. Minimise staff changes wherever possible and give advance warning of any staff changes.

It is usually female Gypsies and Travellers who will take responsibility for healthcare issues within the family and community. It is important that as far as possible, healthcare practitioners are of the same gender as those they are serving. This helps to build trust and is likely to facilitate more honest communication from the patients.

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Female Gypsies and Travellers are unlikely to tell their male relatives exactly what is wrong with them, especially if it is gynaecological. Therefore they may need a healthcare practitioner or other service provider's support to create and maintain a convincing cover story, especially if repeat treatment or hospital stays are needed. For example a stomach complaint rather than a gynaecological one.

Involve the family in any and all aspects of an individual's care where appropriate. Family is extremely important to Gypsies and Travellers and they are likely to want to assist with treatment and decisions. It is helpful to communicate that your services are meant as a complement to the family's care and not a replacement. Dressing informally when visiting people at home may help to put them at ease.

Make a point of finding out about and adhering to the person's cleanliness and hygiene customs.

Privacy is very important to Gypsies and Travellers. It would not be appropriate to remove bed covers if there are family members or others present, either at home or in a health setting. Consider allowing Gypsies and Travellers to provide their own bed linen and clothes if at all possible.

Do not make any promises that can't be kept. Many Gypsies and Travellers have been let down many times and can be very distrustful of people, even those with the best intentions. A phrase which is often used by a Health and Wellbeing Worker working with these communities is 'I can't make any promises'.

If you have made a commitment to be in touch with a community member on a certain day, it is important that you are. Even if you have nothing to update them with, the fact that you have ben in touch and met a commitment will help reinforce the trust in your relationship.

It will be important for Gypsies and Travellers to know in advance of a GP appointment whether they will be seeing a male or a female GP. Female community members will generally only see a female GP or other practitioner.

#### Flexibility and Time

When making appointments to visit a Gypsy or Traveller at home or at a surgery, the late morning period is usually the most convenient as by that time, the morning household tasks

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will have been completed.		

Consider providing summary handheld records both for individuals and parents of children so that they can be presented at any UK GP surgery. This would be particularly important for families that travel.

At a GP or other primary care appointment, be prepared to see more than one member of a family. It is possible that a relative could attend either instead to have their own needs attended to or together with the person appointed to be seen. Try to accommodate this.

When a Gypsy or Traveller needs inpatient care, allocate a bed near an entrance/exit or a single room in order to accommodate a potentially large number of family visitors, some of whom may have travelled long distances. Identify a close relative to speak with about visiting arrangements and managing numbers.

### The Value of Peer Support - Training for Gypsies and Travellers

- 43. Research<sup>14</sup> shows that training Gypsy and Traveller women in providing some types of healthcare, advice and advocacy is beneficial to the community in a number of ways. Trust is already there as is cultural understanding. Training also has the effect of empowering the person in receipt of it and increasing their sense of self worth as well as their income if a position is paid. Family and community members feel involved in something that is theirs thus increasing participation in whatever the service is. There is therefore wide benefit to be had from the skills acquired, not least the onward sharing of information and knowledge throughout the community and increasing the likelihood of others coming forward to seek help and discuss their needs.
- 44. There is however an opposing view which relates to the issue of privacy which has already been discussed. In this context, this includes keeping personal matters private from other Gypsies and Travellers. There could also be the need to keep matters confidential within the immediate family so care needs to be taken when discussing issues within the family home. Therefore do not assume that a Gypsy or Traveller health advocate trained to give advice about health matters will always be welcome.
- 45. It should be noted however that some research<sup>15</sup> warns against a reliance on outreach healthcare provision as it can have the effect of exacerbating the social exclusion felt by Gypsies and Travellers. This is why it is important to ensure that all healthcare staff receive appropriate training in Gypsy and Traveller culture.

<sup>&</sup>lt;sup>14</sup> http://www.raceequalitvfoundation.org.uk/publications/downloads/health-gypsies-and-travellers-uk; http://www.gypsy-traveller.org/your-family/health/practitioners-health-documents-and-reports/
https://www.gov.uk/government/uploads/.../Inclusive\_Practice.pdf

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46. Overall however, the research tends to support outreach provision as this method is preferred by Gypsies and Travellers and when some of the delivery is undertaken by community members themselves. In light of this, LHBs working in partnership with other relevant agencies would benefit from considering developing health and social care assistantships and training programmes for Gypsies and Travellers.

#### **Ethnicity Monitoring**

- 47. The importance of collecting ethnicity data cannot be underestimated. Without the ability to identify inequalities, strategies and actions to combat inequality do not have a sound foundation. There is a wealth of research and evidence which highlights the health inequalities experienced by Gypsies and Travellers but little quantitative data is available. What is known is that they are excluded from a range of monitoring data which adds to their invisibility in terms of mainstream and other service use and provision. Work undertaken in the preparation of this guidance revealed that there is wide variation both within and between LHBs regarding how ethnicity data is collected. It was also unclear the extent to which the data was used to inform service development, if at all.
- 48. The Welsh Government recognises that work needs to be done to update the list of ethnic categories in line with those used in the 2011 Census. To do this will encourage the improvement and standardisation of existing ethnicity monitoring arrangements which are in use locally. In the meantime and in recognition of the wide variations in arrangements which exist across and within LHBs for collecting ethnicity data, a Welsh Government Statistical Article Collecting Equality Data Harmonised Standards and Best Practice <sup>16</sup> has been published which provides advice on collecting data on the protected characteristics. The Article lists the questions to be asked in relation to national identity and ethnicity and uses the Census 2011 categories. The use of standardised questions allows for data to be comparable across organisations. Harmonisation is used to establish a common knowledge base of standard definitions and methods.

#### **Health Needs Assessment and Service Development Questions**

- 49. Annex 5 contains a sample Health Needs Assessment form for healthcare practitioner to use with Gypsies and Travellers. It covers a range of questions ranging from literacy skills to health screening. The results from the completion of this form will be central to service development.
- 50. It is important to note that this form is a sample and as such it is deliberately detailed in an attempt to cover as many healthcare and other needs relevant to Gypsies and Travellers as possible. However, the professional judgement of the healthcare practitioner or any other service provider working with the communities will be key in deciding the relevant questions to ask. For example, Annex 4 provides a Sample LHB/local authority Protocol Health Section for Managing Unauthorised Encampments which requires a general health status report to be prepared within three days of an unauthorised encampment being established. In these circumstances therefore, it may not be realistic to ask every question.

<sup>&</sup>lt;sup>16</sup> http://wales.gov.uk/statistics-and-research/collecting-equality-data/?lang=en

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- 51. The MUE guidance states: 'When undertaking the Welfare Assessment, it is recommended that the Single Point of Contact (SPOC) is capable, or accompanied by another colleague who is capable, of assessing the needs of the encampment occupiers. Local authorities should be aware that for cultural reasons some female occupiers will not participate in this process if they are approached by male visitors. It would be good practice for a mixed gender team to undertake the Welfare Assessment, where possible'
- 52. The types of questions the general health status report would be expected to cover include:
  - How many of the occupiers are children;
  - How many of the occupiers are elderly;
  - If any of the occupiers are disabled; and
  - If there are any health issues/medical conditions affecting the occupiers e.g. hospitalised relatives, pregnant women, post-natal mothers and babies, those recovering from serious illness or injury etc.
- 53. The National Assembly for Wales has recently passed the Well-being of Future Generations (Wales) Act 2015. This Act legislates for Local Well-being Plans and will simplify current arrangements by repealing duties to prepare a range of plans for a range of groups, including the duty in the NHS Act (2006) to prepare Health, Social Care and Well-being Plans. Guidance under this Act will set out how these Plans should be prepared.
- 54. Annex 6 sets out a range of initial questions for LHBs to consider when designing health services for Gypsies and Travellers and can be used alongside the Health Needs Assessment form to inform service development.

#### **Examples of Effective Practice**

55. Set out below will be examples of effective practice from across a range of healthcare areas.

#### **General Practice**

Saint Thomas GP Surgery in Haverfordwest serves a large Gypsy and Traveller community in the Pembrokeshire area. It offers longer appointment times and allows family members to take an appointment if someone else from the same family is unable to. The surgery also practices opportunistic interventions such as if a mother is attending an appointment with a GP or practice nurse and brings her child or children with her, then the mother will be asked 'while you're here, shall we...' and offer any immunisations/vaccinations or any other healthcare to the child. The mother will also be offered screening or any other procedure

Saint Thomas Surgery is on Rifleman Lane, St Thomas Green, Haverfordwest, SA61 1QX and the Practice Manager is Jane Stuart-Daters.

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Friends, Families and Travellers have developed a Health Help Card with Gypsies and Travellers living in the Brighton area. The options on the card address specific barriers to accessing primary care that are known to affect Gypsies and Travellers across the UK. It can be accessed here: <a href="http://www.gypsy-traveller.org/your-family/health/health-help-card/">http://www.gypsy-traveller.org/your-family/health/health-help-card/</a>

#### Dentistry

An outreach mobile dental service for Gypsy and Traveller children and young people in the Pontypool area ran from 2001-2009. The service was provided in a van for one day per week. When the van could not be used due to the foot and mouth disease outbreak, home visits were made so as not to break the continuity of service.

#### Aims of Project

- To increase access to a full range of primary dental care and specialised paedodontic care for children and young people from disadvantaged and excluded communities.
- To increase awareness of the importance of good oral health for children and young people.

#### Objectives

- To encourage dental registration by increasing access to dental services via a mobile dental unit.
- To provide clinical dentistry in an acceptable setting for one day per week.
- To provide ongoing support and advice on all aspects of oral health care.
- To make available tooth brushes and fluoride toothpaste to all children associated with the project.
- To act as a point of contact for information and advice for the whole family, via the dental access centre (which was under development at the time.)
- To act as point of referral into secondary services e.g. orthodontics

#### Evaluation

- Improved links with the local Primary Care Team, i.e. health visiting and the school nursing service.
- Greater understanding and awareness of dental issues by the local residents.
- Improved relationships with the local residents.

Since 2009 the Designed to Smile team has been working with the Health Visitor with responsibility for Gypsies and Travellers to provide a fluoride varnishing service for the children.

A dentist bus operates in the Splott and Tremorfa areas of Cardiff which is easily

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accessed by the many Gypsies and Travellers that live in those areas. It is a service that is well used and trusted.

#### Mental Health

Local primary mental health services (as provided for under Part 1 of the Mental Health (Wales) Measure 2010 are available to people even if they are not registered with a GP.

#### Women's Health

Friends, Families and Travellers have produced a women's health leaflet with culturally sensitive information on cervical cancer screening. The leaflet is used by outreach workers and healthcare practitioners to support women to book and attend screening.

Children's Health (including immunisations/vaccinations)

Working in partnership with other agencies, a Gwent area community midwife provides health education classes over a six week period to Gypsy and Traveller children and young people who receive their education outside of the formal education system. The classes, which are located in a demountable building on the Gypsy and Traveller site, are taught separately to boys and girls, in line with Gypsy and Traveller culture. Topics covered include family planning, sexual health, smoking, alcohol and food and nutrition. Other services include Flying Start activities, play groups and after school clubs. Healthcare services are also provided such as fluoride varnishing, childhood immunisations/vaccinations and a baby clinic.

The practice of Nurses and Health Visitors administering childhood immunisations/vaccinations at home is one which is already carried out and is further encouraged.

Chronic Conditions (including cardio-vascular disease, cancers, diabetes, asthma and other respiratory conditions and stroke)

The Coronary Heart Disease and Travellers - Redressing the Balance project, managed by Wrexham Multi-Agency Traveller Forum, aimed to reduce the incidence of heart disease among Gypsies and Travellers

The project improved access to healthcare services, through the appointment of a full-time project worker and the purchase of a specially equipped 'Health Bus' which

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enabled 200 Gypsies and Travellers to be offered health screening, advice and support in a form that is both accessible and acceptable.

The project began in September 2002 and between then and 2006, there were 2442 individual contacts with the Project Health worker, an average of 59.56 a month. More than 95% of the community are also now registered with a GP.

The project was funded by the Welsh Government's Inequalities in Health Fund.

Health Promotion (including measures to combat smoking, alcohol and substance misuse, poor diet etc)

Friends, Families and Travellers has a health trainer from the Gypsy Traveller community who delivers smoking cessation advice, health eating advice and runs a regular Zumba class for travellers in Sussex.

#### Intensive Care

A Nurse Manager of an intensive care unit closed a bed adjacent to a community member to ensure there was plenty of space available for visitors.

#### End of life care

The Estates staff at Withybush Hospital, Haverfordwest set aside a significant area of parking space in the grounds to allow for a large number of trailers to park so that extended family could visit a dying relative.

#### Other

Friends, Families and Travellers have recently supported 10 Travellers through the Royal Society for Public Health Level 1 certificate in Health Awareness. This qualification is about improving health literacy and is often the first qualification that anyone from the communities has achieved.

#### **Evidence Base**

#### Who do we mean by Gypsies and Travellers?

56. Gypsies and Travellers have lived, worked and travelled throughout the UK for over 500 years. They are among the UK's longest established minority ethnic populations.

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- 57. Gypsies and Travellers fall in to a number of categories of ethnic groups:
  - Romani Gypsies (originally of Northern Indian descent and also known as English, Welsh and Scottish Gypsies, Kale and Romanichal)
  - Welsh Travellers
  - Scottish Travellers
  - Irish Travellers
  - Roma/Sinti
  - Bargees or Boat Dwellers/Water Gypsies
  - Fairground or Show People
  - New Travellers
- 58. Romani Gypsies and Irish Travellers are recognised racial groups under Equality Act 2010.

#### How many Gypsies and Travellers are there in Wales?

59. The Census 2011 included an ethnicity category for 'White Gypsy or Irish Traveller' for the first time. The data suggests that a total population of 2,785 Gypsies and Travellers live in Wales. This is 0.1% of the total population and they live within just over 1,000 households. The category includes Romani Gypsies, Irish Travellers, Welsh, English and Scottish Gypsy Travellers and 'New' Travellers or Travellers. This figure does not include Roma who may have identified themselves within the 'Other' category and for which there is no available data breakdown. The total may also exclude other members of these communities who declined to self-ascribe their ethnicity for fear of discrimination, stronger affiliation with other ethnicity categories (e.g. White Irish) or for other reasons, though attempts were made by the Office for National Statistics to address these issues. This data has been disaggregated to the local authority level by the Office for National Statistics.

#### Where do Gypsies and Travellers live in Wales?

#### Caravan Accommodation

60. The Census evidence set out above is part of the limited statistical data available about Gypsies and Travellers in Wales. Other Census data tells us about a range of other socio-economic characteristics such as health status. The other data collected is the bi-annual Caravan Count undertaken by local authorities for the Welsh Government. The most recent caravan count states that there are 1,020 Gypsy and Traveller caravans across Wales over 100 sites. 845 caravans are accommodated on authorised sites with 628 of these on local authority sites and 217 on private sites. The number of authorised sites has increased from 53 in January 2014 to 57 in January 2015 (for the 20 local authorities that responded to both counts). In relation to unauthorised sites, there are 71 caravans on land owned by Gypsies and Travellers and 104 caravans on land not owned by Gypsies and Travellers. Where the land is owned by Gypsies and Travellers but is deemed to be unauthorised by the local authority, this is because planning permission has yet to be granted. Where the land is not owned by Gypsies and Travellers, these would

<sup>&</sup>lt;sup>17</sup>http://gov.wales/statistics-and-research/gypsy-traveller-caravan-count/?lang=en

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either be 'tolerated' unauthorised developments or unauthorised developments subject to enforcement.

61. The Caravan Count provides a snapshot two days per year of where Gypsies and Travellers live in Wales. Data from the Count indicates that there is a Wales-wide shortage of suitable authorised sites, both for settling and for short terms stops. The Caravan Count is also not designed to provide an estimate of the Gypsy and Traveller population. Its primary use is to assess housing needs and the level of mobile home pitch provision across Wales.

### 'Bricks and Mortar' (Housing) Accommodation

62. According to the 2011 Census, there were 2,785 self-identified Gypsies and Travellers living in Wales. Of those, 1,004 households live in 'Bricks and Mortar' (housing) accommodation. There is a fairly even spread of residency across the tenures although they predominantly live in social or private rented housing<sup>18</sup>.

### What do we know about barriers to accessing health and healthcare?

- 63. A number of pieces of primary and secondary research have been carried out, both UK-wide and in Wales. These reveal much about the poor access to healthcare experienced by Gypsies and Travellers. Research and visits undertaken in the preparation of this guidance show that there are instances of Gypsies and Travellers being prevented from registering with a GP. On the one hand, barriers to access exist as a result of:
  - the cultural tradition of travelling or from being evicted from sites which cannot legally be used by Gypsies and Travellers.
  - Gypsies and Travellers' mistrust and fear or experience of discrimination, marginalisation and low expectations have led to negative attitudes towards services<sup>19</sup>. There are connections here also to evidence which shows the pride that Gypsies and Travellers feel in self reliance: looking after oneself, one's families and communities and that there is no benefit to be had from any type of outside help<sup>20</sup>.
  - limited awareness on the part of Gypsies and Travellers regarding the importance of appointment systems and, wider than this, of how the NHS works.
  - the lack of accessible public transport near where authorised sites are located.
- 64. On the other hand, research<sup>21</sup> shows that some healthcare practitioners consider Gypsies and Travellers to be resistant to services and are poor attendees at appointments. Poor attendance can be seen as wilful non-compliance by

http://www.better-health.org.uk/resources/research/fair-access-all-gypsies-and-travellers-sussex-gpsurgeries-and-barriers-primary-h

http://live.ehrc.precedenthost.co.uk/uploaded\_files/research/12inequalities\_experienced\_by\_gypsy\_a\_nd\_traveller\_communities\_a\_review.pdf

<sup>&</sup>lt;sup>18</sup> ONS, accessed 20 May 2014, NOMIS table *Tenure by Ethnic Group* 

<sup>&</sup>lt;sup>19</sup>/<sub>20</sub> http://www.raceequalityfoundation.org.uk/publications/downloads/health-gypsies-and-travellers-uk

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- practitioners<sup>22</sup>. This may be true in some cases and links with the attitudes described in bullets 2 and 3 above.
- 65. Overall, those that travel and those that live on some types of unauthorised sites experience the worst access while those that live on authorised sites and in 'bricks and mortar' housing experience better access. While access to healthcare was better for those living in authorised and 'bricks and mortar' housing, there are still significant health issues. These are summarised next.

#### What do we know about the health status of Gypsies and Travellers?

- 66. A Census 2011 release which covers England and Wales confirms what is known from primary and secondary research: that White Gypsies or Irish Travellers had the lowest proportion of any ethnic groups rating their general health as 'good' or 'very good' at 70% compared to 81% of the overall population of England and Wales.
- 67. In addition, the White Gypsy or Irish Traveller ethnic group was among the highest providers of unpaid care in England and Wales at 11% (10% for England and Wales as a whole) and provided the highest proportion of people providing 50 hours or more of unpaid care per week at 4% (compared to 2% for England and Wales as a whole).
- 68. Also, just under half of White Gypsy or Irish Traveller households had dependent children (45%), which is significantly above the average for the whole of England and Wales at 29%.
- 69. Research also shows that poor conditions and facilities on the sites where Gypsies and Travellers live have an impact on many of the above types of ill health, for example, poor respiratory health and poor mental health.

#### Gypsy and Traveller Culture

- 70. Gypsies and Travellers see themselves primarily as separate ethnic groups, beyond their national identity as determined by their country of origin. This aspect of their identity is viewed as inherited and not chosen. Research<sup>23</sup> shows that there is considerable fear of losing one's culture through a forced change of lifestyle. Cultural rules exist and breaking them brings with it the risk of being outcast. Keeping a separate existence from non-Gypsies and Travellers (known as Gorgers or country folk) is seen as an important aspect of maintaining a strong cultural identity and passing it on to the children. There is however a conflict between pride in cultural identity and a need to hide that identity to avoid discrimination.
- 71. Gypsy and Traveller culture differs to that of predominant Western cultures in many ways. Being nomadic does not fit with many traditional Western ways of life nor many of its accepted ways of doing things. Research<sup>24</sup> shows that Gypsies and

http://live.ehrc.precedenthost.co.uk/uploaded\_files/research/12inequalities\_experienced\_by\_gypsy\_a\_nd\_traveller\_communities\_a\_review.pdf

<sup>22</sup> 

www.leicestershiretogether.org/gypsy travellers the truth.pdf

http://www.raceequalityfoundation.org.uk/publications/downloads/health-gypsies-and-travellers-uk; Dion, X. Gypsies and Travellers: Cultural Influences on Health, 2008

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Travellers can often be fatalistic about their lives and have low expectations about their health as their lives are so different to many settled populations. Poor health is seen as normal, an inevitable consequence of living in a society that does not accept them. It can be argued that the cultural concept of deferred gratification, i.e. that 'the best things come to those who wait' or doing things over time will reap rewards, is very different to their need for instant gratification as a result of how they live their lives. Lives that are rooted in travelling and living from day to day are all about living to survive. This mindset often remains even when Gypsies and Travellers move in to 'bricks and mortar' housing.

#### Accommodation and Health

- 72. Some research<sup>25</sup> has argued that moving into 'bricks and mortar' housing is a deliberate choice on the part of Gypsies and Travellers, intended to benefit families by 'fitting in' with the rest of society and improving their access to services. Other research has argued that moving in to 'bricks and mortar' housing is because Gypsies and Travellers have little or no choice but to do so. The shortage of suitable sites, both permanent and temporary, the poor conditions and facilities on many sites, including the accessibility of trailers should health and mobility deteriorate and the lack of access to healthcare and other services, have resulted in Gypsies and Travellers feeling forced to move into 'bricks and mortar'.
- 73. Research<sup>26</sup> shows that Gypsies and Travellers experience loss and bereavement extensively in a range of ways, including for travelling lives no longer lived and the breakdown of community and extended family living. Nomadism is associated with freedom and the sense of loss of freedom is shown to have a profound effect on the psyche of Gypsies and Travellers. These factors are known to contribute to poorer mental health as a result of isolation and discrimination by those within the established settled communities, whether real or perceived. Even in 'bricks and mortar' housing, the lack of access to healthcare and poorer health outcomes may remain: mistrust and fear or experience of discrimination, marginalisation and low expectations all have their role to play.
- 74. In both regards then, the research shows that moving into 'bricks and mortar' housing can have a negative effect on health and as already mentioned, the poor quality of some sites can have a similar impact.

#### Attitudes and Beliefs of Gypsies and Travellers regarding Health

75. The impact of long term cultural and structural discrimination and oppression and how this prevents Gypsies and Travellers from engaging with services is a key overall set of issues which healthcare practitioners will have to be aware of. Research shows that Gypsies and Travellers tend to think in terms of social and environmental factors as key determinants of theirs, their families and communities health as opposed to medical models based in concepts of disease and medication. Self reliance and depending on ones family and community are seen as core to

http://england.shelter.org.uk/ data/assets/pdf file/0010/57772/Working with housed Gypsies and Travellers.pdf

<sup>25</sup> 

http://www.better-health.org.uk/resources/toolkits/insight-health-gypsies-and-travellers-booklet-health-professionals-cambridgeshire

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maintaining health. Indeed, as mentioned earlier, some do not believe that health professionals can improve health, seeing the sharing of bad news such as a diagnosis of a potentially fatal illness as contributing to the diminution of resilience. There is, for example, a great fear of cancer and this is often referred to not by name but by description such as 'that bad complaint', 'that bad condition' or 'that dirty thing'. Health professionals in primary and palliative care need to be aware of such perceptions to manage individuals and help their families effectively.

- 76. There is a strong gender divide in Gypsy and Traveller culture. Gypsy and Traveller women are responsible for maintaining family life, caring for their children, sharing childcare responsibilities with other women in the community and caring for older and disabled relatives: 'the man is at the head of the family. The woman is at the heart of it'. It is a cyclical culture of putting others needs ahead of ones own and their health suffers as a result. For example, women are twice as likely as men to experience poorer mental health.
- 77. Women generally do not speak about healthcare issues in front of men and generally will not see male healthcare practitioners. Men generally do not engage in their own preventative health or healthcare services at all. Privacy is very important to Gypsies and Travellers and linked to this is their strong preference to maintain continuity of care from a culturally competent practitioner who knows the individual's and family history.
- 78. There are strong cultural rules relating to cleanliness and hygiene. Toileting and washing facilities are often removed from caravans on purchase as it is considered to be unhygienic to have these facilities inside. On authorised sites, separate bathroom blocks are built alongside the accommodation.
- 79. Research shows that Gypsies and Travellers have a tendency to regard most health problems as needing immediate attention, even relatively minor conditions. If the problem cannot immediately be attended to, the individual may conclude that the healthcare professional is disinterested in them and does not wish to help. This relates to other research which shows that Gypsies and Travellers tend to use hospital Accident and Emergency services rather than GP services, not only because there are no issues regarding registration and providing identification, but even if the wait to see someone is several hours, they know that they will be seen that day. This is also the case when a Gypsy or Traveller has ignored a health problem but can do so no more as it has become acute. Further to this, other research<sup>27</sup> shows that when a Gypsy or Traveller is registered with a GP and a trusting relationship has been developed, they are prepared to travel hundreds of miles to see them.

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http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/54885.aspx; https://www.gov.uk/government/...data/.../Promising\_Practice.pdf