### Bath and North East Somerset Gypsy, Traveller, Boater, Showman and Roma Health Survey 2012-2013

A report prepared for

**Bath and North East Somerset Health Authority** 

By

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#### **EXECUTIVE SUMMARY**

# The Bath and North East Somerset Gypsy, Traveller, Boater, Showman and Roma Health Survey 2012

#### **Background and Purpose of the Study**

This report is the culmination of a specialist health project which was commissioned to run between late Summer 2012 and Spring 2013. The research was jointly commissioned by B&NES Local Authority Public Health Department/Primary Care Trust and North Somerset Primary Care Trust (as they then were) with each commissioning partner receiving an individual report on the circumstances and needs of their local Gypsy, Traveller, Showman, Roma and Boater populations.

The study was complex and multi-dimensional, consisting of a mixed-methods survey (supplemented by additional focus group/individual interview) data from services users from the above communities, as well as a survey (and additional depth-interviews) with health professionals working with the populations to explore issues of health care need, barriers to access and potential solutions for improved delivery of care to the above populations, as well as consideration of the training needs of health professionals working with the groups.

The purpose of undertaking the health audit of Gypsy, Traveller, Boater, Showmen and Roma residents lies both in the local health authorities' commitment to ensuring good practice in equality of delivery to minority ethnic (and other potentially vulnerable) groups, as well as in a desire to be at the cutting edge of engaging with new equalities duties inherent upon Clinical Commissioning Groups to meet the needs of local service users, as embedded within the Health and Social Care Act 2012.

Interviews and the survey with health professionals from a range of disciplines were included in the study to ensure that commissioners are aware of both levels of experience, best practice, skills audit and training needs of professionals within the study locale.

The **Aims of the study** were to: improve understanding of the health needs of Gypsy/Traveller/Boater/Showmen communities in B&NES with a particular emphasis on their experience of accessing health services, and health behaviours.

#### With the **Objective** of:

delivering	а	reliable	information	source	to	inform	the	planning	and
commissio	ning	of health	services						
providing re	eco	mmendati	ions, informed	from be	st pr	actice, of	fserv	ice models	

#### Methods

The study utilised a mixed-methods approach. Trained community interviewers from the communities in question administered face to face surveys to 66 Gypsies/Travellers/Showmen and Boaters.

In addition an e-survey (see further below) was administered to 40 professional health staff.

Follow up depth interviews were undertaken with 3 health care professionals and a further 3 Boaters and New Travellers in addition to a focus group with members of the Boater community.

Analysis was undertaken using a combination of 'framework' (thematic analysis of qualitative data) and statistical/quantitative analysis of the Excel spreadsheets into which all other information had been entered.

#### Sample Size/Key Topics

In total, 66 very in-depth interviews were achieved with the following groups of service-users: 5 English Gypsies; 6 Irish Travellers; 1 Scottish/Welsh Traveller; 21 New Travellers; 2 Showmen; 30 'Boaters' and 1 individual who classified themselves as 'other'. Despite significant efforts to achieve a sample from the Roma population it was impossible to do so within the time scale as a result of geographical movement amongst this population within the survey period.

Only 6 Boaters (20%) had moorings. Most who responded (56%) reported a high degree of nomadism enforced by their circumstances/Canals and River Trust legislation, moving every 2 weeks.

Respondents (all categories) reported living in their present home location for an average of 5-8 years ranging from 2 months to 20 years and 2 months.

The duration/average length of remaining in one location was greatest for Ethnic Gypsy/Travellers living either in housing or on authorised sites. One English Gypsy respondent indicated that they had lived on their private authorised site for slightly over 20 years, and an Irish Traveller housed respondent had been in her current (privately rented) property in excess of six years. One housed New Traveller (seasonally mobile) had lived in housing for 10 years. Irish Travellers (all housed) had been in their current property for an average of 39 months.

Of those New Traveller respondents living on roadside/unauthorised encampments who provided a duration of stay at their current location, the average length of residence was 25 months. Respondents were also surveyed across a range of issues pertaining to the physical environment at their current location (access to water, heating etc) with the majority reporting a satisfaction rating of around 4-5/7 in terms of facilities. The attitudes

of neighbours to Gypsies/Travellers remained however the lowest rated score across all domains and for all communities.

#### Subject matter of Questionnaire

Whilst Boaters and New Travellers were willing to provide information across a full range of topics (including access to contraception; substance (mis)use and use/preference in sexual health services); for strongly held cultural reasons no Irish or Welsh/Scottish Travellers and no English Gypsies would respond to these elements of the survey.

Significant information was gathered from all communities included in the sample in relation to access to services (including emergency care and experiences of A&E services), health needs, barriers to registration with GP and other primary care services; prevalence of particular conditions (including findings pertaining to high levels of smoking, substance issues within some populations) and preferences and experiences of terminal care for members of their communities. Data was also collected on the strength of community networks/availability to support from peers during times of illness.

Across all communities the degree of intra-community cohesion was stronger than found amongst the majority of 'mainstream' communities indicating thick levels of social capital. In contrast all populations surveyed demonstrated levels of distrust and only moderately good relationships with surrounding populations who were reported to relatively unfriendly towards Gypsies/Travellers in their midst. Boaters reported the lowest levels of discrimination towards their community although some concerning findings emerged in relation to attitudes of some health staff towards Boaters, a theme echoed by New Travellers who reported stereotypical assumptions by some health staff in relation to presumptions of substance misuse by this population, leading at times to refusal of adequate analgesia following injury.

Full information on the survey topics can be found by reviewing the questionnaire provided at Appendix A to the full report.

#### Professionals' Survey

The 'professional' health workers e-survey (see Appendix B of the full report) was made available to a broad range of health professionals (including dental surgeons) via an 'survey-monkey' e-link<sup>1</sup>, as well as in alternative paper or email format. This element of the study was administered by the commissioning Local Authorities/Primary Care Trusts (PCT) who organized distribution of the survey to their staff and associated networks (e.g. opticians, dental surgeries, etc). The professional survey was significantly shorter than that administered to service users in respect of time constraints and the themes

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<sup>&</sup>lt;sup>1</sup> Surveymonkey is a commercial programme which allows (for a very reasonable subscription charge) questionnaires to be set up on-line and emailed to an infinite number of participants. Use of the programme permits simple analysis to be undertaken at the point of downloading of responses into a simply Excel spreadsheet. See further: http://www.surveymonkey.net

which we wished them to address which varied although complemented those selected for service users.

In total 40 health care professionals from B&NES participated in the e-survey which explored subjects pertaining to degree of experience of working with different Gypsy/Traveller/Boater/Showmen communities, understanding and concerns pertaining to specific health conditions/barriers to engagement across the communities, questions around the relevance of 'hand-held' medical records, training needs for health care professionals and recommendations for engagement with the communities in question.

Follow up depth interviews (as well as the single focus group held) explored a number of these findings in greater depth with both professionals and service users to allow triangulation of specific themes from the point of view of services users and providers (e.g. how health care is accessed; understanding of culture and community; particular difficulties in relation to ease of attendance for appointments or health care professionals ability to deliver services at sites and on towpaths. The topic guides used with both professionals and service-users for depth interviews/focus group can be accessed at Appendix D to the main study.

#### **Summary of key themes**

#### Findings from Questionnaire / Community Members' Survey

Whilst there is an increasing body of evidence on the unequal health status of Gypsies and Travellers and increased rates of morbidity and mortality (e.g. Cemlyn et. al., 2009; Parry et. al., 2004²) to the best of our knowledge this is the UK's study of the health status of 'Boaters' (itinerant Canal dwellers) and one of a tiny handful of studies which includes information on the health status and beliefs of New Travellers (see further Cemlyn et. al. 2009).

Findings from this study has revealed that members of these populations are marginalised from mainstream health care and experience significant barriers to access to services as a result of their lack of secure accommodation raising concerns that these populations (including children) are at significant risk of experiencing like-for-like health exclusion when compared with 'ethnic' Gypsy and Traveller populations. Moreover, there is a general absence of recognition of the needs of these communities by health practitioners who in the main fail to monitor their health status and access to services.

<sup>&</sup>lt;sup>2</sup> Cemlyn S, Greenfields M, Burnett, S, Matthews, Z & Whitwell, C (2009) *Review of inequalities experienced by Gypsy and Traveller communities* London, Equalities and Human Rights Commission (EHRC), available at:

http://www.equalityhumanrights.com/en/publicationsandresources/Pages/InequalitiesGypsyandTraveller.a spx; Parry, G; Van Cleemput, P, et al (2004) *The Health Status of Gypsies and Travellers: Report of Department of Health Inequalities in Health Research Initiative*, Sheffield: University of Sheffield, available at:

http://www.shef.ac.uk/polopoly\_fs/1.43714!/file/GT-final-report-for-web.pdf;

The study has revealed that whilst the small number of 'ethnic' Gypsies and Travellers accessed in B&NES are relatively well served in terms of access to health care, residents of authorised sites (Romany Gypsies) are as likely as those on unauthorised sites to report that health professionals (even on occasion ambulances) will not come out to sites, referring to difficulties in identifying locations by postcode.

Of those respondents who replied to questions on numbers of enforced moves/evictions within a three year time period – Boaters averaged 4 moves and New Travellers 3 such movements although the majority of respondents emphasised continual 'semi-voluntary' movement on a fortnightly basis to comply with Canal and River Trust (CRT) regulations or in the case of Travellers prior to accessing the local 'tolerated' sites, to avoid eviction/negative engagement with local authorities.

Whilst a significant proportion of New Travellers cited moving to a site to join family and friends/lifestyle issues amongst Boaters 59% stated that they had adopted their current lifestyle as a result of the high cost of living in housing. The demographics of boat dwellers (whilst including a percentage of young couples and women) tended towards middle aged and older males (often single) and anecdotal evidence (coupled with indications from self-reported health conditions) suggested that there may be an over-representation of alcohol misuse and depression amongst this latter group. Other communities were significantly more likely to be co-residing as couples, often with resident children (average of 2 per household other than Irish Travellers who averaged 3 school age children per household).

GP registration was frequently only obtained for our sited sample after some considerable difficulties, on occasion (even for households with families) following intervention by specialist services such as Julian House (homeless health services) who were regarded by Travellers as helpful and highly supportive but not necessarily appropriate for meeting their needs given their moderately long-term residence at local sites.

There was fairly low use (in the main) of optical and dental services even amongst some populations at risk of age-related visual degeneration. Use of screening services was also relatively poor amongst the majority of the sample, largely because of challenges to registration and a culture of only accessing primary care services at times of need.

In relation to attitude to health service use, 30% of respondents said they would only use a doctor/hospital as a last resort if someone in their family was very seriously ill/injured, and a further 21% said they would use a GP/hospital whilst, for example, using alternative medicine at the same time.

A number of respondents reported self-treatment varying from buying and administering pain-killers over the counter to pulling their own teeth. One respondent (with medical knowledge) interviewed in depth recounted a fellow- Boater who had taken a

dangerously high level of pain-killers after experiencing problems in accessing appropriate health care.

Alternative medicine (including use of herbal remedies) is used by two thirds of the sample including all but one New Traveller and most (87%) of Boaters.

Limited use was made of pharmacists for seeking health advice amongst the sample and the majority of medical advice was achieved via GPs (problematic for some people), via the internet or through specialist Gypsy/Traveller websites.

Significant interest was expressed by the overwhelming majority of ethnic groups/communities in using trained community health advocates for assistance with accessing health promotion advice and to liaise with service providers.

It was in fact suggested by one professional (Pharmacist) that pharmacy-outreach including safe dosage/compliance advice and medical checks could effectively be delivered to site residents as part of a package of multi-disciplinary care offered to sited Gypsies/Travellers resident in the local area.

Whilst midwives and health visitors are the practitioners most likely to attend and deliver services in a variety of locations – including on boats and at unauthorised sites at difficult locations – there is a lacuna in services for many of the individuals interviewed.

Boaters in particular are likely to experience continual movement as a result of CRT regulations and in many cases GPs were in excess of 20 miles distant from the current place of residence. Boaters in particular reported experiencing numerous injuries associated with their way of life (spinal injuries, falls, cuts and chainsaw accidents) as did some New Travellers.

Health care staff and ambulances were not always able to identify or reach individuals at unauthorised locations and boaters in areas with limited towpath access (or where a location is only identifiable by 'bridge numbers' which is not accessible via SatNav systems) could in effect be cut off from health care leading to significant risk of severe injury or death, 'self-treatment'; or long journeys to A&E for treatment.

Smoking, anxiety and depression were revealed to be key health concerns for both service users across the communities as well as being identified by health care providers as issues they had encountered. Injuries associated with residence on sites and in boats (e.g. saws, axes, muscular-skeletal pain) and arthritis/asthma were also somewhat over-represented amongst the populations surveyed.

Given challenges to accessing health care when mobile, there was a relatively high degree of interest in accessing hand-held medical records amongst service-users (43% of the sample).

For those patients who are registered with a GP access to appointments/level of care are regarded as reasonably good. Strongly gendered preferences for access to a GP of the appropriate gender were found (unsurprisingly) amongst Irish Travellers and English Gypsies significantly more so than for the other communities surveyed.

Although satisfaction levels with primary health care were reasonable, information was provided on instances of prejudice or lack of understanding of the barriers experienced by Traveller/Boater communities. Suggestions for training of health staff – particularly reception and A&E practitioners in 'respect' and 'cultural issues' were particular stressed by some New Travellers and Boaters.

It was emphasised repeatedly that the communities who participated in the studies would welcome specialist in-reach to them on health – as long as it was devised in partnership with service users and was 'appropriate' and not patronising.

There was a relatively high degree of interest in accessing 'healthy living' events with 21% of respondents indicating that they would participate in special Traveller/Boater health events.

In addition, a number of respondents to the survey (as well as the depth interviews) reported that they would be interested to some extent in engaging with health care staff to work on devising health promotion materials and sharing 'ownership' of any future initiatives such as 'health boats' or 'towpath clinics' for Boaters.

One finding of particular concern regarded the very low level of reporting/help-seeking behaviour indicated by the survey in relation to domestic violence or substance misuse. It is strongly recommended that sensitive in-reach should be undertaken in partnership with health professionals with experience of the communities (or who are of the communities) to consider ways of encouraging trust and addressing issues of this type in a way which proves acceptable to service users from these populations.

There was a very strong concurrence across all parties that care of older and disabled Gypsies/Travellers and Boaters as well as terminal care as required would be preferred within community settings although a number of barriers to accessing support were reported by participants – not least refusal of assistance in relation to 'non-standard' support packages such as asking carers to assist in chopping wood or opening lock gates. As such care is typically provided on a voluntary basis by community members and levels of knowledge of support packages remains low, whilst social care staff are often highly unfamiliar with the needs of Gypsies/Travellers/Boaters.

Information pertaining to bereavement support practices and preferences were provided in some detail – overall whilst only very few respondents had made use of professional bereavement support services, there were indications that if culturally aware counsellors were available that 64% of Gypsy/Traveller/Boaters respondents would potentially make use of such services.

#### Findings from the Professionals' survey and interviews

Overall 32.5% of respondents to the Professional/Practitioner survey reported having had contact with Gypsy/Traveller/Boater communities in their practice.

Both those with experience of the communities and those without tended to identify similar concerns in relation to supporting Gypsies/Travellers and Boaters health, mainly issues of ensuring continuity of care for mobile communities, lack of understanding of culture/culture clashes over compliance with treatment, and the challenges of working on sites/towpaths. These were key themes raised consistently by across a fairly wide range of practitioners.

Whilst there was some adherence to stereotypes (e.g. substance misuse issues for New Travellers, domestic violence amongst Irish Travellers; stress and anxiety within the communities, etc.) in the main professionals indicated similar health priorities/prevalence ratings to those flagged up by service users, with the exception of recognition of the high rate of smoking within some populations.

Around 37% of all respondents indicated that they did have worries or concerns about delivering care to Traveller/Boater populations – and again these tended to consist of a mixture of practical issues – movements/compliance with treatment and openly expressed fear (e.g. of dogs, of going on site etc).

A substantial minority indicated strongly that their lack of cultural knowledge was of concern in terms of delivering treatment to these communities. There was very poor knowledge amongst professionals of the existing specialist health visitor services available to Gypsies/Travellers/Boaters whose members possess significant expertise which can be drawn upon by other medical/care staff. Interest existed with regard to the potential to commission cross-boundary expert teams to work with Gypsy/Traveller and Boater populations.

Overall whilst professionals are generally interested in working with these populations and concerned about their state of health (and see further Qualitative data gained from one-to-one interviews/focus groups presented in Part Four of the main report) there appears to be (other than amongst a small group of experienced Professionals) limited knowledge of the populations, lack of confidence dealing in Gypsies/Traveller/Boater populations and poor knowledge of where and how to access specialist advice. Accordingly this leads to lost opportunities to make positive impacts on the health and wellbeing of members of these populations.

Whilst there are clear commissioning/boundary difficulties to be overcome there is a consensus that inter-area working would be useful for both professionals and community members.

The oft-cited anecdotal barriers to engagement with GRT/Boater communities had not been experienced by the professionals interviewed for this section of the report.

Overall the effectiveness of READ (a coded thesaurus of clinical terms Read Codes are the basic means by which clinicians record patient data pertaining to key factors impacting on health, conditions and procedures in health and social care IT systems across primary and secondary care (e.g. General Practice surgeries and pathology reporting of results) codes in identifying patients would appear to be low and two professionals expressed some unease over perceived targeting of populations.

There was little knowledge over how to undertake in-reach to housed populations of GRTs in the local area.

Hand held records (either by app or in paper format) to be retained by patient with a copy at a central location were regarded by all respondents as of use in their particular areas of expertise and a positive step towards ensuring continuity of care for mobile patients.

The use of tailored materials on health literacy/promotion for GRT/Boaters and diverse mechanisms for delivering these was regarded as a step to be welcomed, with participants offering a range of ideas which are known to have worked for other populations or in different areas.

#### **Recommendations for Practice**

This concluding section of the Executive Summary) draws together a range of themes from across the findings of all three elements of the study and summarises suggestions for health improvement/good practice across B&NES and the wider locality.

#### Recommendations for Commissioners targeted at 'professional' staff

#### Registration with GP surgeries and access to primary care

Given the barriers to registration reported by a high percentage of mobile respondents (including those with children or long-term conditions) there is an **urgent** need to engage with surgeries over the issue of registration of GRT/Boater/Showmen populations as both temporary and permanent patients. (potentially through emphasizing Duty of Care responsibilities).

Use of READ codes (for all services in contact with the populations) should be urgently reviewed to include flagging for cases of members of the above communities. We would suggest that as a minimum recommendation that all coding should be entered to ensure that New Travellers and Boaters as well as Gypsies/Travellers and Showmen are entered as sub-categories of a particular code to enable monitoring of prevalent health conditions/awareness of potential environmental health dangers.

Department of Health (DH) guidance on fast-tracking Gypsies/Travellers (Primary care service framework: Gypsy and Traveller communities, 19th May 2009) should be emphasized to all primary care and front-line staff (including receptionists)

http://www.pcc-cic.org.uk/sites/default/files/articles/attachments/ehrg\_gypsies\_and\_travellers\_pcsf\_190509.pdf

It may be that particular practices wish to apply for 'enhanced service' status in relation to Gypsy and Traveller (and Boater) groups following discussion with CCGs – a model utilized with great success in Leicestershire where levels of trust have been enhanced, immunization rates increased and rates of A&E use and emergency hospital admissions for these populations have decreased. See further Annex 3 of the DH guidance 19/5/09 (above).

It is to be recommended that in line with Health Inclusion priorities practices which are known to have Gypsy/Traveller/Boater populations on their books in either a temporary or permanent basis should take the opportunity to undertake 'outreach' work and encourage health checks/screening, immunisations for a number of standardized conditions (e.g. cardio-vascular, BP, weight, diabetes etc.) as well as engaging (where possible) with communities/conditions outlined elsewhere in this report (see Table 7) and discussing with community members whether they require referrals/monitoring of other conditions.

Where possible continuity of care (ability to see the same GP) and an automatic offer of 'same gender' practitioners should be offered to all patients. 'Ethnic' Gypsies and Travellers are however particularly likely to require access to same gender physicians for cultural reasons.

Midwifery services should be encouraged to review home birth policies and consider if these are flexible enough to offer home births to Travellers/Boaters where circumstances are safe.

Guidance on the 'postcode' issue should be provided to surgeries (as well as other practitioners required to attend call-outs to site dwellers/boaters) to ensure that reliance on sat-navs and IT technology does not result in vulnerable individuals and families being denied care.

Guidance is also **urgently** required on the use of 'bridge numbers' for attending/accessing patients on boats as well as open discussions on whether staff feel able to 'cross gangplanks' or enter onto sites – e.g. training on hazards and fears for professional staff.

Assistance should be routinely offered in regard to form-filling/literacy. We would recommend that this takes place for all patients to avoid stigmatizing particular groups.

It is recommended that rather than rely on letters to contact patients which may be sent to 'care of' addresses, greater use is made of phone calls/personal visits and texts to contact GRT/Boaters (following discussion with service users re: practicality of various methods of contact).

Care should be taken to ensure that follow-up care (e.g. post hospital discharge) is provided to residents of sites/boaters and that awareness of 'danger signs' are

understood as well as what actions should be taken (cf. example of infected wound experienced by Boater – Part Four)

#### Hand-Held Records

It is recommended that trials of use of hand-held records are undertaken in B&NES (as well potentially as surrounding areas) to see how effectively they can be used/how feasible they are for different communities and ensuring continuity of care during cross-boundary movement. In the longer-term there may be some scope for use of Apps on mobile phones or remote access to records via lap-tops to allow patients to retain at least some crucial health records pertaining to on-going care.

#### Cultural/Health Awareness Training

Immediate (and relatively cost-effective) changes which could be brought into force are delivery of specialist training (including on the findings of this report) to a range of health professionals, access to specialist resources (drawn up potentially with local Boaters/Travellers as well as utilizing pre-existing health resources from agencies such as Derbyshire Gypsy Liaison Group; Leeds GATE and Friends, Families and Traveller and those under development via Inclusion Health projects, as well as enhanced awareness of the existence of specialist Traveller health visitors in the B&NES locality.

Commissioners and all healthcare staff should be made aware of the sense of 'difference' articulated by Boaters and GRT people with regard to their health care needs, cultural practices and the evidence on increased rates of health needs amongst particular communities (see Table 7).

Training materials should be devised (in partnership with community members where possible – perhaps through the auspices of creating health fora for potentially vulnerable groups) which a) highlight health conditions and cultural factors pertaining to different communities and b) include wherever possible active participation of members of the communities in question to deliver training on their culture and health care preferences, as well as permitting consideration of devising information which challenges common practices (e.g. information on low take up of screening during pregnancy amongst pregnant NTs) in an acceptable manner to service-users.

Practitioners from a range of disciplines should be strongly encouraged to attend cultural/health awareness training in relation to GRT/Boater/Showmen. CPD points could be offered as part of the incentives for attending such training. Training may potentially be delivered as part of a wider training day (see comments above from reception staff) or as stand-alone modules.

That consideration should be given to training and employing (perhaps on a sessional basis) 'community health advocates' from local service-user groups given the very high level of interest in engaging with local GRT/Boaters employed in such roles.

Health Care providers should be alerted to the potential strengths of membership of GRT/Boater communities (see findings re: support when ill) as well as receive training on the potential tensions/discrimination experienced by housed GRT people, as well as the risk of isolation/impact on community members of movement into housing.

Showing Dignity and Respect – participants need to receive information on the practical difficulties which may pertain for GRT/Boater/Showmen in terms of muddy sites, physical space on boats/in trailers or evictions during training. Practitioners should be encouraged to consider both practical challenges faced by service-users as well as to reflect on stereotypes they may hold – e.g. attitudes cited by a number of respondents pertaining to provision of adequate analgesia for New Travellers/Boaters treated at walk in and A&E clinics; assumptions of high risk of substance misuse, or 'fixed' health beliefs; receptionists objecting to 'mud on floor' when someone comes in from a site etc.

#### Other

It may thus be, that there is some scope for benefits advice outreach work to be undertaken by local advice agencies/CAB etc. (potentially through 'site drop in'/floating clinics etc. if these are utilised) with Romany Gypsies and Boaters given the percentage of these populations with no knowledge of benefits rights reporting caring for household members had a range of conditions including mobility problems, cardiac difficulties, depression etc.

Where service users have indicated that they require information on particular health care topics this information should be provided (confidentially) to those who made such an approach.

There may be scope to wider information dissemination on walk in confidential services in relation to contraception, sexual health and sources of advice on Domestic Violence assistance within the communities. This may be targeted (e.g. through leaflets etc.) or take place at special 'drop-in' services in accessible locations e.g. Julian House etc.

Inter-agency training and close liaison with a range of agencies (including Avon Consortium Traveller Education Service: ACTES who will already have contacts with housed Gypsy and Traveller populations) as well as local authority social care should be carried out to ensure service users are alerted to specialist health care initiatives and practitioners/agencies receive materials on/have increased awareness of a) greater prevalence of some health conditions including common stress/mental health issues, substance misuse amongst some communities and b) that for individuals in need of a social care assessment for support, chopping wood, carrying water and moving boats are not 'unusual' and hence should be included in assessments of need as standard if detailed by clients as part of their lifestyle.

Terminal/Palliative care services – delivery of information and advice on GRT/Boater preferences for palliative care should be shared with care providers. Liaison and shared policy approaches should where possible be devised with agencies such as

hospitals, hospices and the CRT in relation to delivery of care, and for boaters access to longer-term moorings and support for boaters with health conditions and long-term/terminal illness to support them in remaining at home or dying with dignity in their preferred environment.

#### In-Reach and Specialist/Shared Services

We strongly recommend that consideration is given to commissioning cross-border/shared practice inter-disciplinary teams to undertake work with Boaters and New Travellers/nomadic Gypsies and Travellers (including the church/spiritual groups working with Boaters).

Professionals from a range of disciplines should be encouraged to liaise with health specialists and 'meet communities' (e.g. through liaising with local site residents and being introduced as health care professional with an interest in working a particular population - see comments under Part Four by Pharmacist) or as an option during training/refresher courses.

Pharmacists/Dentists and Opticians with a particular knowledge of or interest in working GRT/Boater/Showman populations could apply for a logo/sticker (similar to a quality mark) which could be displayed subject to training/service-user review of services indicating 'enhanced services' (including willingness to provide 'walk-in' services/ medicine reviews etc.) as possible. Such practices (as well as GP surgeries and experienced HVs etc.) should be made known to specialist websites/community groups for recommendation to callers/website users. Julian House (Bath homeless unit) could also retain a list of experienced/enhanced service providers in B&NES and neighbouring areas.

Based upon best practice and community/expert practitioner experience we would suggest that an identified GP or HV lead (a 'health champion') should be appointed (perhaps attached to an enhanced service GP practice if this is the preferred/selected model) and the coordinating practitioner is able to call upon the services of pharmacists, dentists, psychiatric nurse and other specialists such as sexual health and smoking cessation teams as required to offer 'on site'/towpath clinics on occasion (e.g. 3 x a year at specified locations), as well as being the designated first point of contact for newly arrived GRT/Show/Boater populations who prefer to access a specialist rather than utilize standard community/primary health care facilities. The lead practitioner would also operate as a referral point and liaise closely with Julian House and/or practices known to be used by relatively high numbers of Travellers/Boaters.

Practitioners embedded within communities (e.g. nurses living on boats) should be encouraged to self-identify and be offered the opportunity to take on a designated liaison role or 'health champion' post for their population.

We would encourage commissioners to consider developing/commissioning programmes such as the Buckinghamshire New University/Buckinghamshire PCT/One

Voice for Travellers 'smoking cessation' course delivered to Gypsies/Travellers by trained members of their community which included the use of culturally tailored materials and was perceived of as 'not patronising' by recipients

As READ codes become used more commonly for these communities it will be easier to map patterns of service use and numbers of GRT/Boater/Showmen registered with practitioners across B&NES and neighbouring areas assisting in health intelligence and targeting of resources.

#### Sources of information/health promotion materials

A variety of health promotion and health rights materials (e.g. cartoon, DVD, leaflets, apps. etc. as detailed within the report) should be devised in conjunction with community members (to enable 'ownership') and health professionals with experience of working with these groups of service users to promote healthy lifestyles, eating, and enhanced awareness of gendered approaches to health promotion/symptoms.

There should be a targeted drive to reduce use of A&E by service users other than when urgent, by improving awareness of and access to preventative care/minor injury units as well as active encouragement of GPs to register patients.

Materials should be developed for distribution in conjunction with local service users and GRT specialist community groups (preferred route of health advice for some survey participants) in relation to common conditions, as well to encourage take-up of pharmacist services; increased access to dental and optical services and screening for common health conditions. Materials aimed specifically at male GRT/Boaters should be considered a priority given findings in relation to attitudes to health care and service use.

Specialist materials (health promotion, rights to temporary registration and information on the availability of services designed in partnership with community service-users) could be disseminated at locations where GRT/Boaters are known to use services (e.g. Julian House, markets, community centres etc. as well as made available via specialist website and community agencies such as the K&A boaters group, Friends, Families and Travellers, as well as distributed to residents of new unauthorized encampments and made available to health professionals resident on canals for distribution to fellow Boaters.

See above for recommendation on the training of health advocates within particular communities who are linked to specific communities/locations (e.g. tolerated sites) in addition, 'help lines' where GRT/Boater communities know that on particular dates or times they could speak confidentially to a 'health champion' with regard to particular health issues/conditions etc. could be promoted in conjunction with other 'out-reach activities'.

#### Recommendations for engagement with service-users

#### Registration with GP surgeries and access to primary care

Given that one third of New Travellers and 20% of Boaters were unaware of the right to register as a temporary patient (although most 'ethnic' Gypsies/Travellers and Showmen were) there is an **urgent** need of health rights information campaigns for these particular categories of respondent.

As noted above there is an urgent need to liaise with health and social care professionals living on sites/in boats and engaging them along with other community members (e.g. Showmen, Gypsies, Irish Travellers) in health fora/reference group to work closely with CCGs in devising and planning outreach services, involvement in training and the preparation of relevant information and health promotion materials for dissemination to their communities.

Materials developed – e.g. gendered health promotion, information on inoculations, rights to follow-up care, information on particular conditions etc. should be reviewed and disseminated via community groups and forum members wherever possible.

Work with Boaters in particular should be undertaken which enables consideration of forward planning for suitable health and social care services to be delivered to an ageing population/where cultural barriers may lead to self-neglect of conditions through fear of lack of understanding from service providers. For Boaters in particular this will involve potentially setting up and convening space for working with CRT over supporting older boaters and access to moorings for health requirements or the equivalent of 'floating retirement moorings'.

If health advocates are to be trained/appointed there is a need for 'ground work' to be undertaken with community members in advance of such programmes being put into action. We would recommend that such outreach commences as soon as possible whilst there is a momentum and interest in the findings of this project.

#### Acknowledgements

#### Project team

Core team members: Dr. Margaret Greenfields; Liz Lowe; Sylvie Parkes; Jackie McPeak (Buckinghamshire New University and IDRICS)

We especially wish to thank the following associated team members: advisors/interviewers/external experts for their assistance and support with this project without which it could not have been completed.

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Justine Curtis; Shelley Oakley; Kay Sandy.

Coordinating Client Contact: Denice Burton

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# The Bath and North East Somerset Gypsy, Traveller, Boater, Showman and Roma Health Survey 2012

#### **PART ONE**

#### 1. Introduction and Background

This report is the culmination of a specialist health project which was commissioned to run between late Summer 2012 and Spring 2013. The research was jointly commissioned by B&NES Local Authority Public Health Department/PCT and North Somerset PCT (as they then were) with each commissioning partner receiving an individual report on the circumstances and needs of their local Gypsy, Traveller, Showman, Roma and Boater populations. The study was complex and multi-dimensional, consisting of a mixed-methods survey (supplemented by additional focus group/individual interview) data from services users from the above communities, as well as a survey (and additional depth-interviews) with health professionals working with the populations to explore issues of health care need, barriers to access and potential solutions for improved delivery of care to the above populations, as well as consideration of the training needs of health professionals working with the groups.

The purpose of undertaking the health audit of Gypsy, Traveller, Boater, Showmen and Roma residents lies both in the local health authorities' commitment to ensuring good practice in equality of delivery to minority ethnic (and other potentially vulnerable) groups, as well as in a desire to be at the cutting edge of engaging with new equalities duties inherent upon Clinical Commissioning Groups (CCG) to meet the needs of local service users, as embedded within the Health and Social Care Act 2012.

Interviews and the survey with health professionals from a range of disciplines were included in the study to ensure that commissioners are aware of both levels of experience, best practice, skills audit and training needs of professionals within the study locale.

It has been long established that Gypsies and Travellers experience poorer health than surrounding main-stream populations (Parry et. al., 2004; Irish Traveller Movement Britain, 2012a; Ministerial Working Group, 2012; Cemlyn, et. al. 20093). Whilst there are

<sup>&</sup>lt;sup>3</sup> Parry, G; Van Cleemput, P, et al (2004) *The Health Status of Gypsies and Travellers: Report of Department of Health Inequalities in Health Research Initiative*, Sheffield: University of Sheffield, available at:

http://www.shef.ac.uk/polopoly\_fs/1.43714!/file/GT-final-report-for-web.pdf; *Ministerial Working Group on tackling inequalities experienced by Gypsies and Travellers,* (2012), paragraph's 3.1 - 3.4

http://www.communities.gov.uk/documents/planningandbuilding/pdf/2124046.pdf
Cemlyn S, Greenfields M, Burnett, S, Matthews, Z & Whitwell, C (2009) *Review of inequalities experienced by Gypsy and Traveller communities* London, Equalities and Human Rights Commission (EHRC), available at:

http://www.equalityhumanrights.com/en/publicationsandresources/Pages/InequalitiesGypsyandTraveller.a

increasing numbers of small scale health studies or best practices interventions across the UK which set out to explore the circumstances of local Gypsy and Traveller populations or to engage with identified inequalities (for example a number of Department of Health funded 'Pacesetters' projects in the early-mid 2000s focused on Gypsy and Traveller populations), and despite the fact that members of the 'ethnic' Gypsy and Traveller populations are known to reside in or resort to around 94% of local authority areas (Cemlyn et. al, 2009; CRE, 20064) knowledge is at best 'patchy' on access to services and general health needs and preferences of these populations.

Whilst Gypsy Traveller Accommodation Assessments (GTAAs) such as the West of England GTAA, (Greenfields, et. al, 20075) have been able to shed some light on population demographics and prevalence of health conditions amongst Gypsy/Traveller survey respondents, it is the considered opinion of a number of specialist Gypsy/Traveller voluntary sector agencies (such as the Irish Traveller Movement, 2012b6) that the current state of knowledge (particularly in the light of very limited ethnic monitoring of the populations by NHS agencies) is inadequate and incapable of enabling health services providers and commissioners to fully address the lowered life expectancy and oft-reported barriers to service access found amongst these groups. Moreover, for non-ethnic 'nomadic/Traveller' populations (e.g. New Travellers, Showpeople) and the relatively new migrant East European Roma populations, the state of knowledge is even less, given that these groups tend to be excluded (either actively or by default) from health research /outreach initiatives.

Boaters (narrow boat/canal residents) are another group about whom almost nothing is known. Their inclusion in this current study is (to the best of our knowledge) completely unique in the UK, and whilst they clearly are distinct from other groups included in this research they perhaps bear the greatest resemblance to 'New Travellers' coming (overwhelmingly) from formerly sedentary populations, and in some cases being former 'New Travellers' who have migrated onto the water to avoid eviction and site access problems. Whilst facing broadly similar accommodation/enforcement issues to other nomadic populations (a theme which emerged strongly in focus groups and individual interviews), this population, which are fairly numerous in the B&NES area as well as in other localities have been completely ignored in health data terms in the past, and thus prior to this study it has been impossible for health authorities to gain any concept of the extent of their health needs or population demographics with the intent of planning for service delivery.

spx Irish Traveller Movement (Britain) (2012a), *The Health and Wellbeing of Gypsies and* Travellers: an ITMB briefing, London, ITMB available at: http://irishtraveller.org.uk/wp-content/uploads/2012/03/ITMB-Gypsy-and-Traveller-Health-Briefing-March-20122.pdf

<sup>&</sup>lt;sup>4</sup> Cemlyn et. al., (2009) op. cit.; Commission for Racial Equality (CRE) (2006) *Common ground: equality, good race relations and sites for Gypsies and Irish Travellers*. London: CRE.

<sup>&</sup>lt;sup>5</sup> Greenfields, M. Home, R et. al. (2007) West of England GTAA available at: http://www.southwest-ra.gov.uk/media/SWRA/RSS%20Documents/Gypsies\_and\_Travellers/West\_of\_England\_GTAA.pdf 
<sup>6</sup> Irish Traveller Movement Britain (2012b) Inclusion and ethnic monitoring of Gypsies and 
Travellers in the National Health Service: an Irish Traveller Movement Britain report available at: 
http://irishtraveller.org.uk/wp-content/uploads/2013/01/ITMB-Health-Report-Inclusion-and-Ethnic-Monitoring-of-Gypsies-and-Travellers-in-the-NHS.pdf

The continued vulnerability of Gypsies and Travellers (and related groups) have meant that the Department of Health/Cabinet Office convened 'National Health Inclusion Board' have designated Gypsies and Travellers as one of four most vulnerable groups (the others being sex workers, vulnerable migrants and homeless people) as key priority groups for health Commissioners, strategic bodies and front-line staff to engage with, with the intent of improving access to primary health care. Other recent significant changes, such as the transfer of duties to Public Health England, also potentially offer opportunities for health and local government departments to work together to tackle wider health determinants and inequalities.

It is thus within this change framework where this innovative project sits, creating a possibility for B&NES CCG to work with partner agencies (such as the Local Authority whose 2012 GTAA was received just prior to this research being completed) to plan and deliver complementary services for those groups considered within this report. In part, this study was commissioned with the explicit intent of supporting a multi-phase joint needs assessment.

Preliminary discussions and planning for this project commenced in late Spring 2012 at which time a joint commissioning brief (devised by B&NES and North Somerset Public Health Commissioners) was prepared, based in part upon the findings from current best-practice and knowledge of Gypsy, Traveller, Roma (GRT) health and the findings from the health elements of the 2007 GTAA (Greenfields et. al., 2007, op. cit.).

#### 1.1 The Health Study Brief

The brief consisted of the following key elements:

To undertake a mixed methods study which incorporated a range of elements (all included in the Questionnaire available as Appendix A) to be administered to a sample consisting of 110 Gypsy/Traveller/Roma/Showmen and Boater community members, with the intent of fulfilling the aims and objectives below.

<u>Aims:</u> to improve understanding of the health needs of Gypsy/Traveller/Boater/Showmen communities in B&NES with a particular emphasis on their experience of accessing health services, and health behaviours.

#### Objectives:

to have a reliable information source to inform the planning and commissioning of health services

to provide recommendations, informed from best practice, of service models.

It was agreed at a very early stage of the contract brief being produced that in line with IDRICS practice in relation to Gypsy/Traveller projects, and successful follow-up studies to our GTAAs, - community interviewers would be commissioned and trained to work on this study, supported by the core academic team from Buckinghamshire New University.

Where possible it was agreed that interviewers who had worked on previous GTAAs (as well as the recent 2012 site identification study for North Somerset) would be recruited to work on this project. However (see further below under methodology) this did not prove as simple as envisaged and as a result of various personal circumstances as well as difficulties in accessing respondents a number of interviewers were unable to remain with the project for its full lifespan leading to changes of personnel and the need for some interviewers to attempt to engage across ethnic groups in terms of seeking interviewees.

Despite the fact that this programme was first envisaged in early 2012, as a result of pre-existing commitments the Buckinghamshire New University research team were unable to commence the project until the late summer/early autumn of 2012. Thus ultimately the research was commissioned to commence with training for community interviewers in early September 2012 with a completion date of the study in late March 2013. This report presents the results of the consultation.

#### 1.2 Development of the Sampling Frame/Access to Sample

As part of the planning phase of the study an indicative sample was drawn up (shown at Table 1 below) consisting of all of the main groups known to be resident in the area.

Some considerable debate existed over including Roma populations into the sample as the health authority were unaware of any Roma resident in B&NES. IDRICS team members had however noted Roma present in the locality selling Big Issue in Bath and surrounding areas and a (in retrospect overly ambitious) number of Roma were included in the sample frame with the intent of discovering more about the needs of these populations in the study area.

Regrettably, despite a number of attempts to contact Roma and very helpful on-going liaison with the Big Issue local office and outreach projects in Bristol who had had contact with local Roma the research team were totally unsuccessful in accessing members of the Roma community. In part, we understood that this related to the sudden (although not uncommon) departure of local Roma families who had been in contact with the Big Issue staff team to other unknown areas, shortly before a planned attempt to engage with the sellers at the Big Issue offices in Bath; and secondly, the discovery that a number of Roma who utilized services, or worked in the B&NES study area were in fact resident in Bristol and surrounding localities, commuting for employment purposes.

Two interviews with Roma did in fact take place and it was believed that they were residents of B&NES but after interview, on reviewing the postcodes provided for their primary place of residence it was found that they were also living within the Bristol locality although they had initially indicated to the IDRICS team member (who was able to provide translation services for those particular interviewees) that they were B&NES residents.

In drawing up the remainder of the sampling frame (see Table 1 below) we concentrated largely on New Travellers (of whom a relatively large number of households are known to be resident at two sites in B&NES) and Boaters, as although we were also keen to access local Gypsy and Traveller residents, we were aware that a generally greater understanding of the health needs of those populations exists, in contrast to the minimal state of knowledge pertaining to the other groups in B&NES. Showpeople were also included in the sample although we were aware from contacts within the Show community that only very limited numbers of occupational nomads who are members of the Showmen's Guild and other associated professional bodies reside in the locality.

The sample was divided by housed and sited populations and framed/based upon the best information available to us from the earlier (2007) GTAA and local knowledge provided by health professionals, existing information on sites provided by the local authorities and advice provided by the community interviewers recruited for this study.

A concentrated effort was made to access respondents at all sites, and at various canals/towpaths with (in some cases) three or four attempts made to gain interviews (see further under Part One (2) Methodology). In practice, not all Romany Gypsy/Irish Traveller sites were accessed as a result of difficulties achieving interviews or local circumstances.

Significant levels of pre-interview leafleting took place (in the cases of Boaters our very energetic interviewers actually made up small posters and positioned these along towpaths) occurred as well as attempts to access informants via word-of-mouth messages to Travellers and professional contacts (e.g. Julian House in Bath; the Big Issue offices) and repeat return visits at various times of the day and evening, as well as weekends and weekdays to sites, houses and towpaths. In addition IDRICS staff attended Traveller Education Service events and met/liaised with Roma outreach specialists in surrounding areas in attempts to ensure that we could access all of the populations included in the sample.

We were fortunate in that B&NES commissioners were as flexible as possible in terms of supporting our attempts to ensure good coverage of all of the populations to be included in the study and agreed to enable a booster sample of Boaters and New Travellers to enhance in-reach to these populations. Ultimately, despite information indicating that perhaps in excess of 60 households of New Travellers reside in B&NES we were only able to achieve interviews with 21 out of anticipated 40 respondents (see below, Table 1).

Regrettably, despite significant efforts by all members of the team (IDRICS staff and community interviewers) and our supportive health and Voluntary Sector contacts we were in the time frame available unable to achieve the sample size initially planned.

Ultimately interviewers were however able to access respondents from all categories other than Roma, carry out interviews at a fairly wide variety of locations (housed, sites,

and towpaths) and achieve a relatively wide sample (equivalent to 60% of the initial sample frame, and - if one excludes the category of Roma - 73% of the anticipated interviews. (See further under methodology for a discussion of the not insignificant challenges met in achieving this number of interviews).

We therefore consider that this ratio of achieved to anticipated interviews may be considered robust enough to provide clear indications of the health needs and delivery preferences of current Gypsy, Traveller, Boater and Showman residents (and their immediate household/family members) within the Bath and North Somerset local/health authority area.

<u>Table 1</u> below presents the anticipated sample and actual number of respondents achieved by category, accommodation type, gender and the age-range of the sample interviewed)

Whilst significant efforts were made to reach housed Gypsy, Traveller and Showman families' resident within the B&NES area, there was rather a short-fall in the number of such households who participated in this study. One community interviewer reported back (in common with comments included in the 2012 GTAA for the locality) that "people don't want to be identified if they are in a house, they are lying low and just access services like anyone else".

Table 1: Sample size by category of respondent, housing status and gender

Ethnicity Category of Interviewee	Anticipated	Housed	Achieved	Housed	Percentage (of planned sample) interviewed	Gender	Age/Range
English Gypsy	5	2 to 3	5	2	100%	3F, 2M	36-64(f) 46-64(m)
Irish Traveller	5	2 to 3	6	6	120%	4F,2M	26-74(f) 36- 64(m)
New Traveller	40	5	21	4	53%	13F, 8M	26-45 (1 m, 1f age u/k)
Showman **	5	2 to 3	2	1	40%	1M, 1F	46-55 (m,f)
Roma	20	20	n/a	2*	0%	-	-
Welsh/Scottish Traveller	0	-	1	1	-	1F	18-25
'Other' (English Traveller)	0	n/a	1	1	-	1M	56-64
Boater 35		n/a	30		86%	12F, 18M	36-74 (m) 28-64 (f)
TOTAL (all categories)	110	25	66	13	60% (excluding Roma = 73% of planned sample)	33M 33F	,

Further information on the Demographics of the service-user respondents is provided below (see Part Two) within the discussion of the findings of the Survey.

#### 1.3 Research Methodology

#### 1.3.1 Professional Survey

As noted above this project consisted of a multi-element research project, accordingly mixed methods (e-survey, face-to-face questionnaire administration, focus groups and follow-up phone/face-to-face interviews were included in the research design for both categories of respondent: health care professionals and 'service users'.

The 'professional' health workers e-survey (see Appendix B) which was made available to a broad range of health professionals (including dental surgeons) via both a 'survey-monkey' e-link7, as well as in alternative paper or emailable format was administered by the commissioning Local Authorities/PCTs, who organized distribution of the survey to their staff and associated networks (e.g. opticians, dental surgeries, etc.). The professional survey was significantly shorter than that administered to service users in respect of time constraints and the themes which we wished them to address which varied although complemented those selected for service users.

These questionnaire for professional staff was drafted by the IDRICS team in conjunction with the public health commissioners in both B&NES and North Somerset and sent out by email by the Directors of Public Health in both areas, along with an explanatory note explaining the purpose behind the study (to explore knowledge of the diverse nomadic/Gypsy/Traveller/Showman and Boater populations in the area, and to enable discussion of training needs and barriers to engagement with services identified by experienced staff).

The covering letter which was distributed with the survey requested that team leaders in a variety of roles, e.g. pharmacists, health visitors, GPs, practice managers etc. distribute the survey to their colleagues and those whom they line manage. Information was also included on how to receive further information about the purpose of the study, or how to contact IDRICS staff members to discuss the overall project.

<sup>\*</sup> subsequently excluded from sample/analysis on discovering not resident within B&NES. A summary of these responses is available on request.

<sup>\*\*</sup> includes one person of Showman heritage who currently lives on a Boat

<sup>&</sup>lt;sup>7</sup> Surveymonkey is a commercial programme which allows (for a very reasonable subscription charge) questionnaires to be set up on-line and emailed to an infinite number of participants. Use of the programme permits simple analysis to be undertaken at the point of downloading of responses into a simply Excel spreadsheet. See further: http://www.surveymonkey.net

Respondents to the survey were offered the opportunity to either participate anonymously or to provide contact details if they wished to have the opportunity to take part in subsequent depth-interviews or focus groups (see further below). In total 40 health care professionals from B&NES participated in the e-survey (further detail of their professional affiliation is provided in Part Three).

#### 1.3.2 Service User Questionnaire/Survey

The commissioning brief and preliminary discussions prior to the commencement of this study agreed that that the research team would replicate so far as was possible the methods utilised during the 2007 West of England GTAA (op. cit), recognizing this as a offering perhaps the most effective way of gaining access to community respondents, particularly when 'sensitive' questions were likely to be asked as in the current survey.

Whilst some aspects of the methodology utilised in the 2007 study were not required as a result of the smaller scale and different emphasis of the current project, certain core elements were adhered to: specifically the use of trained community interviewers with knowledge of the local population and area, and the relatively time consuming although highly effective methodology of undertaking face-to-face interviews with consultees, This method is recognised as being the most effective in terms of maximizing responses from Gypsy and Traveller community members who may be reluctant to self-complete forms or electronic surveys or participate in telephone interviews or who may face literacy and practical barriers which limits their ability to utilise these methods.

As with the 2007 GTAA and the North Somerset 2011-12 site identification study, trained community interviewers undertook the vast majority of interviews with site residents and housed families, although they were supported by an academic team who were available by phone at all reasonable hours to discuss any issues which arose: for example; concerns over interview results or difficulties in accessing or identifying participants. Given the significant difficulties in achieving the sample for this study (see further below) and major concerns expressed by some Gypsy and (ethnic) Traveller interviewers in relation to the personal nature of a number of the questions in the study, IDRICS team members were required to undertake a considerable degree of negotiation, liaison and support during this project at times, as well as needing to work very closely with potential contacts such as staff at the Big Issue office at B&NES. As explained below, there was a far higher turn-over of interviewing staff on this project than the IDRICS team had ever before experienced and reviewing reasons for 'drop-out' and supporting remaining team members was both enlightening and time-consuming.

In addition to the above, the academic team were available to provide feed-back after reviewing completed questionnaires, acted as an information liaison point between the commissioners and interviewers as well as providing administrative support with regard to the practicalities of mileage claims, setting up meetings, focus groups and liaising with interviewers etc.

#### 1.3.3 Recruitment of Interviewers and Training Procedures

Although some attempt was made to re-recruit the B&NES interview team who had participated in the 2007 study, for various reasons – e.g. household changes; moving home; family commitments etc. – none of the original interview team was available to participate in this current study. We were however fortunate enough to be able to recruit a (male) Romany Gypsy advisor from the 2007 study (who is also a member of the Gypsy Council) as a community interviewer, who undertook interviews with Gypsies and Irish Travellers in both B&NES and North Somerset for the linked health projects.

In line with our standard practice we sought to obtain a mixed group of interviewers (by gender and community background) in both B&NES and North Somerset, comprising of New Travellers, Boaters, English Gypsies and Irish Travellers. Based on the anticipated sampling frame we were conscious that we would require a majority of New Traveller and Boater interviewers and we therefore contacted the local (highly organised) Boater community through the auspices of the Kennet and Avon Boating Community website and obtained two experienced community activists who had interviewed in other circumstances (one for academic projects). Both of these interviewers also acted as a conduit to the community and assisted in drafting up questions of specific relevance to this population. In addition, we were able to utilize pre-existing contacts in the B&NES area who were known to have connections with local New Traveller site residents and who were able to assist us in recruiting recommended New Traveller interviewers. Through one expert adviser we were also placed in contact with potential interviewers in both the New Traveller and Boater communities who participated for certain periods of the study.

Whilst we recruited simultaneously for both the B&NES and North Somerset studies, in practice the training events took place at different locations (one in each area) and on different dates. Highly regrettably, two of the Romany Gypsy interviewers who had participated to some extent in an earlier North Somerset projects dropped out of the study at a very early stage, in part we believe as a result of discomfort over asking 'intimate' questions of members of their communities. Accordingly, obtaining Romany/Traveller interviewers available to work in either area proved remarkably difficult, until we were able to call upon the assistance of a former team member who had been involved in the 2007 study. This gentleman participated in interviews in both locales, although was unable for cultural reasons to discuss some topics with female interviewees from his community, which caused some difficulties in terms of data gathering. IDRICS staff therefore attempted to make up the short-fall on Romany Gypsy/Irish Traveller interviews although only with limited success in the North Somerset study area.

In B&NES we were fortunate that despite our failure to obtain Roma interviewees (even though team members spent in excess of 12 hours of staff time on phone calls, attempt to engage with Roma populations at various locations and liaison with the Big Issue office who were able to ultimately advise us that local Roma has left the area in November 2012) our interviewers were relatively successful in obtaining New Traveller

participants (although we did not achieve the full sample). As a result of the energetic networking and persistence in seeking interviews of the Boater team almost the full sample was met for this sector of the population.

Additional barriers which created significant problems in terms of accessing New Traveller populations consisted of the loss of several interviewers as a result of pressing family circumstances such as obtaining a place at university and moving location, flooding of sites, work pressures/opportunities, health concerns and childcare responsibilities, as well as the appalling weather which persisted throughout the entire interview period meaning that both interviewers and interviewees were frequently unable to make a meeting or found that their local circumstances (flooded roads, mud etc.) inevitably had to take priority over undertaking casual interviewing work.

Ultimately, despite the difficulties outlined above, our community interviewer team consisted (despite variable staff members on occasion as a result of the circumstances detailed above) of a core of one Romany Gypsy man, two Gypsy women who were able to participate to a limited extent in the study; three Boaters (two female and one male) two New Travellers (both female) as well an additional three New Travellers (one male and two female) who were unable to remain as part of the project team for long after training had taken place, but who between them delivered several interviews and helpful community contacts.

The ages of interviewers varied between their early 30s and 50s and the team included participants with a wide range of experience and knowledge, including (at times) students, health and social care professionals and community activists. In addition the core IDRICS team included staff with in excess of 50 years of working with Gypsy, Traveller and Roma communities (including in Traveller Education Service settings), and the ability to translate from and to various Roma dialects.

Once the (initial) team had been recruited, following the model used successfully elsewhere, community interviewers worked with the academic team to devise an information sheet (using 'plain English') for distribution to potential interviewees in advance of interviews. This leaflet explained the purpose of the study and anticipated outcomes and benefits of participation. The leaflet (see Appendix C) incorporated culturally accessible images of sites and boats, details of how to contact interviewers and the names and contact information for members of the academic team in case further information was required prior to deciding to participate in the study.

Whenever a number of the interview team were 'lost' from the study, the contact names were amended as required and new information leaflets printed and photocopied for distribution.

In addition to handing out leaflets IDRICS arranged that publicity for the study would be disseminated through the Big Issue office in Bath, local Traveller friendly outlets such as Julian House, via the website and printed in the hard-copy version of the community journal 'Travellers Times'. Furthermore the Kennet and Avon boating community also

actively publicized the study through their website, word of mouth, leafleting towpaths, emails and by putting up notices along the towpath to ensure that Boaters were able to have their voices heard in relation to health needs.

An additional leaflet was prepared by IDRICS/community interviewers for distribution after participants had been interviewed which thanked respondents for taking part and provided a list of helpful health and local authority and regional contacts such as housing departments; health and education services; local authority planning teams; race equality councils; police liaison officers; specialist Boater, Gypsy and Traveller advice groups and organisations who could be contacted with regard to any concerns or information/support needs (see further Appendix C). Drafts of these leaflets were prepared by the academic team prior to the training days and these were then reviewed and amended in partnership with the community interviewers in advance of the pilot phase of the study commencing.

The community interviewers all participated in a full training day where they worked with the academic team to discuss and expand the questionnaire (see below), undertook practice interviews and explored issues such as dealing with negative responses or overly long discussions/misunderstandings arising during interviews; explanation of ethical issues such as respondents' right to refuse to participate or terminate the interview at an early stage; probing for answers and dealing with a range of health and safety and child and vulnerable adult protection issues which would trigger a need to discuss a case with an academic team leader and/or potential referral onto social care departments. Significant debate took place with Romany Gypsy respondents over the nature of a number of questions pertaining to access to certain services such as family planning or mental health and substance misuse services which they regarded as potentially taboo amongst ethnic Gypsy/Traveller populations and Showpeople.

Unsurprisingly, we neither expected, or received, statements of concern in relation to these matters from team members from New Traveller or Boater populations, although as with all interviewers we stressed that the questionnaire was ordered in such a way that particular sections could be 'skipped' to enable key data to be gleaned whilst minimizing the likelihood of an outraged participant ending the interview encounter at an early point in time.

The IDRICS team were alert to the fact from the earliest stages of the project that some questions could be regarded as offensive and potentially lead to termination of the interview but after lengthy discussions with both the commissioning team and community interviewers over the importance of attempting to seek information from all sectors of the community we opted to develop a core questionnaire for all populations and simply provided training on use of the survey so that interviewers could indicate when a 'sensitive' area was coming next, refer to the content of the section and then allow the participant to decide whether or not they wished to respond to that set of questions (see Appendix A for the content of the questionnaire).

#### 1.3.4 Questionnaire design and Access to Interviewees

The pilot questionnaire was based heavily on the relevant (health) sections of the 2007 GTAA, current needs of the commissioning public health departments and local authorities, additional suggestions made by the project team, and drawing upon the concerns of current Department of Health and Department of Community and Local Government consultations, or research focus (e.g. levels of contact with health services, ease of registration; desirability of particular forms of medical/care services). In addition, with the intent of seeking some form of measure of community integration and awareness of the networks of support available to individuals if they were in need of assistance and care we embedded questions on the numbers of weekly and daily contacts with family, friends, neighbours and wider community in their local area.

The draft pilot questionnaire was then discussed and adapted following consultation with the full interview-academic team during the training days which took place in September and October 2012. Following amendments to the questionnaire, information and 'thank you' leaflets, and production of 'interviewer packs' the community interview team then proceeded to undertake a small sample of pilot interviews to gain experience of use of the interview schedule/questionnaires. On completion of a small number of questionnaires these responses were then reviewed by the academic team for quality control purposes and once it was clear that the data gathered was of a satisfactory nature, interviewers were able to proceed to the full data gathering phase.

Whilst the entire data gathering exercise took considerably longer than anticipated as a result of the complications outlined above and change of circumstances of some team members, community interviewers were able to work at a time and pace to suit their other commitments, with the flexibility of this model of work meaning that they could attempt to access respondents during the day, in evenings and weekends. Where they were unable to obtain interviews on their first attempt they were expected to leave information about the project and either telephone the potential respondent (if they were willing to give a phone number) or arrange to call back again at a later date to attempt to gain an interview. Information sheets contained the phone numbers of interviewers (with their permission) so that potential participants could phone them once they had had an opportunity to consider participation or discuss the project with friends and relatives. If an interviewer was called by a potential interviewee they would then arrange a suitable date to undertake the interview. Some community interviewers in particular made a number of repeat visits (for instance, in one case a Boater cycled and walked to various locations in repeated attempts to meet one person with particular health circumstances and needs which were considered highly relevant to the study) prior to being able to obtain access to respondents.

Community interviewers initially divided up the various locations between themselves to ensure that respondents could either speak to someone they knew (e.g. if an interviewer had friends/relatives on a particular site or were of the same community/ethnic group as residents. If the interviewer (or the respondent) felt it would be more appropriate for someone to be interviewed by someone from a different

community or locality it was possible for another community interviewer or an academic team member to travel to the location and carry out the interview. As it became evident by November 2012 that we were facing significant problems in ensuring that the sample could be achieved (for example we experienced surprising numbers of refusals or promises to be interviewed which were then revoked or people were not present at a time and date agreed), and the interview team became smaller in the face of winter commitments or practical difficulties associated with living on flooded sites or impassable roads, we blurred the boundaries of the study further, so that our Romany interviewer carried out one or two interviews with Boaters and New Travellers when he was in the appropriate area and achieved positive responses, and a Boater interviewer began attending New Traveller sites after an introduction was effected by another team member.

All sites were visited on at least two occasions to attempt to survey residents. In addition to the problems outlined above we were constrained to some extend in maximising our sample within the optimum time-frame by the lengthy Christmas and New Year break when many potential respondents were enjoying time with their families and did not wish to take part in this study.

Whilst we did have a 'mixed' gender team for some populations, having only a male Romany interview (albeit assisted by an Irish Traveller woman in relation to the Irish Traveller interviews) may have acted as a barrier to obtaining responses from women in some circumstances. This gentleman advised us that at times he had to ask men questions pertaining to their wives' use of services or people refused to respond to entire sections of the interview schedule. In contrast, it may be that the fact the majority of Boater interviews were carried out with men, resulted from greater willingness for men to speak to a male interviewer.

Despite these setbacks and the shortfall in the sample, ultimately we feel that the response rate has proved satisfactory and we are confident in the validity and reliability of our findings.

#### 1.4 Analysis of the Survey Data

All data gathered from both the 'Professional' and 'Service User' surveys were entered into Excel databases (divided by community membership/ethnicity then broken down further into housed and Sited/Boatdwelling local residents); anonymised in line with our commitment to the respondents (by removing names/addresses from the database although this information was retained in confidential file format to ensure that we were aware of the location of interviews and could establish that participants were not dual interviewed/counted) and subjected to statistical and qualitative analysis. Once we had achieved the maximum number of surveys possible within the time frame for the study (i.e. by the end of February) we ceased data gathering and commenced the production of tables and charts, thematic discussion and the write-up of this report.

Findings from Service-User and Professional surveys are presented separately (Parts 2 and 3 respectively)

#### 1.4.1 Qualitative Data: Focus Groups and one-to-one Interviews

In December 2012, based upon the key findings from the early questionnaire returns and analysis of the professional survey (which 'closed' in November 2012 and was analysed prior to the Christmas holiday period) and in close consultation with the commissioning clients, IDRICS staff drew up two topic guides. One for use in focus groups with professional health staff and the other for use with service-users. The topic guides focused in more depth on aspects of barriers to service use and how these could be improved, as well as staff experiences or perceptions of barriers to effective service delivery with Gypsy, Traveller, Roma, Showman and Boater clients.

The Topic Guides can be found at Appendix D.

All survey respondents (professionals and service-users) were asked if they would be willing to participate in a focus group or follow-up interview to discuss key themes which emerged from the survey. In total six health care professionals across the B&NES study area agreed to be interviewed or participate in a focus group (including the only pharmacist in the sample) five New Travellers and four Boaters. No Gypsies, Showpeople or Travellers wished to participate in group or individual depth interviewees. Accordingly we anticipated holding two focus groups for community members and one for health care professionals in the first two months of 2013. In practice it proved substantially difficult to obtain participants for the focus groups despite numerous phone calls, preliminary booking of venues (which had on two occasions to be cancelled) and attempts to rearrange dates and locations. Health staff in particular were understandably difficult to pin down with regard to availability and we found that sudden cancellations occurred amongst Travellers and Boaters as a result of work or family commitments.

Ultimately we achieved one remarkably helpful focus group with Boaters (3 participants, with two further individuals not being to attend despite their best intentions) which yielded very rich data but were unable to convene the remaining focus groups. Instead, we substituted individual (taped, with the permission of participants) phone interviews with interested professionals (See Part Four – Qualitative findings), New Travellers and one Boater who had not been able to participate in the focus group but who was very keen to have his voice heard in the debate over service provision. The topic guide prepared for use in focus groups was used on an individual basis with all participants and findings are presented elsewhere in this report (Part Four), anonymised in line with our commitment to staff and service users.

# 1.4.2 Analysis and Presentation of the Qualitative Data

After transcription of the focus group and one-to-one interviews simplified Framework8 thematic analysis was undertaken to identify key issues and draw our recommendations and comments on particular modes of service delivery/barriers to access from participants.

Given the relatively small pool of interviewees (particularly amongst health professionals) and in order to protect the confidentiality of participants, Part Four of this report will use relatively minimal direct quotations (and in particular will exclude those which can identify the job role of an individual unless they have explicitly indicated that they do not mind their profession/employment or site/residence location/ethnicity being disclosed), and will focus on representing a summary of the views and key thematic areas raised by participants.

<sup>&</sup>lt;sup>8</sup> For an explanation of 'classic' framework analysis see Ritchie, J. & Spencer, L. (1994) "Qualitative data analysis for applied policy research" in A.Bryman and R. G. Burgess [eds.] *Analyzing qualitative data*, 1994, pp.173-194.

### **PART TWO**

# Findings of the Service User (community) survey

For the sake of clarity when discussing the findings from the different groups of respondents, the table outlining categories of respondent is reproduced again below (Table 1a)

Table 1a: Demographics of Sample size by category of respondent, housing status and gender

Ethinicity Category of Interviewee	Numbers Interviewed	Housed	Gender	Age/Range
English Gypsy	5	2	3F, 2M	36-64(f) 46-64(m)
Irish Traveller	6	6	4F,2M	26-74(f) 36-64(m)
New Traveller	21	4	13F, 8M	26-45 (m,f) (1 m and 1 f age u/k)
Showman **	2	1	1M, 1F	46-55 (m,f)
Roma	n/a	2*	-	-
Welsh/Scottish	1	1	1F	18-25
'Other' (English Traveller)	1	1	1M	56-64
Boater	30		12F, 18M	36-74 (m) 28-64 (f)
TOTAL (all categories)	66	13	33M 33F	

<sup>\*</sup> subsequently excluded from sample/analysis on discovering not resident within B&NES. A summary of these responses is available on request.

# 2.1 Demographics

# 2.1.1 Age Range of Respondents

The age range of respondents is not ascertainable on an individual basis as we opted in this case merely to provide 10 year bands which could be selected by respondents as most closely approximating to their age. (see Appendix A – Service User Questionnaire)

<sup>\*\*</sup> includes one person of Showman heritage who currently lives on a Boat

Thus, for example, with regard to the 'oldest' respondents (a female Irish Traveller living in privately rented housing for excess of 5 years), it is impossible to identify whether the lady in question is in fact nearer to 65 or 74 years of age.

# 2.1.2 Accommodation Type

The Showman (male) who was interviewed is residing in owner-occupied housing in B&NES. The other person in this category self-identified as a 'Showman-Boater' and has Showperson cultural heritage. She is currently residing on a narrowboat without residential moorings.

All but one (male, 65-74, resident in owner-occupied house whilst utilizing a boat on occasion) 'Boaters' were currently residing in live-aboard accommodation (including the woman with Showman heritage whom we have elected to analyse as a 'showman' whilst including relevant comments (e.g. relationship between moorings and health) under those attributed within the category of 'boaters'.

Whilst the high preponderance of male middle-aged respondents and individuals without access to long-term moorings (all but six interviewees (20%) were continual cruisers/people without moorings) may be reflective of the networks amongst our community interviewers we are aware that there is a significant shortage of affordable moorings (a theme which emerged again and again in interviews and during analysis of the data), and we do not consider that this is a significantly disproportionate picture of the characteristics of the Boater community in the B&NES area. As a crude observation of other localities in which Boaters reside, we would tend to suggest that amongst Boaters, young single women (under 30) young couples without children or with children under the age of five and somewhat older males are the most preeminent groups in terms of demographics for live-aboards. The relatively large number of pensioner couples who may be seen on narrow-boats during the summer season are overwhelmingly likely to have access to leisure moorings/housing or residential moorings for use during the winter months. Of those respondents (6) who had access to moorings, four reported moving in the summer and retaining an average 2 week stop at each location during that time frame as required by legislation.

Of the New Traveller respondents, four respondents were living in housing (one owner-occupier, two living in Registered Social Landlord (RSL) accommodation and one privately renting) Six New Travellers living on sites/or in 'temporary accommodation/benders etc.) indicated that their accommodation did not fall easily into the categories of 'unauthorized sites/roadside' noting that they were 'lying low' or discreetly parked up but failing to provide further information on their circumstances for fear of enforcement action. The remaining respondents in this sample were resident at the known unauthorized/tolerated sites in B&NES.

Of the 'ethnic' Gypsy/Traveller respondents. All six of the Irish Traveller respondents were housed. One woman did not specify precisely which type of housing, although the remainder were accommodated as follows: two owner-occupiers, one in private rented accommodation and two RSL tenants. The Scottish/Welsh Traveller lived in private

rented housing. Of the English Gypsy respondents, one person lived in an owneroccupied house, another in private rented accommodation and three dwelt at an authorized private site.

The remaining respondent (self-classified as 'Other') was resident in housing,

## 2.1.3 Duration of residence in current accommodation

Only 6 Boaters (20%) had moorings. Most who responded (14/25 = 56%) reported a high degree of nomadism enforced by their circumstances/Canals and River Trust legislation, moving every 2 weeks, while 7/25 (28%) move every 3-4 weeks. Four (all of whom have moorings) said they move in the summer.

In total, respondents reported living in their present home location for an average of 5.8 years (n=62), ranging from 2 months to 20 years and 2 months.

The duration/average length of remaining in one location was greatest for Ethnic Gypsy/Travellers living either in housing or on authorised sites. One English Gypsy respondent indicated that they had lived on their private authorised site for slightly over 20 years, and an Irish Traveller housed respondent had been in her current (privately rented) property in excess of six years. One housed New Traveller (seasonally mobile) had lived in housing for 10 years. Irish Travellers (all housed) had been in their current property for an average of 39 months. Whilst the actual duration of living as a Boater was in excess of 10 years for one-third (10) of that sub-sample, All boaters had been dwelling in that form of accommodation for at least five years. However, residence at a single location was shortest for individuals in this category (see above).

New Travellers in the main reported a reasonable long period of living at their current site/location. Of those New Traveller respondents living on roadside/unauthorised encampments who provided a duration of stay at their current location, the average length of residence was 25 months.

The average duration for New Travellers in 'other' forms of sites (e.g. staying on relatives'/friends land) discreetly hidden up, etc. was 33 months. Currently housed New Travellers (5) had been in such accommodation for between 2 months and 10 years.

## 2.1.4 Previous Experience of residence in housing

In addition to the respondents currently living in housing five Boaters and two New Travellers had lived in housing within the last 5 years. Two respondents (New Travellers) indicated that cost of living in a house was prohibitive "and I'd lived in a trailer before when working" and one female New Traveller said that she had moved into housing "In order to work - work as a teacher - need to be able to wash etc. Also felt like needed a change - had lived at previous site for 7 years" but had subsequently moved out again and was now resident in 'other' types of accommodation.

### 2.1.5 Reasons for moving to site/boat

Fourteen respondents gave reasons for moving onto their current site, 50% giving more than one reason. The most popular reason was 'to join friends and family' (x 9) followed by 'cost of living' (x 5), the latter being mostly cited by New Travellers.

Amongst Boaters, 16/27 (59%) who gave reasons said they moved onto a boat due to 'the cost of living'. Four said they couldn't settle in housing and 3 moved to join friends/family (two female, one male).

Six New Travellers explicitly stated that there living on a site (even if had spent time in housing) because of 'lifestyle' factors and one Irish Traveller woman currently in housing expressed that she wished to be living on a site because of cultural issues.

# 2.1.6 Number of (enforced) moves in the past 3 years

Boaters unsurprising recorded the highest average number of enforced/required movements, followed thereafter by New Travellers.

On breaking down number of moves by category of respondent, one English Gypsy woman had been forcibly moved/evicted on two occasions in the past three years prior to obtaining space at a private authorised site some 18 months prior to interview. Of those New Travellers who responded to this question the average number of enforced movements was three whilst this rose to 4 for Boaters although a significant number emphasized that they moved on voluntarily every two weeks to avoid enforcement action. One boater spoke of being moved on by threats of prosecution on seven occasions in the preceding three year period.

### 2.1.7 Household Structures/Resident Children

Overall, (excluding single category respondents e.g. 'other' and the two Showman interviewees) Boaters were most likely to be living in a single person household with only 16/30 (53%) living with someone else. Of these, the majority of cohabitants consisted of a partner of a similar age (although males were somewhat more likely to be living with a slightly younger female in the next lowest age-band).

Most Boaters (23/30 = 77%) reported having just one generation (couple of singler person) living in their boat. However, one family of Boaters reported having 3 generations co-residing. (No other ethnicities reported 3 generations living together.) One Boater respondent was a male lone parent. In total six Boater respondents had co-resident children (with only one respondent having more than one child living on their boat). Children ranged in age from four years to 21 years of age with only three children being of secondary school age, and one past school leaving.

Seven New Travellers did not provide data in relation to household structure, and of the remainder only one male (46-55) lived alone. The remainder of the respondents were partnered mainly with someone in the same age category. Eleven of these thirteen respondents (84%) had resident children. Only three lone parents (all female) responded to the survey. Lone parent households had between one and two children and these tended to be over the age of 11, although one lone parent had a pre-school age child. Of the eleven parents in this sub-sample, the majority had primary or pre-school age children in some cases with children of varying age-groups (8 households with pre-school age children; four households having secondary age children (of which two also had children in the younger age-range) and one with a child of post-school age. The average numbers of children co-resident with New Travellers was two per household. Two families had children of below one year of age.

One Showman family (housed) had one secondary school age child residing with them), as did the household classified as 'Other' and living in housing, whilst the housed Scottish/Welsh Traveller had one pre-school aged child living in their house.

Of the English Gypsy respondents, one site resident declined to provide data on his household structure, another older lady and her husband residing in an owner-occupied home did not have younger family members in their household, and the remaining (all sited) respondents were married with an average of 2 children co-residing. Only one child was of primary school age, as may perhaps be expected given the average agerange of this group of respondents (mid 30s and older) with the remainder being in their mid teens. The oldest co-resident child in the household of English Gypsies (potentially reflecting early marriage patterns and new household formation) was aged seventeen.

All Irish Traveller households (other than one housed family where the married couple were in their 70s) had children co-residing and dwelt in two generation households. The average number of co-resident children was 3 per household. The age range of children in this category consisted of between three years and nineteen years of age. Two households had pre-school aged children. All five households with children had primary aged children co-residing, and in addition, two households had children of secondary school age or older. Similarly to the English Gypsy households, no respondent had a co-resident child aged above nineteen years, indicating culturally congruent relatively early age of separate household formation.

In total, (all respondents) twenty nine respondents (44%) reported having children living with them, 12 of whom (18%) had more than one child, with 6 (9%) having 3 or 4 children. 10 families (15%) had children of secondary school age living with them and 5 (8%) had a baby under the age of one year.

### 2.2 Access to Services

This section of the Questionnaire (questions 20-45) focused on 'basic access' to services (GP surgeries), service providers' perceived levels of cultural knowledge and sources of health advice utilized by service users.

# 2.2.1 Levels of registration with a GP/Distance from surgery

When asked whether they, their partner and/or children and other co-resident relatives were registered with a GP, all respondents (other two New Travellers living on an unauthorized site) replied that their families were registered with a practice. Somewhat concerningly, one respondent who indicated that they were not registered with a GP had three children co-residing, of which two were below school age. Subsequent answers from this respondent did however indicate that the family accessed (presumably as required) GP services within the region, presumably, through 'temporary patient' registration.

A small number of respondents (responding to this question and subsequent related ones pertaining to access – see further below), indicated that they had found it difficult to register with a surgery, e.g., due to a lack of a post code and had needed to use their parents' or other settled acquaintance's post code to be accepted as a patient.

• "Very difficult [to register]...needed to lie about address".

Of the 34 respondents to this question who were not Boaters, 30 (83%) had a GP within 5 miles of their current location. There were five non-responses to this question (three Boaters, One New Traveller and an English (Romany) Gypsy participant.

In stark contrast, only 5 of the 27 Boaters who replied to this question (17%) were registered with a GP within 5 miles of their current location. The average distance from their GP for the remaining (22) Boaters who responded was 19.15 miles. In two cases Boaters reported that their 'home' GP was over 60 miles distant from their current location.

Of the 34 respondents who were not Boaters, 28 (79%) had a GP within their local health authority area. However this figure was only 19/30 (63%) for Boaters, with over one third having a GP in another region.

58/64 (91%) respondents reported being aware that they had an NHS number (2 non-responses). Only two people (3%) stated that they did not have an NHS number (one Boater, One New Traveller) One Romany Gypsy and One New Traveller (3%) did not respond, and two Irish Travellers (3%) did not know if they had an NHS number.

Most respondents (53/66 = 80%) knew that they could register with a GP as a Temporary Resident. A breakdown by ethnicity reveals that only NTs and Boaters, only

one (privately sited, 56-64 year old male English Gypsy) respondent was unaware of 'temporary' GP registration facilities.

In contrast however, 33.3% of New Travellers and 20% of Boaters (of which threequarters were male) were unaware of this right, suggesting that (when coupled with comments about 'lying' to retain access to a GP at a parent's or friend's address), there is an urgent need of health rights information campaigns for these particular categories of respondent.

### 2.2.2 Hand-held medical records

Only 3 respondents (all New Travellers) had hand-held medical records (= 4.5% of the sample).

However, there was considerable interest in acquiring some form of hand-held records – the 63 respondents who replied gave an average rating of 4.54/7 to this question, with 27 respondents (43%) saying they were very interested and only 14 (16%) being very disinterested.

Most interested were Irish Travellers (average rating 5.33/7) and Romany Gypsies (4.8/7). However, the sample of Boaters was very heterogeneous in this respect, with many answers given in both extremes of the range.

There was relatively little interest in acquiring alternatives to medical hand-held records – the 63 respondents who replied gave an average rating of 3.27/7 to this question.

However, 59 respondents gave a slightly more favourable rating (3.76/7) when considering the value of acquiring portable records for when they are travelling/mobile or utilizing the canals.

Those who responded/gave ratings of interest for possible alternatives to paper records gave an average rating of 2.83/7 for mobile phone, 2.7/7 for laptop and 1.24/7 for tablet.

The (few) qualitative comments revealed that either respondents did not own the necessary hardware (e.g. no tablet or laptop) so felt that non-paper-records were not applicable or felt that records kept centrally by the NHS were adequate.

## 2.2.3 Dental and Optical Registration and use of services

All but two of the Romany Gypsy respondents (both housed, older people), were registered with an NHS dentist, as were all but one Irish Traveller. The Scottish/Welsh Traveller household were also registered with an NHS dentist. However, only 10 New Travellers (48%), 23 Boaters (77%) and neither of the Showmen were registered with a dentist at all.

26 respondents (39%) were registered with an optician. Those registered included 60% of Romany Gypsies, 50% of Showmen (interestingly the showman-boater rather than Showman in housing), 53% of Boaters and 40% of Irish Travellers. This finding is significant (representing far higher levels of registration for these groups than in comparable studies) given the generally very low level of use of opticians amongst 'ethnic' Gypsy/Traveller households. Importantly, the oldest age group amongst Gypsies/Irish Traveller/Showmen were not registered with opticians – the category most at risk of cataracts and macular degeneration, as well as being groups who might potentially benefit from regular eye-checks to monitor other potential complications such as diabetes etc.

The Scottish/Welsh Traveller family were not registered with an optician although this may potentially relate to the young age of the household given that use of opticians tends to increase with ageing.

The relatively low rate of Boater registration with opticians is also of concern, in particularly as only four respondents were aged >46 by which time regular eye-tests are generally recommended and only two were above retirement age,.

Worryingly, a mere 19% of New Travellers were registered with an optician, all of whom were women under the age of 45. It is to be recommended that information on the benefits of regular eye-tests are delivered in a range of formats to encourage use of services (although a few qualitative comments and statements in interviews indicated that 'cost' of using opticians or obtaining glasses if needed was prohibitive for many).

## 2.2.4 Regularity of seeing GP, Dentist and Optician

44 respondents (67%) reported that their family sees a GP at least annually. A breakdown by ethnicity reveals 80% of Romany Gypsies, 83% of Irish Travellers, all Scottish/Welsh Travellers and all Showmen and 67% of Boaters report that they and their households see their GP at least annually.

However, only 57% of New Travellers reported seeing their GP at least once a year. On exploring reasons for not having greater levels of contact, qualitative data reveal no specific barriers. In part, limited contact with GPs may pertain to the age-range of respondents as well as attitude toward use of services/existing conditions.

Respondents (of all groups) either explained that they and their families have regular access due to ongoing health issues, or that they only go to the surgery when needed to: i.e. when quite ill.

## Typical comments include:

 "I have asthma – so go for an annual review; I take citalopram (for anxiety) review periodically. Children taken as required". (New Traveller)

- "Annual health check for my heart problems. On Warfarin" (Irish Traveller)
- "Since becoming pregnant I go regularly" (New Traveller).
- "We go to GP if we need to" (Boater).

Dentists: 47% of respondents (31) see their dentist at least annually. There were few barriers explicitly cited, but one Boater said she had not got around to re-registering near to her local area, and another cited expense as a barrier to dental care. "Money and cost of treatment".

One Irish Traveller and one Romany Gypsy respondent both indicated that they whilst they do not see their dentist regularly that they ensure that their children have regular check-ups:

- "The children do, I don't only as required."
- "My two middle kids do [have regular dental appointments], but only in recent years [since moved into housing].

It was of some concern (relating potentially both to the low rate of registration amongst New Travellers (and also some Boaters) and the concerns about cost of treatment, that 53% of respondents (35/66) reported 'self-treatment' for dental problems. On examination, the number of respondents reporting 'self-treatment' ('take lots of painkillers'; 'pull the tooth myself') was 7/21 NTs; 13/30 Boaters; 3/5 Romany (English) Gypsies and 2/6 Irish Travellers. Men were noticeably more likely to resort to more drastic actions such as 'self-pulled' a bad tooth whilst women cited 'trying over-the counter things' or 'herbal medicine/cloves' for toothache.

Opticians: Overall 24 respondents, (overwhelmingly those were 'registered' with an optician) report seeing their optician at least annually for check-ups. Over half (16) of respondents in this category are middle-aged and older male Boaters; the group of four young NT women, and the remainder are Gypsy and Irish Traveller respondents.

## 2.2.5 Use of alternative Medicine/Therapies

Alternative medicine is used by 44 respondents (two thirds of the sample) including all but one New Traveller and most (87%) of Boaters.

On being asked if they or their household members would ever use a range of 'alternative' treatments for health conditions, overall, two-thirds of respondents (all categories) reported they would or do make use of non-allopathic medicines or treatment in some circumstances.

20 respondents (30%) said they would only use a doctor/hospital as a last resort if someone in their family was very seriously ill/injured and a further 24 (21%) said they

would use a GP/hospital whilst, for example, using alternative medicine at the same time.

However, only 5 respondents (7.5%) said they were very unlikely/unlikely to go and see a doctor if they had a medical problem, with a further 10 (15%) being somewhat unlikely. 29 respondents (44%) were very likely/likely, with this positive attitude spread fairly evenly across ethnicities. The overall rating, amongst those who gave a rating, was 4.92/7.

11/30 (37%) of Boaters report that they would only make use of allopathic/clinically recognised/medical care as did 40% of Irish Travellers, 1/2 Showmen, the only Welsh-Scottish Traveller respondent and 80% of Gypsy respondents. Unsurprisingly perhaps New Travellers were most likely to report use of alternative medicines, including herbalism, acupuncture, reiki and other massages.

Table 2 (below) specifies the frequency of citation of forms of alternative medicine/health care used by category of respondent.

Table 2: Non-Medical (alternative) Treatment used for health care/illness (by category of respondent)

Treatment Type	Romany Gypsies	Irish Travellers	Boaters	Showman	New Travellers
Herbal/traditional medicines	1	3	13	1	18
Homeopathy	-	-	8		13
Infusions	-	-	10	1	7
Acupuncture	-	-	4		6
Massage	-	-	10	1	10
Reiki	-	-	3	1	4
Other (specify) *	-	-	7	1	8

Not all respondents who indicated 'other' forms of treatment for ill-health provided information on what this was. Forms of alternative care cited by respondents were as follows:

New Travellers: Eating super-foods x1 Kinesiology x 4 Osteopathy x1 Reflexology x

Shiatsu x 1

Boaters:

Aromatherapy x 1

Chiropractor x 1
Counselling x 2
Floral essences x 1
Reflexology x 1
Shiatsu x 3
Spiritual healing x1

Yoga x 2

Showman (Boater): Reflexology x1.

Women respondents were most likely to cite the use of reiki, reflexology and homeopathy and slightly more likely to refer to massage or use of herbal medicines. Males were more commonly to be found referring to 'infusions' although men (particularly from ethnic minority communities also made reference to use of traditional/herbal medicine.

When asked the circumstances when alternative medicine/treatment would be used, 21 respondents provided information (1 Gypsy, 9 NTs, and 11 Boaters).

The most common responses (more than one could be given) were as follows:

Use first (before seeing GP) and by preference: x 21 responses – all groups as above

Use alternative treatment (e.g. herbal remedy/massage) at the same time as GP/hospital treatment x 14 (no Gypsy/Irish Traveller respondents)

Always use instead of GP/hospital treatment/services x 3 (all NTs)

Only see a doctor/hospital as a last resort if someone has a very serious injury/illness x 13 (9 Boaters, 4 NTs)

Other (specify) x 2 (1 NT and 1 Boater)

Additional qualitative comments indicated a pragmatic and safe attitude to the use of 'alternative' medicines: examples include:

- Use 'alternative medicine' first before seeing a GP unless it is life threatening (Gypsy respondent)
- It is hard work getting an appointment with a doctor (Irish Traveller).
- Depends if minor. Use herbal remedy etc. If out of my area of knowledge will see doctor (NT)
- Use the GP mostly before any other alternative (Showman)
- I'd use treatment appropriately as per condition (NT)
- Would depend on problem, e.g. Cold, bad back use alternative, [massage/chiropractor] or herbal stuff. (NT)

### 2.2.6 Sources of Health Information.

On being asked whom they would contact for further information if there was a health scare (e.g. measles outbreak) in their neighbourhood or site. Respondents replied as follows:

Table 3: Sources of Health Information (health scare)

Source	Romany Gypsies	Irish Travellers	Scottish Welsh Traveller	Boaters	'other'	Showman	New Travellers	Total
GP	4	4	1	16	1	2	3	31
Specialist Health Visitor	1	-	1	-	-	-	1	3
Chemist Pharmacist	1	1	-	4	1	1	1	9
Helpline	•	-		2	-	-	1	3
Wait and see if got ill (or family member)	-	1	-	2	1	-	1	4
Specialist Traveller/Boater advice group	3	1	1	1	1	1	1	7
General media (paper/radio etc)	ı	1	ı	14	ı	1	1	17
Wouldn't bother	-	-	-	1	-	-	14	15
Other (specify) *	-	-	-	13	-	-	4	17

The majority of respondents who indicated 'other' forms of advice did not provide further details. However, of those who did, a number referred to making use of the internet (including one Boater working in a health care setting who referred to the Health Protection Agency as a source of advice).

One New Traveller indicated that if they were really worried about an epidemic or outbreak they could consult a herbalist or homeopath, whilst a Boater said they would simply leave the area if there was an epidemic/outbreak of a serious illness.

Amongst Boaters, by far the most popular sources of information in this situation were GP (favoured by 53% of Boaters) and general media (TV / newspaper / radio) – favoured by 47%.

43% of Boaters also said they would turn elsewhere for information, with those specifying an alternative predominantly citing the internet.

14% of New Travellers said they would ask their GP, but the majority (67%) said they would not bother seeking information advice, e.g., as they do not have confidence in inoculations etc.

For all other (ethnic) Traveller groups, the GP was the preferred source of information in a health scare followed by specialist Gypsy/Traveller agencies.

Some respondents commented on the sources of information they would use in the event of a health scare:

## Comments from New Travellers:

- I would see either a homoeopath or a herbalist if I was worried
- Internet and Health Visitor
- If really worried might look on internet
- Internet

### Comments from Boaters:

- Work in a hospital so would be informed there
- Research it, via internet and word of mouth
- Word of mouth. 'Towpath telegraph'
- Research the internet
- Towpath gossip
- Internet first, then see if anyone got ill
- Read on internet
- Health protection agency website but I would also find out through work

Perhaps the most significant findings in this section pertain to the high levels of trust and role in information dissemination of specialist advice lines/community groups for 'ethnic' Gypsies and Travellers and the limited awareness of the value of contacting pharmacists for health advice (on which see the very helpful comments within the qualitative section — Part Four) by a pharmacist. There appears to be very little knowledge amongst B&NES residents of the role of specialist health visitors and it would appear that this service could be better advertised to local residents. GPs were still identified clearly as the primary point of information by most respondents, with general media coverage highly relevant to Boater populations who are perhaps the most isolated of the groups in terms of ease of access to sources of medical information. To avoid over-use or inappropriate use of GP surgeries there would appear to be evident scope in times of health emergencies for tailored information to be delivered to Gypsies, Travellers and Boaters/Showmen via specialist resources including advice agencies and trusted organizations/community groups.

# 2.2.7 Preference for continuity of GP care/gender of medical practitioner and availability of preferred treatment.

Access to GP of course was generally perceived of as good

Of the 31 respondents (47%) who reported wishing to see the same GP on successive visit only 8 (12%) reported finding it difficult / very difficult to see the same practitioner. Of these respondents 5 were New Travellers. The average rating (amongst all 49 respondents who gave a rating) was 3.86 out of 7 in terms of continuity of care.

Amongst New Travellers the average rating was 3, amongst Boaters 3.83, and Romany Gypsies 4.4. Irish Travellers were the most satisfied, with an average rating of 5.17 out of 7.

# Gender preferences

16 respondents (24%) expressed a preference for a GP of their own gender. This was most noticeable amongst 'ethnic' Gypsies/Travellers although perhaps lower than anticipated at 60% of Romany Gypsies and 50% of Irish Travellers. Only 2 (3%) of respondents reported that they found it difficult to see a GP of their preferred gender.

Boaters and New Travellers were much less concerned about the gender of their GP – just 16% of Boaters and 19% of New Travellers expressed a preference by gender.

Comments relating to gender preferences or waiting to see the same GP as at a previous appointment revealed a mixture of pragmatic common sense and cultural attitudes. Fixity of concepts of cultural probity (even at the cost of good health) were most strongly expressed by male Irish Travellers.

## Comments from male Irish Travellers:

- I only see a male, women see a woman
- Men see male, women see female [doctors].

# Comments from female Romany Gypsy:

Prefer a female GP

### and male Romany Gypsies:

- Prefer to see male doctor
- Would only see a male

In contrast (as expected) <u>New Travellers</u> were slightly less concerned about the gender of their carer although some females still would prefer a woman GP:

- Female doctor because she's female. I don't want to undress in front of a man
- Depends what I am going for...
- Prefer female but [she is] only available half the time

### ...and male New Traveller:

• Women [GPs] are not as dismissive as men (male)

Boaters interestingly seemed slightly more concerned about the gender of their health care provider

# **Comments from female Boaters:**

- Would not want to see a male gynaecologist or midwife [otherwise don't mind]
- Prefer female, even if in hospital but don't always get the chance

- I always ask to see a female doctor
- Usually go to doctor for personal female issues. [But] physical distance from GP makes it hard to see GP I want on the day I am available
- Rather see a female doctor for female illnesses [gynaecology etc.]

### ...and male Boaters:

- I prefer to see a male GP. If I need emergency treatment I don't mind
- I prefer same [sex] GP (Male)

Only 12 (18%) of all respondents reported finding it difficult/very difficult to obtain their preferred type of treatment (e.g. if someone wanted CBT/counselling but was offered 'pills' for depression/anxiety instead). Eight of the twelve dissatisfied respondents were New Travellers.

The average satisfaction rating (amongst all 61 interviewees who responded) was 4.23 out of 7 (slightly higher at 4.45 amongst all respondents who were not New Travellers).

Most respondents felt they have enough time to speak with their GP (47/61 = 77%). Of the 14 respondents (23%) who reported being given insufficient time with their GP, 11 were New Travellers.

# 2.2.8 Cultural Barriers to accessing health

Only 8 respondents (12%) experienced that they had encountered such barriers to accessing appropriate health care. This included 6 New Travellers, one female Showman (who lives on a boat) and one Boater.

When asked to explain how cultural barriers/misunderstandings impacted on care received the following comments were recorded on questionnaires (and see below and in part four qualitative comments on medical personnel's 'suspicion' of New Travellers, reluctance to prescribe pain killers/controlled substances, etc).

### **New Travellers:**

### Cultural barriers

- Refused treatment even on temporary basis "don't want your sort round here" for blood pressure - doctor getting impatient about the amount of layers she was wearing and [respondent] has been told off for leaving mud in the reception area. She needed her BP taken. It was winter and she was wearing several layers. Doctor tutted and made remark to student medic about this, even though the doctor knew she lived outdoors. She has also been told off for having muddy boots in the reception area.
- A lot of Travellers distrust conventional society and with that conventional medicine. There is a huge culture of self-medication on site as a result

- People unable to comprehend how we live why we might look muddy or dirty.
   People are wary of us.
- The fact that we live in caravans and vehicles often gets in the way. E.g. Respondent's daughter broke her leg. After her operation, consultant came to visit and the first thing he asked was "why do you live in a caravan then?". Service user found this extremely insulting as shouldn't be first thing to discuss his daughter's health most important. This fuelled his mistrust of whether social services would become involved in their case.
- A lot of Travellers have trust issues and fear of authorities getting involved which stop people from accessing health care. As a child (young second generation NT) her father would never take her to a doctor.
- Always might meet some health care providers who you might feel judge you but equally it might be your own paranoia and in your head.

## Showman (boat-dweller):

• Doctors that don't understand or try to understand my lifestyle. It is not like most people's living conditions and I have to travel and I have no car [only a liveaboard boat].

### Boater:

• I was refused registration with a GP when I said I was itinerant.

# 2.2.9 Difficulty finding a GP surgery which will accept Gypsies/Traveller/Boaters

Very positively, only 6 respondents (10%) reported finding it difficult to find a GP who would take them – 3 New Travellers and 3 Boaters.

Overall, 32 respondents (48%) reported finding it very easy/easy to register with a GP. The overall rating given (based on the 55 respondents who gave a rating) was 5.36 out of 7.

Despite this initially positive rating for access to GP surgeries, subsequent questions revealed that a substantial minority (24% of the sample) consisting of 10 New Travellers, 5 Boaters and one Irish Traveller reported having been refused the support they needed by health care professionals. Although few comments were given, these typically related to failure to engage with patient preference, attitude to Travellers or understanding of the difficulties in accessing services some distance away (see below), or the responses from reception staff on seeking to register as a patients.

- I would like to get (be able to afford) Chinese Medicine for my son's asthma (NT).
- We get tarred with the same brush so we get met with the same stigma (IT).

Prejudice/discrimination was also a perceived barrier for some New Travellers in terms of accessing appropriate care:

- This is because they think all Travellers are blaggers, especially when it comes to controlled drugs.
- Prejudice health professionals deciding/assuming the reason for the depression is living on site in a truck.
- The two local surgeries [X and X] have experienced definite prejudice from staff
- Health professionals judging our life styles as being bad and the reason for poor health.

### Postcode Problems

When asked about difficulties finding a GP who would take them, several respondents raised the issue of address/postcode.

# New Travellers:

- This is impossible [getting a GP] because we haven't got a postcode).
- There is no postcode for where they live and the council are refusing to provide them with one. The name of the lane where they live is unclear and she's consequently without an adequate address. She tried to register at two local surgeries (within 5 miles of site). Both of these surgeries refused to help and would not register her or her son. The receptionist at one surgery took a step back from the desk when interviewee explained she was a Traveller. Very hostile and prejudice experiences. Interviewee then went to next nearest surgery. This time, she took her neighbour (from site) with her, as neighbour had been successful in getting registered - (see xx interview). The surgery however refused to take her, despite the neighbour being there to explain she was a registered patient and they lived in next door caravans to each other. Interviewee has now resorted to using the father of her son's address (despite their poor relationship and stress this caused). With this address she is now registered at Tiverton surgery, where they have been very helpful and supportive. She explained her situation to the receptionist when trying to register and they took her immediately without any problems.
- Where they live has no postcode. Council are refusing to give them one. When she approached her two local surgeries, they refused to take her on these grounds. She then went to a third surgery further away as a temporary resident. Saw the doctor who said she could not give her a repeat prescription as a temporary resident. However, her condition is so serious he registered her in the surgery despite being outside the catchment area and with no valid postcode.
- When travelling it is only easy [to access GP care] if I have a 'care of' address.

- People don't always have an address to give apart from 'NFA' [no fixed abode] which can make it had to get treatment and feel like you won't be judged.
- When living on a site, when travelling around the country away from where you are normally based; the lack of address is difficult. Often, GPs don't want to take on temporary residents.

## **Boaters:**

- Very difficult. Need to lie about address.
- Because I have a postal address in Bath [parents. It is ok] otherwise it would be harder.
- GP in B&NES and needed to give a B&NES address for registration
- Again, have been lucky enough to use friends addresses to register while 'sofa surfing'/and now boating, i.e. I have been reliant on local contacts.

### Lack of a fixed address

14 New Travellers, 21 Boaters and one Showman cited 'other' barriers. In practice, qualitative comments were often closely related to the above postcode issues).

# Boaters:

- Being a Boater and not having secure postal address [to receive letters/appointments].
- Being able to register without an address
- Access for emergency services and telling them where we are [in case of emergency call-out – and see further comments from the Boaters focus group] no postcode
- Being a Boater road access [difficult].
- Having to continually cruise greater distances each year.
- Being itinerant

# New Travellers:

- Again, the difficulties of lack of address.
- The real issue is being able to access health care without an adequate address
- Lack of address has been difficult for [NT] friends in the past

Accessing transport to GP surgery/clinics was cited as a major issue of 14 occasions

### **New Travellers:**

- Distance from the homeless surgery in town, and not being able to register with GP nearby.
- People on site have transport problems. Maybe a doctor could visit site periodically...?
- I have Osteoporosis so it is hard to get to treatment centres. This is because the site is located miles from town and is not on a bus route.

- People often can't drive and are reliant on others for lifts to minor injuries unit for example sites are often isolated and some distance from bus services etc.
- Possibly mobility getting to and from site- doctors if you don't have a car/drive; as sites are often in the middle of nowhere.

### Boaters:

- Transport being a boater.
- Constant moving means have to travel long distances to own GP or to find nearest emergency help if don't know an area well.
- Without a vehicle, distance and access is problematic
- Transport most boaters don't have cars they cycle not possible if not well.
- Distance and transport to services
- Being able to get to the doctor you are registered with
- Distance [from GP surgery] can be a long way up to ten miles.
- Distance and access to medical care
- Distance travelling
- Being far away from a doctor

Other barriers raised included the need for more home visits and keeping track of health records (nb: see above under discussions re: use of hand-held records). Comments were again only made by Boaters and New Travellers under this heading

### Boaters:

- Emergency access difficult, no mobile reception to call 999. Many rely on public transport so need the cash on you [if need to go to a minor injuries clinic or GP surgery] because no cash point nearby.
- A lot of boaters aren't strongly integrated with society [lack of knowledge/suspicion of health care providers]
- Getting home visits
- Lack of home visits.
- It affects those with long-term health issues, those that can't hide the fact that they live on a boat (i.e. registering)
- Keep track of records (mine have been lost twice)

### **New Travellers:**

 The homeless surgery is used to seeing people who are in transit so are not used to keeping peoples' records [without access to a regular GP, service user needs to be able to access retained medical records when attending the homeless clinic for care].

Overall, the most significant barriers raised in relation to obtaining medical care/GP registration consisted of issues of lack of postcode as well as not having a fixed address.

These issues inevitably had the greatest impact on Boaters and New Travellers amongst our sample. When coupled with the limited knowledge amongst NTs of the right to temporary registration (see above) it would appear clear that there is a need for educational work to be undertaken with health professionals around these issues to ensure that service providers are aware of the very real challenges faced by individuals living on sites who need health care.

The theme of mobile outreach health care for Travellers and Boaters (see Part Four Qualitative Data) emerged in several occasions as a good practice example which would (for routine care at least) alleviate some concerns over contact with service users in relatively remote locations without access to public transport.

# 2.2.10 Whether differing/special healthcare needs of Gypsies/Travellers/Boaters are understood and catered for by health care professionals

24 respondents (36%) of the sample reported that they felt that Gypsies/Travellers/Boaters have health needs which differ from other (sedentary/non-ethnic Gypsy/Traveller) people's needs.

In addition, 41 (62%) of the sample felt that their community was more prone to certain illnesses or conditions than the general population, specifically:

### **New Travellers:**

- Arthritis, Hepatitis C
- Stuff related to drug and alcohol problems. There is a high prevalence of this
- Arthritis and cold related problems. Respiratory problems.
- Arthritic complaints [caused by] living conditions, muscle and physical stress. Wooding and fetching water are hard on your body.

# Romany Gypsies:

- Yes, we can get other illnesses [distinct from mainstream populations] caused by living on sites and near sewer works
- Heart trouble is the main problem in the Travelling community

### Showman:

Chesty coughs in winter 'cos of fires and damp.

# Boaters:

- Physical injuries.
- Bad backs and back pain.
- Mental Health and dental services.
- Alcohol and substance dependency/depression.
- I believe a higher percentage of boaters have mental health conditions than population as a whole but the ability to be a boater helps them cope with life.

- Respiratory problems, if you're prone that way; musculo-skeletal problems if boat moored on a tilt all the time (due to low water levels) injuries from boating - poor bank conditions, moored far from bank [jumping across gangplanks and carrying heavy loads on and off gangplanks].
- Respiratory problems, muscular-skeletal problems, joint problems; neglect related health issues (self neglect i.e. Alcoholism). It's more the effect of isolation from health care input, greater number of the "poorly compliant" don't look after themselves. Dysfunctional men who don't look after themselves - would be great to be a "district nurse" of the community.
- Damage to limbs, cracked bone, more opportunity to hurt yourself.
- Bronchial infection; boaters have a much higher incidence of mental health issues; but it's the mental health issues that make them become boaters and from that leads to drug and alcohol abuse and heavy smoking - this is my perception.
- Weil's disease. I doubt many GPs would spot the signs until too late they need to be aware.
- Illness related to cold and damp
- Maybe less likely to see a doctor and get treated early than other communities.
- Respiratory issues from burner and damp. But in other ways healthy. E.g. Doesn't get colds. Increased mental health problems - e.g. Loneliness in winter.
- More prone to pulmonary infections. Back pain.
- More prone to back injuries.
- Alcoholism stress backs

In contrast one (younger male) respondent felt that compared to other populations "I feel it is a healthier, active lifestyle".

Thus self-identified conditions ranged mainly for New Travellers (and Gypsies) and Boaters as resulting from the physical vagaries of a fairly hard physical life, (back injuries, injuries to limbs re cutting/tearing etc.) to those caused by residing in poor environmental conditions (Weils Disease, living at sewage works etc.), as well as the exacerbating factor of living in wood/metal containers (boats, trailers, vehicles) for a long time with increased risk of cold and damp triggering conditions (arthritis, chesty cough, respiratory problems etc.).

The other set of problems (noted by New Travellers and Boaters alike) consisted of individual pathologies such as mental health and substance misuse issues which might either be exacerbated if in a situation/community where these are normalized, or be to some extent pre-existing conditions which could potentially have been relevant in an individual's choice to move onto a site/become a boater (for example several respondents during qualitative interviewers referred to divorced men who might have drunk or had substance misuse issues prior to becoming a boater/Traveller but which then became more of an issue once 'no wife to keep them on the straight and narrow' or 'marriage broke up, can't afford to buy or rent a house so get a boat if you're a man who has hung about in boats when married, or is a bit practical - nobody to think about but himself.. and then heavy drinking is normalized amongst a lot of Boaters'. The

comments made by several interviewees (and to some extent endorsed by health care professionals) about the reluctance of New Travellers/Boaters to engage in preventative health care (and see below re comments on gender) can also lead to untreated substance misuse/mental health problems for individuals who receive a degree of support from other community members rather than accessing external assistance.

Finally as clearly identified in existing health studies (Parry et. al. 2004, op. cit. and Cemlyn et. al. 2009, op. cit.) the Romany Gypsy respondent was alert to the grossly disproportionate risk of heart disease causing premature mortality and morbidity amongst this ethnic minority population. The combination of genetic predisposition, and as has been suggested in the above some studies, changing lifestyle and declining exercise amongst Romany populations has led to this being a leading cause of death within this community.

Despite the fact that a substantial proportion of health conditions cited were specific to Gypsy/Traveller populations and pertained to living condition/lifestyle factors, Out of the 62 respondents who answered the question 77% said that they felt their needs were understood by health professionals. This included 80% of Romany Gypsies, 83% of Irish Travellers, 79% of Boaters and all Showmen and Scottish/Welsh Travellers.

Despite one NT stating that they "don't feel that there are any particular needs to understand", only 43% of members of that community felt that health care professionals fully understood their lifestyle and health care needs. Typical comments from <a href="New Travellers">New Travellers</a> included:

- Some do, some don't. There are some that are just good non-judgmental and understanding.
- They find it difficult to understand we can live comfortably in caravans that our lifestyle is not a cause of our problems.
- Lack of understanding regarding having no address and [problems] getting healthcare.
- Because all they want to do is treat with painkillers i.e. mask the problem rather than treating the route cause
- Don't understand our need to live outside in a caravan
- The cultural issue of how we live is not understood by many
- Most of them [understand lifestyle impact on health needs] except for the odd bigoted one
- Some are awkward with Travellers

Overall, 42 respondents (64%) felt that the NHS fully provides for their health needs as a Traveller/Gypsy/Showman/Boater. The remainder either did not respond or in a handful of cases referred to earlier comments re: not being registered with a GP or merely being offered painkillers rather than sent for tests and treatment for an underlying condition etc.

Very few people provided qualitative comments, e.g.

- "Present doctor does. I've had sciatica doctor put my needs etc. in notes to physio. But my husband has postal [c/o] address - we want to stay with that GP but anticipate problems. Using a PO Box address is another issue..." (Female Boater, mid 40s)
- "Not for continuity of treatment in different places". (Boater, male)
- "The GP understands that sometimes we have to live on sites near tips and sewers" New Traveller

# 2.2.11 Gender differences in attitude towards seeing GP/accessing preventative health care

Given the number of comments which had referred to gender differences in self-care (and see further qualitative data in Part Four) as well as the indicative prevalence of middle aged and older male Boaters, we were keen to explore whether respondents considered that different (gendered) attitudes prevailed within their communities in relation to health seeking behaviours:

Of the 50 respondents to replied to this question (shown at Table 4 below) fairly strikingly, 39 respondents (59%) felt that men were much less likely to see a GP or other health care provider than were women.

Table 4: Perceptions of Gender differences in seeking health care

	Yes, There's a difference	No there's no difference	I don't know	Total
Male respondents	15	2	3	20
Female respondents	20	9	1	30
Total	35	11	4	

This view was particularly strongly held by New Travellers (16/21 = 76%) although not shared by Irish Travellers (1/6 = 17%) despite evidence from other studies which suggests that Irish Traveller and Romany Gypsy women consider that their husbands are likely to 'ignore a problem until it is too late' (Greenfields, 20089).

### Comment from female Irish Traveller:

Men let wives look after them

### Comments from male New Travellers:

• Women would go, men might wait.

<sup>&</sup>lt;sup>9</sup> Greenfields M (2008) A good job for a Traveller? Exploring Gypsy and Travellers' perceptions of Health and Social Care Careers, a report for Aim Higher South East High Wycombe: Buckinghamshire New University

- Women are better [and seeking health advice].
- Women will go, men will not.
- Men less likely [to go to a GP]
- Women tend to go before men

### Comments from female New Travellers:

- Women will seek medical attention, men usually don't.
- Women much more likely
- Men more stubborn
- Men very unlikely to go to doctor until condition is really bad
- Men are very reluctant more so than women
- Traditionally men less likely to admit there is something wrong.
- Men more reluctant again don't like to appear vulnerable
- Men probably less likely to go.

# Comment from male Romany Gypsy:

• Women go more [to the surgery]

# Comment from female Showman:

 Women tend to go sooner; men will leave it until they know something seriously wrong.

# Comments from male Boaters:

- Men often leave going to a GP until it is too late.
- Young men don't respond to serious health conditions.
- Cultural thing don't think men's health issues are as well advocated as women's.
- Women do, men don't
- Depends on the person
- Feels men are less likely to go to GP (in general)
- Pretty sure women would make earlier appointments.

## Comments from female Boaters:

- Women are far more likely men often go 'cos wives tell them to.
- Men expected to 'tough it out' but things are changing good sign.
- Delay in how quickly men will seek treatment.
- Women are more likely to go.
- Men are more reluctant to go.
- Men tend to ignore health issues more often than women.
- Men are less likely to go to GP (in general)
- Women are more likely to see a doctor.
- Women are more likely to see a doctor.

It was of some note that more women than men answered this question (30 vs. 20). Interestingly, (perhaps based on knowledge/experience of preventable health problems

amongst their own gender) perceptions of male 'self-neglect' was greater amongst the male sample, 75% of whom thought that men are less likely to see a GP for a medical problem, than it was amongst women (67% of whom answered that men were loathe to seek health care).

However, male respondents were also more prone to express uncertainty on this issue (15% of men v. just 3% of women replying that they 'Don't know').

# 2.3 Experience of Using NHS Primary Care services

In the following sections of the questionnaire we explored with service users their experiences of utilizing particular health care services – for example GP surgeries and A&E departments, asking questions about quality of access and attitudes of staff.

Questions relating to ease of registration at GP surgeries/cultural barriers to service delivery have been explored above in Section 2.2

Table 5 (see below) presents average ratings by ethnicity across all of these elements.

### 2.3.1 GP surgery opening hours and dealings with reception staff

In contrast to the difficulties noted in relation to registering with a GP opening hours were generally regarded with favour by respondents. Over 75% of respondents reported that opening hours were convenient or 'good' (average rating 6/7).

Only two NTs, four Boaters, One Gypsy and one Irish Traveller rated their satisfaction level at 3/7 or below with regard to opening hours. It is possible that the difficulties associated with accessing GP surgeries some distance from towpaths and sites (see above) were reflected in dissatisfaction rates with opening hours amongst some respondents.

Of the 56 respondents who replied to this question, 22 gave a rating of 6-7/7 for opening hours, including all the remaining English Gypsies and Irish Travellers; followed by over half of Boaters, although slightly more dissatisfaction was noted amongst New Traveller respondents who were in a third of cases reported 'average' levels of satisfaction (5-6/7).

The ability to get a convenient and rapid appointment with a GP was a matter of considerably less satisfaction amongst the 56 people who replied to this question. Forty percent of Irish Travellers and 50% of English Gypsies rated it difficult 1-2/7 to get an appointment with a further two Irish Travellers and five boaters, rating the service as 3/7 in terms of access to appointments. The remainder of the sample felt that it was averagely easy to obtain a GP appointment.

Only 19/56 (including one Gypsy, one Irish Traveller and one Showman respondent with the remainder split between NTs and Boaters claimed that it was easy to obtain an appointment, rating the service 6-7/7)

Satisfaction levels with reception staff were particularly low amongst 'ethnic' Gypsies and Travellers with 60% Romany Gypsies, 80% of Irish Travellers, Showmen and the single Scottish Traveller all rating reception staff attitudes at 3/7 or less. As one Irish Traveller stated "they tar us all with the same brush". Comments above re complaints about mud on GP reception floors and how this made a service user feel, do not add to the impression of being 'unwanted' noted by some respondents. Boaters and New Travellers were more likely to report that reception staff were good with an average rating of 6-7/7 from respondents in these communities.

The difficulties in engaging with reception staff has been noted elsewhere in studies into Gypsy and Traveller health. Whilst it may be that perceptions of particular hostility are erroneous as the gatekeeper function of reception staff, (particularly when an individual is unwell or needs an urgent appointment) may lead to communication issues between service users and staff; negative impacts on health care may nonetheless accrue, a fact noted by Van Cleemput (2009) in her PhD study into understanding of communication styles between staff and Gypsy patients10.

Levels of satisfaction with the quality of the waiting area/privacy etc. were rated by all respondents between 5-7. Satisfaction with waiting times varied however, with 40% of Irish Travellers and 60% of Gypsies rating waiting times at 4/7 whilst a lower percentage (only 20% of Boaters and New Travellers considered that waits were very bad or bad (one each of Boaters and New Travellers rated waiting time at 1-2/7) whilst a further 8 Boaters and New Travellers giving a rating of at or below 4/7 in this element of the questionnaire. The remainder of the sub-sample considered that waits were average or good 5-7/7. No Gypsy, Showman, Scottish/Welsh Traveller or Irish Traveller rated waiting times at higher than 6/7 although ten Boaters/Showmen reported that they were very satisfied with the wait (7/7).

## 2.3.2 GP services and follow-up care

Satisfaction with the levels of GP consultations/care were generally very high amongst the 56 respondents to this question. Only three respondents (1 X Gypsy, 1 x Irish Travellers and 1 x Boater) rated the quality of their GP's care as 3/7 (the lowest score provided); 3 x Irish Travellers; 1 Irish Traveller, 5 x NTs and 9 Boaters recorded a midrange satisfaction score of 4-5/6 and the remainder of the respondents (3 English Gypsies; 4 Irish Travellers; 10 NTs; 2 Showmen and 7 Boaters) graded their quality of GP service at a 6/7.

Van Cleemput, P (2009) Abstract of thesis: Gypsies and Travellers accessing primary health care: Interactions with health staff and requirements for 'culturally safe' services.
Journal of Research in Nursing 14 (4) 365-369

Interestingly there is a virtually inverse degree of satisfaction amongst 'ethnic' Gypsies and Travellers in relation to treatment by reception staff, waiting times and the quality of received GP care whilst Boaters and New Travellers record limited variation in scores across all categories of satisfaction in terms of GP services.

In relation to receiving prescriptions from GPs and ability to access medication there was a resounding 80% satisfaction rating amongst all respondents with only a small number of Boaters and New Travellers grading the service at, or below, 4/7.

# Satisfaction with follow-up care provided by GP services/staff.

Once again (other than a relatively small percentage of New Travellers and Boaters who it may be posited are potentially disadvantaged as a result of site locations or ability to access surgeries) satisfaction with follow-up care were generally high. All Gypsies/Irish Travellers/ Scottish-Welsh Travellers and Showmen rated this element of service at 5/7 or above. The most common responses amongst Boaters and New Travellers were (interestingly) 4/7 (low average satisfaction) or 6/7 (satisfied) with follow up care, indicating potentially variable practice in terms of follow-up care and staff attached to GP surgeries. Four New Travellers and one Boater rated their GP surgery's follow-up services as 'very good' or 'outstanding' as did one Irish Traveller. The majority of other 'ethnic' Gypsy/Traveller/Showman respondents rated follow-up care at 6/7.

**Table 5: Patient Experience of Using GP surgery services** 

Average ratings (out of 7) given by each ethnicity were as follows:

	Romany Gypsy	Irish Traveller	New traveller	Boater	Showman	Other
GP surgery opening hours	4.6	4.8	5.55	4.87	5.5	4.5
Making an appointment	4.8	4	5.3	4.52	5	4
Reception staff attitude etc.	4.2	3.5	5.1	4.57	4	4.5
Quality of reception area	5.4	5	4.82	5.57	6.5	5
Waiting time	4.6	4.33	5.34	4.82	5	5
Quality of consultation	4.8	5.5	5.17	5.04	6.5	4.5
Getting prescriptions	5.4	6	5.91	5.13	6.5	5.5
Follow-up treatment / care	5.4	5.83	4.6	4.45	5.5	5

# 2.4 Emergency and Out of Hours Care (Access to Other Health Services)

#### 2.4.1 Out-of-hours care

Sixty four of 66 respondents replied when were asked where they would go if they needed medical treatment in the evening or at the weekend, and which services they would prefer to use.

Breaking down the findings by ethnicity revealed that Irish Travellers reported a strong preference for use of A&E (80% as first choice service) whilst 60% of English Gypsies use A&E by preference although one elderly Gypsy respondent pointed out that they have "problems getting there though". Walk-in clinics were preferred access points (80% Gypsies and 20% Irish Travellers respectively) for out of hours care.

One Irish Traveller noted approvingly: "A&E- Quicker and accessible. You get in the system straight away".

In contrast approximately 60% of both Boaters and New Travellers would wish to utilize A&E for out of hours, preferring (at around 75%) to make use of walk-in clinics. Only a limited number of respondents (only one 'ethnic' Gypsy/Traveller) would consider going to an emergency dental service in an emergency, preferring even with dental issues to attend at A&E.

Table 6 Use (and preference) for types of out of hours care

	Used	Preferred
Hospital A&E	46	26
Walk-in clinic	41	31
NHS Direct	16	5
Emergency dental clinic	12	2
Other	4	0

It was interesting that although hospital A&E were the most commonly used form of outof-hours medical care, respondents indicated that they would prefer to use walk-in clinics, suggesting that limited availability of such services is a limiting factor which may impact on inappropriate or unnecessary A&E use by Travellers/Boaters.

### A&E

Overall only 8 respondents (12%) reported having had difficulties with using A&E services – 4 New Travellers and 4 Boaters. Comments showed that the problem of excessive waiting times (and distance between services for some respondents) is the main complaint, as it is for settled communities.

- Long wait, few and far between so travel long distance to get there.
- Long wait due to staffing levels emergency with friend's child's eye staff said either drive to Swindon or accept there's a risk of Noro-virus [if remained].

However, one New Traveller's comment was highly pertinent in terms of the attitude of staff to them and despite what was clearly a high priority case of a child with head injury reluctance to provide care. The interviewer's notes recall:

• "[service user] took friend's son to A&E with head injury - refused to treat/see them until they could give an adequate doctor's address. Attitude of staff very unhelpful - left them alone for 3 hours with toddler covered in blood. Felt this because they were obviously Travellers and being discriminated against".

# **NHS Direct**

Only very few respondents (12 = 18%) they would have, or had experienced difficulty in using NHS Direct. Other than one English Gypsy and one Irish Traveller the remainder of these respondents were split equally between Boaters and New Travellers. The main barrier cited for these respondents being the expense of the telephone call and difficulties for boaters in achieving mobile phone coverage.

### Visiting services from GPs, Health Visitors, Midwives and ambulances

11 respondents (17%) reported that they had difficulty getting health professionals to visit them 'at home'. The complainants were, mostly Boaters (8 cases) and also 3 New Travellers. However, no other ethnic groups reported difficulties. We would note however, given the comments below re: emergency access (ambulances) that some of this apparent satisfaction may mask the fact that some services simply no longer offer home visits to patients. Several Boaters commented to the effect that "if I was moored near a road might be able to" or "I suppose the ambulance could get bridge access" but had no experience of seeking such care.

Of the 31 respondents (47%) who stated that they did receive home visits 22 (one third of the total sample) were living on sites/boats – meaning that 2/3rds of respondents did not receive such 'home visits/care'. Commendably all housed respondents reported that they were able to access home visits (nurses, emergency services) if required.

Health Visitors were singled out for particular praise amongst six respondents (all Boaters and New Travellers). One English Gypsy living on an authorized site reported that "the Health Visitor refused to come out to our site". In once case a New Traveller reported that a sympathetic doctor would attend on site "but he shouldn't really as I'm out of his catchment area now" and two others reported that GP as well as midwives and health visitors would attend their unauthorized site.

It was however of deep concern (and we suggest that this is addressed as a matter of urgency - perhaps through issuing guidance on use of bridge numbers/attending at

sites – that one (sited) Romany Gypsy, 2 New Travellers and 2 Boaters reported that ambulances will not attend where they live.

Whilst the over-whelming majority of respondents reported that they had never tried to call for emergency medical care, some comments indicated that respondents were concerned that should they need to do so, no help would arrive. A major barrier for Boaters (and some New Travellers) was not having a postcode to give. Boaters were reliant upon 'bridge numbers' which are little known outside of boater circles, and vehicular access was also an issue for some respondents if there was no easy access to a tow-path for long-stretch.

### Comments from New Travellers:

- No postcode
- Main worry no postcode to get an ambulance. If children have an accident they won't be able to get help from an ambulance
- They would have real trouble in the winter during snow and icy times, the track is impassable and site is unreachable unless you have a 4x4

### Comments from **Boaters**:

- They did [arrive] in this case, but probably 'cos we gave them nearest bridge no.
  it meant nothing we had to get someone to go to nearest road and wait for
  ambulance.
- Yes, if can give a postcode locating things is difficult for them even with SatNav giving name of pub and village didn't help had to give them directions they can't understand where you are. God knows what you'd do in a proper emergency.
- I don't know how they would get there there's no road access on a lot of the canal.

# 2.5 On-going health conditions

Respondents were asked whether they or any of the family/household members with whom they live with have a range of health problems. A number of options were offered (see Appendix A – Service Users Questionnaire) with the option to add additional categories. There was a marked difference in 'openness' of responses amongst the different categories of respondent, with ethnic Gypsies/Traveller less likely to provide precise details of health matters (as highlighted by our community interviewers - see Part One of the report). In total 60% of English Gypsies and 50% of Irish Travellers provided information on some health conditions. No responses were received from the Scottish-Welsh Traveller or the household categorized as 'other'.

The frequency of reported health conditions is shown below. The main issues were smoking, reported by 35 respondents (53%), nerves/depression/stress, reported by 17 respondents (26%) and eyesight problems (15 respondents – 23%).

Interestingly (and not unrelated we suggest to the age range of respondents as well as potentially living in smokey environments in boats/limited use of opticians) eyesight problems were particularly an issue for Boaters. Concerns over smoking (highlighted figures indicate those of most importance) were more of an issue for New Travellers than any other category of respondent. Diabetes, cardiac disease and high blood pressure which are regarded as major causes of ill-health and premature morbidity/mortality amongst Gypsies and Irish Travellers were found at a lower prevalence rate than in a number of studies (as were concerns pertaining to depression/nerves) although the minute sample size means that this finding is not statistically significant, and merely adds to an increasing body of evidence in relation to ethnicity and prevalence rates of certain conditions with relatively early onset of heart disease as per the data on the respondents recorded here.

Table 7: Reported health conditions by ethnicity of respondent

	Romany Gypsy	Irish Traveller	New Travellers	Boater	Showman	Total
ADHD/autism	-	-	-	1	-	1
Alcohol dependency	-	-	-	2	-	2
Cancer	-	-	-	-	1	1
Dementia	-	-	4	-	-	4
Diabetes	1	1	-	2	-	4
Eating disorder	-	-	-	2	-	2
Epilepsy	-	-	-	-	-	0
Eyesight problems	-	-	2	13	-	15
Hearing problems	2	1	1	4	-	7
Heart problems	1	-	-	2	-	3
High blood pressure	1	-	-	3	-	4
High cholesterol	-	-	-	1	-	1
Mobility, standing, walking	-	1	2	6	1	10
Nerves, depression, stress	1	-	7	9	1	18
Non-prescribed drug use	-	-	2	2	-	4
Respiratory problems	-	-	3	6	-	9
Smoking	2	2	13	18	-	35
Total number of respondents by category	3	3	19	27	1	53

A breakdown of health conditions by ethnicity (Table 8a) as percentages of ethnic groups shows that 43% of Boaters cited eyesight problems as an issue which affects their family. Smoking was the most significant issue for New Travellers, affecting 62% of them. It was noteworthy (although unsurprising given earlier comments re the physicality of living on a boat that a relatively high number of Boater respondents reported mobility difficulties (and see further below re: additional comments from respondents). Depression and stress were also substantial amongst insecurely sited

New Travellers and Boaters who were required to move on every 14 days. The stress of their lifestyle was linked during some comments in the focus group (see Part Four) with higher rates of smoking and substance use amongst some Boaters and New Travellers.

Table 8: Health Conditions of respondents/household members by percentage and ethnicity

	Romany Gypsy	Irish Traveller	New Traveller	Boater	Showman
ADHD/autism				3%	
Alcohol dependency				7%	
Cancer					50%
Dementia			19%		
Diabetes	20%	17%		7%	
Eating disorder				7%	
Epilepsy					
Eyesight problems			9.50%	43%	
Hearing problems	40%	17%	5%	13%	
Heart problems	20%			7%	
High blood pressure	20%			10%	
High cholesterol				3%	
Mobility, standing, walking		17%	9.50%	20%	50%
Nerves, depression, stress	20%		33%	30%	50%
Non-prescribed drug use			9.50%	7%	
Respiratory problems			14%	20%	
Smoking	40%	33%	62%	50%	

## 2.5.1 Access to talking therapies

Given the high percentage of depression/anxiety amongst our sample, and known to affect Gypsies/Irish Travellers (e.g. Parry et. al., 2004. op. cit) we explicitly asked whether 'talking therapies' had been offered to respondents reporting these conditions. Of the 18 respondents who had answered that they or their family had been affected by nerves, depression and/or stress, 10 (56%) reported that they were offered talking therapy and 6 (33%) said that they were not. (2 =11% - did not respond to this follow-up question). Five respondents said that talking therapy had worked for them, and 5 (including 3 New Travellers) said that it had not had any effect on them/did not work.

Overall, 11 respondents said that they/their family preferred this form of treatment to taking pills whilst only 2 said they preferred to be offered medication (both male Boaters aged 46-55). The attitude towards talking therapy was particularly positive amongst Romany Gypsies although other studies (e.g. Greenfields, 2008 op. cit; Cemlyn et. al., 2009) have found that in many areas there is low rates of offering these services to Gypsy/Traveller patients who have reported being 'fobbed off with a handful of pills' in some localities.

Respondents reporting depression/anxiety/nerves were also asked if they had been offered access to 'specialist help' and if so, if they had taken it up. No additional comments were recorded (but see below under 'dual diagnosis issues' and 'sensitive subjects' re: substance misuse at S2.7)

# 2.5.2 Dual diagnosis

Four respondents reported that someone in their household had been told they have a 'dual diagnosis', e.g., substance use and mental health or learning disability. These were one female Romany Gypsy, 2 New Travellers (male and female) and 1 male Boater. All reported that they were receiving enough help from professional services they were in contact with, apart from the male New Traveller. Despite, this New Travellers in the main appeared less content with services than were other respondents.

Comments made by <u>New Travellers</u> were as follows:

- I need transport in order to attend hospital and doctor appointments. It would be good to be able to register with a GP who is nearby, instead of going into town every day to see the homeless doctor.
- I want help and I am looking, but I don't want to be palmed off with more addictive drugs. I want some sleepers really.
- I don't know what else they could do to help.

The one male NT who was deeply unhappy with the quality of care/support provided enough detail to warrant concern about the level of services he has received:

Depression and alcohol dependency. Previously overdosed - taken to A&E. Spent three days in intensive care. Once recovered, when asked if he was happy to go home, he said no. However, they discharged him anyway with a number to call of the Crisis mental health team. They failed to contact and inform his friend of his discharge and effectively 'kicked him out' in just a t-shirt in middle of winter. CRISIS team not particularly helpful. GP - refuses to change antidepressant medication saying they are the best. However, interviewee has read the contraindications which include increased risk of suicide attempts and hates taking them.

#### 2.5.3 Additional Health Care Needs.

In addition to the above (listed) health issues, 17 respondents (all New Travellers and Boaters) reported having other health needs. 15 of these respondents provided further details on their health needs:

### Male New Travellers:

- Impotence. Seen 4 doctors, but treatment it hasn't worked. This does play on my mind. It is also very embarrassing
- Ulcerated foot. Get dressings off the homeless doctor. Needs a specialist to look at the foot. He has had the problem for eleven years and it has not been resolved yet.
- Prolapsed disc back pain. Osteopath (privately paid for) NHS doctors not much help referred to physio but nothing ever came of it [re moved on].
- Possible spina bifida just beginning to investigate it now via GP
- Muscular-skeletal ones wrists, shoulders and chronic back pain. He (partner) won't go and get medical help.
- Knees and back pain (long term previous injury) no treatment/support available

### Female New Travellers:

- Problems with recurring miscarriages. Has had help from fertility and generit testing which has ruled out any medical reasons for the miscarriages
- Hypo-thyroidism –yes, receiving support on a repeat prescription for medication – only reason she got accepted in surgery.

### Male Boaters:

- Back pain pain relief obtained via the chiropractor.
- Pain/mobility. Getting support? None problems with shopping, cleaning, moving boat, getting water, emptying toilet, etc. opening bridges.
- Undiagnosed mental health problems. No treatment has no faith in NHS. Doesn't know what extra help he would like/is available.

### Female Boaters:

- Migraine, headaches, Irritable Bowel Syndrome. GP has prescribed medication and gave advice about not taking too many pills - maybe need physio; some is due to muscular problems.
- Back, shoulder problems and balance. Received physiotherapy. No extra help it just means I don't do lock gates when bad it [back] has kept us from moving
  on a few times
- Childhood leukemia need annual checks but have had none recently/at present

### Male/female Boaters:

• Depression (Partner and self) – would like talking therapy – a need for more community based mental health services

Respondents were also asked which health issues were most important to them in terms of daily life and concerns for their family (open text question).

## Female Romany Gypsies:

- I just try to make sure they are OK
- We try to make sure we help each other when we can.

## Male New Travellers:

- Smack, smoking, substance abuse. To sort these problems out.
- To stop drinking or at least control it more.
- Reducing alcohol intake.
- Living healthily, eating well.
- Mental health issues how to improve
- To avoid stress of where to live.

# Female New Travellers:

- I am scared of getting cancer. Asthma problems with my son.
- Smoking, drinking alcohol, exercise.
- Being healthy in general.
- · General mental and physical wellbeing.
- Exercise.
- Her son's development
- Looking after yourself in general i.e. eating well, listening to your body
- She is a breatharian [??].
- Taking lots of exercise and smoking less

# Male Boaters:

- Cardiology.
- Access to medical treatment when needed.
- Getting older, achieving more.
- Not getting ill I suspect if I did get ill it would be very difficult to get better because of the additional physical stress of living on a boat it worries me.
- Healthy eating
- Eating healthy. Worry about smoking
- Physical and mental health issues
- Ambiguous question
- Teeth at the moment
- Good health

## Female Boaters:

- Diet, stress, mobility (mobility affects the dynamics between me and partner; I have to do a lot he can't do). Stress attacks us all.
- My energy levels (iron deficiency), headaches and back injury (twisted pelvis on boat and not fully recovered neck injury.
- Child health and family planning.

- Staying active and having the strength and stamina to carry on we worry as we get older we won't have strength/stamina to keep it up.
- Being fit and strong; being able to get over colds, flu etc. fast.
- Healthy eating and exercise
- · Currently female health issues.
- Mental health
- Mental health issues as I believe it's poorly understood in all walks of life.

# 2.5.4 Access to Benefits/level of knowledge about Benefits for Disabled/III family members

Respondents were asked if they or a member of their family had a long term condition if they were aware of benefits were available to them. In total only one New Traveller and Three Boaters who reported household/family members with a range of health conditions reported that they were not informed about potential benefits for carers/people who were unwell.

This theme was revisited later in the questionnaire when respondents were asked about knowledge of benefits available to someone caring for a terminally ill or severely disabled person and the same respondents (as well as an additional two English Gypsies and one Showman) indicated that they did not know about available support for carers.

It may thus be, that there is some scope for benefits advice outreach work to be undertaken with Romany Gypsies and Boaters given two out of the three Boaters and both Gypsies with no knowledge of benefits rights reported that household members had a range of conditions including mobility problems, cardiac difficulties, depression etc.

# 2.6. Antenatal Care/Maternity Services

Of the 66 people surveyed, 11 were able to provide information on their own/household members' experiences of ant-natal and maternity care – (8 New Travellers, 2 Irish Travellers and 1 Boater).

Of the 10 women who provided information on maternity/antenatal care, all confirmed they had been offered regular appointments to see the midwife/doctor, and all but one of these (a New Traveller) reported taking up antenatal appointments.

Apart from one Irish Traveller, all of the women reported being offered scans and accepting this service (including the woman who refused regular antenatal appointments).

All but one New Traveller reported being offered standardized screening for abnormalities, but one New Traveller said she was not offered screening. Both Irish

Travellers and the single Boater respondent accepted screening but only one New Traveller out of the eight women in that category took it up (i.e., 7/8 New Travellers declined screening). No reason was provided for declining screening or regular antenatal appointments by the women who did not accept these services.

# Home births

Both Irish Travellers (housed) said they had been offered the option of a home birth, and the Boater replied 'not applicable' to this question. Of the 7 New Travellers who replied, 5 reported that they had not been offered a home birth. Both of the NT women offered home births were resident on sites so it is not immediately self-evident why they were offered this option when other women on unauthorized sites were not.

Some respondents commented on reasons for the option of a home birth being denied. Mostly, reasons were the same as for the settled community, e.g., due to health problems such as hypertension or complications with a previous birth. Other comments (all made by New Travellers) were as follows:

- They didn't offer, but I know that Travellers are usually discouraged from having home births in caravans, especially if it's your first child.
- Have been cautioned about weather snow may make site inaccessible for midwives.
- Wasn't offered but [we] said that is what we were doing anyway.
- Just wasn't offered.
- [Medical team] Supportive of home birth option however high BP forced hospital admission.

All of the 7 New Travellers replied said they had been allocated Health Visitors after giving birth. However, only one Irish Traveller stated that she had access to a Health visitor whilst the other Irish Traveller and the Boater said they had not received this service.

# Midwife/Health Visitor Understanding of culture

Very few comments were received under this heading. However, only 2/4 New Travellers said they felt their midwife and hospital staff understood about Gypsy/Traveller/Boater culture and attitudes to childbirth.

One Irish Traveller replied 'yes' to cultural understanding but provided no further details and the other woman did not respond. The Boater said that she 'did not know' if medical and midwifery teams were aware of any cultural issues which might pertain.

In contrast, 4 out of 5 New Travellers who responded to this question and both Irish Travellers, felt their Home Visitors understood about clearly about their culture and attitudes to childbirth and pregnancy.

# Comments on understanding by hospital/midwife (all made by New Travellers):

- In the end they respected me and my wishes. The Health Visitor was [initially] trying to scare me about my daughter sharing a bed [with her parents].
- No real difference in culture they were supportive in leaving us alone to get on with it whilst in hospital.
- Hospital obstetrician reported [family] to social services for living in a caravan. She asked a series of inappropriate questions regarding their lifestyle and then sent a referral to the social services. Interviewee wrote a letter of complaint to the hospital and the obstetrician has since been disciplined. Interviewee's community midwives also wrote a letter of support to the social services saying there was no cause for concern. However it has taken nearly six months to persuade the social services to leave them alone. It has caused a lot of stress and anxiety; and the family came very close to hitching up the caravan and leaving the county.
- The home birth experience in B&NES was better than their previous home birth in East Sussex. However, in both cases midwives seemed uncomfortable/unsure about being in a caravan. They hung about at the door and took ages to arrive. Both times, mostly spent their time talking and making conversation with [male] interviewee rather than going to see/support his partner in the early stages of her birth. Spent a lot of time chatting about living in a caravan and asking questions, rather than doing their job. Generally though Midwives in B&NES friendly, unlike those in Sussex who were quite rude.

# General satisfaction with maternity services and after-care

Respondents were asked to rate their levels of satisfaction (out of 7) with the care they had received at various stages in their pregnancy/birth. Table Nine (below) summarises the responses received.

Table 8: Satisfaction with maternity services and after-care by ethnicity of respondent

	Irish Traveller	New Traveller	Boater
	n=2	n=8	n=1
Happy with treatment during pregnancy	4	5.75	7
Happy with treatment during childbirth	5	5.79	n/a
Happy with follow-up treatment afterwards	4	6	n/a

Respondents were asked if they had any additional comments or recommended changes in relation to ante-natal/maternity care offered in the area to Gypsies/Traveller and Boaters.

- I think that they are good. Sometimes the doctors can be funny though [with Travellers]. I would like to see more alternative therapies on the NHS.
- The Health Care staff are very good, but I would have liked a home visit following child birth. If people have babies in hospital then they should be allowed to stay longer if they live in a caravan.
- Local surgery refused to take them [on as patients] reasons given as possibly anti-Traveller.
- Less prejudiced [than some services]
- More education/awareness of caravan living/vehicle living so that it doesn't overshadow the treatment, experience of midwives.

# **Vaccinations**

Both Irish Travellers and 7 New Travellers reported that they had been offered vaccinations. Whilst it is perhaps surprising that inoculation programmes were not routinely offered to new babies there is evident success in the B&NES area in encouraging uptake, as of these 9 respondents, only 2 New Travellers reported declining the service for their children.

Respondents were also asked if they had been offered information about breast feeding. All seven New Travellers and one Irish Traveller who responded to this question reported that breast feeding advice was offered. No women reported that no advice had been received.

# 2.6 Healthy Living (aspirations and sources of advice)

Respondents were asked about what their priorities would be for achieving a healthier lifestyle. In total 51 (77%) of respondents answered this question. Table 10 summarises the themes by ethnicity of respondents.

Table 9: 'Healthy Living' priorities by ethnicity of respondent

	Romany Gypsy	Irish Traveller	Scottish /Welsh	New Traveller	Showman	Boater	Total
Stop smoking	-	2	-	12	1	15	30
Lose weight	1	-	-	5	-	4	10
Eat more healthily	-	-	-	5	-	16	21
Take more exercise	-	-	-	8	-	9	17
Cut down on drinking	-	1	1	10	-	12	22
Relax more	2	1	1	12	-	15	31
Cut down on meds/non-prescribed drugs	-	-	-	2	-	6	8
Total respondents x ethnicity	3	2	1	20	1	24	51

It was noteworthy that approximately 50% each of New Travellers and Boaters and 30% of Irish Travellers reported that they would want to stop smoking. At present there are limited targeted resources available for Gypsies/Travellers in this field, although Buckinghamshire New University have worked with Buckinghamshire PCT and One Voice for Travellers to successfully train smoking cessation advocates from Gypsy/Traveller communities and devised culturally appropriate training materials for dissemination to (ethnic) Gypsy/Traveller community members. Whilst this project is still at an early stage – less than one year post training of advocates – these appear to be regarded as successful tools and we would recommend that consideration is provided to utilization of this or a similar scheme, potentially adapted for use by New Travellers.

Alcohol misuse (and by extension other substances) were also highlighted as a key area of concern for Boaters and New Travellers, and across all categories relaxation, stress reduction and healthy eating were indicated as areas which would warrant the provision of services to the communities. Weight loss and increase in exercise were both noted (by around 20% of the sample in total) but given the degree of physical activity required to maintain a site/boat lifestyle it is unsurprising that amongst New Travellers and Boaters in particular these categories were relatively low.

Qualitative Comments from respondents are presented below by ethnicity of interviewee:

# **New Travellers:**

- Cut down on heroin specifically (male)
- Take my kids to a Chinese Herbalist to sort out their respiratory problems. (female)
- My lungs are f....To relax my body and mind in the moment, meditation. Get rid of controlled drug prescription. (male) would like to access yoga classes

- Move back into a truck would make me physically healthier. (housed female) –
   would like to access hypnotherapy to help with feelings of motivation
- Move out of muddy damp environment (female sited)
- Probably smoking cessation clinic (male)

Another New Traveller said she would like to access the 'Health Start' campaign. (Groups for overweight people to go out walking together). She had seen a poster in the GP waiting room but wasn't sure if she would be welcomed by other participants as a Traveller. Nb: it may potentially be worth considering if 'mixed' Traveller/Gypsy/Boater groups might wish to engage in such gentle exercise campaigns which may also enable the breaking down of any social and cultural barriers which exist between the groups.

# Boaters:

- Would stop hair pulling need help with it (anxiety and habit) and grinding teeth.
   (female) would like to access hypnotism and/or CBT to help with hair pulling
- Less cold and damp conditions; less smoke from coal fire and diesel engine (female)
- Cut down on coffee (female)

One male Boater (no regular GP access) stated that he would like to access counseling services.

Respondents were asked where they currently obtained healthy living information. Although 32 respondents (48% of the sample) of all ethnicities (100% of Showmen, 40% of English Gypsies and 60% of Irish Travellers as well as 46% of Boaters and 42% of NTs) said that they currently go to their GP for advice, 29 respondents (44% of sample) reported also using the internet to access health information, comprising one Irish Traveller, one showman and notably 48% of New Travellers (10/21); 57% of Boaters (17/30).

In total seven respondents (5 of whom were Boaters, one NT and a Showman) reported using specialist Boater/Traveller blogs/advice agencies or websites such as the K&A Boaters website of Friends, Families and Travellers. One New Traveller said she doesn't use any services for advice on health issues – "I don't really, only if kids are ill."

Boaters cited other sources of information they currently use and which could possibly be capitalised on to disseminate health literacy:

- Tiny Buddha [website? If the website appears mainly to focus on use of positive thinking/emotional health – further information required if possible from the interviewer]
- Boating health professionals (of which a number exist in B&NES e.g. nurses, social workers etc.).
- 'Towpath Telegraph' (word-of-mouth community news/advice)

On being asked how they would like/which is the most suitable access to services for themselves and their community respondents provided the following information.

Table 10: Accessing healthy living services

	Romany Gypsy	Irish Traveller	New Traveller	Showman	Boater	TOTAL
Information / advice	1	0	2	1	10	14
Class / support group	0	0	5	0	4	9
One-to-one confidential	1	1	2	1	10	14
appointments	ı	U	2	-	10	14
Health literacy	0	1	0	0	5	6

As with discussions (below) on 'sensitive subjects' it was noteworthy that New Travellers were less likely to request one-to-one confidential support than were other categories, preferring instead to make use (as required) of classes and support groups, indicating a generally high level of comfort with group settings. In contrast, Boaters and Showmen/Gypsies demonstrated a preference for individual, discreet opportunities to access advice and information. Despite the level of engagement on forms of health information/access and the fairly detailed comments on healthy living aspirations, only 8 respondents (12%) said they would personally like to receive more information on any specific health issue (3 New Travellers and 5 Boaters).

All respondents were provided with the opportunity to ask that they are sent/provided with information and separate discussions will be held with the commissioning body to discuss how such materials/information can be disseminated to the individuals who requested follow-up contact.

Qualitative Comments were received from six respondents:

### New Traveller:

• [want information] On [ceasing] smoking, but it's difficult....

#### Boaters:

- Ways of dealing with mental health issues stress, depression, anxiety.
- Maybe info on hair pulling but don't want to focus on it to the extent that I do it more.
- Keeping children safe because it's such an extended community [child protection], but exists in a public space. Also info on what's delivered at school [curricula].

# 2.7 Accessing health information using new technology and alternative sources of information

Respondents were asked whether or not they felt that they and their community might be interested in receiving healthy living information in a range of 'alternative' formats with the intent of insuring that individuals with lower literacy skills, a range of preferred learning styles and/or limited access to GP services or internet access could have access to materials. A number of different options were suggested and respondents were also able to make additional suggestions for dissemination routes of information (qualitative open comments).

Perhaps the most noteworthy finding is that 14 respondents (21% of the sample) expressed interest in attending a special Gypsy/Traveller/Boater Health Event run with and for Gypsies, Travellers and Boaters.

Table 11: Interest in using Non-written sources of health information by community

	Romany	Irish	New	Boater	Showman/other	TOTAL
Talking books / audio	0	0	0	0	0	0
Internet / Podcasts	0	1	6	4	0	11
DVDs / CDs	0	0	1	1	0	2
Graphic art / cartoons	0	0	1	1	0	2
Trained community health advocates from your own community	4	2	3	11	1	21
Special staffed helpline for Gypsies / Travellers / Boaters available at certain times	1	4	3	3	1	12

Trained community health advocates were the most popular option, followed by a special helpline (preferably staffed by health care professionals with knowledge of – or if possible were a member of – Gypsy/Traveller/Boater communities). These were the ONLY options requested by Romany Gypsies and Irish Travellers and again this supports findings from Greenfields (2008) research (a Good Job for a Traveller) and experiences around the UK which has found relatively high levels of turn-out for specialist events.

When the data is considered by 'ethnicity', Romany Gypsies were more interested in the use of trained health advocates, whereas Irish Travellers favoured use of a specialist helpline. Boaters also expressed very strong interest in accessing health and social care advocates, preferably from their own community.

In addition, Boaters and New Travellers reported significant interest in using the Internet / Podcasts to access targeted, specialist health information.

<u>Literacy Support</u>: Respondents were asked whether they might require Literacy support to assist them in engaging with health issues or for general purposes. Only one New

Traveller and 3 Boaters expressed interest in obtaining support with reading and writing for themselves or their family.

The female Showman-Boater said that she actually provides support to other Boaters: e.g., with form filling. One Boater said he would like information, advice and tuition (liaison will take place with the commissioning agency to ensure that this individual is informed of appropriate services). The other 3 respondents did not specify any particular type of support they required.

# 2.8 Sensitive Subjects: Domestic Violence, Sexual Health and Contraception.

As discussed in part one we were aware at an early stage that 'ethnic' Gypsies and Travellers were likely to refuse to reply to these questions. This proved the case (whether this related to interviewer effect/cultural probabilities as well as respondents unwillingness to reply is immeasurable). Accordingly, the replies in this section of the report pertain purely to Boaters and New Travellers (and the one Showman-Boater respondent).

# 2.8.1 Family Planning Services

38 respondents (58%) reported having access to Family Planning Services. However, only 11 respondents (17%) reported NOT having access. Qualitative comments revealed interest in accessing a drop-in centre/walk-in clinic for contraception, which is reflected in the large number of respondents (31) who chose 'walk-in services' as their preferred method of access. The difficulties over registering as a result of not having a fixed address could also be overcome by use of such services.

Respondents were asked about their contraceptive/family planning priorities to probe whether such services could be made more accessible/user-friendly for them. The frequency of elements cited by 19 New Travellers, 20 Boaters and 1 Showman were as follows (Romany Gypsies and Irish Travellers did not answer the more sensitive questions):

Table 12: Contraceptive/Family Planning Services (priorities for use)

	New Traveller	Boater	Showman	TOTAL
Walk-in services	17	13	1	31
Short waiting times	12	8	0	20
Discreet premises (wont be seen by anyone I know)	2	7	0	9
Staff familiar with cultural issues for Travellers/ Gypsies/ Boaters	6	1	1	8
Reassurance service is confidential	5	14	1	20
My community don't talk about/aren't aware of the services	0	0	0	0
Knowing you will see staff who are the same sex as you	2	5	0	7
Non-judgmental services	12	16	1	29
Other (e.g., leave this decision to my partner)	0	0	0	0

Comments on Contraception/Family Planning needs:

# Male New Travellers:

- There is no issue with my community accessing family planning they can access them if they want to.
- They're perfectly accessible to Travellers if Travellers want to access them.
- Don't feel there is any need to make them more accessible as we are all quite capable of functioning like others in society.

# Female New Travellers:

- In the homeless health team, I just had a coil fitted by them
- I would like some free condoms. [doesn't know how to access]
- Doesn't need them as she had her 'tubes tied' fifteen years ago.
- If I needed them.
- Very different for different Travellers we're all different.

# Male Boaters:

- GP/Supermarket/chemist (condoms)
- GP and GUM clinic. Only use condoms.
- Through GP if I need them
- If I was straight I would know where to access [gay respondent]. nb: this may potential raise the issue of whether this respondent has access to condoms/safe sex advice as well

# Female Boaters:

- Use stuff from supermarket, have used morning after pill at GP and community centre.
- Very supportive GP practice.
- Walk in centre
- Either GP or hospital GUM clinic

#### Female Showman:

• I've been sterilised so don't need it [contraception] but it's [sexual health services] there if I need it.

Respondents were also asked where they would prefer to access Family Planning Services.

19 New Travellers, 19 Boaters and 1 Showman replied as follows:

Table 13: Preferred location for accessing contraception.

	New Traveller	Boater	Showman	TOTAL
Chemist	5	5	1	11
Family Planning Clinic	6	8	0	14
GP	8	7	0	15
Hospital	0	1	0	1
Specialist nurse / community services for Travellers / Boaters	2	4	0	6
Other	2	3	0	5

Respondents were asked if they would know who to contact in their local area if they or their family needed advice on terminating a pregnancy. All 21 New Travellers, 19 Boaters and 1 Showman answered this question. 19/21 New Travellers (90%), 11/19 Boaters (58%) and the Showman (100%) replied that they did know who to contact.

Respondents also made some suggestions as to how Contraceptive Services could be made more accessible to Gypsies/Travellers/Boaters etc. As with some other services the issues of lack of knowledge and not having a fixed address/postcode proved problematic in terms of accessing sexual health and contraceptive services for some respondents.

#### New Travellers:

- Friends, Families Travellers and services like them could do this [offer contraception/advice]
- Have people visiting site.
- More info regarding where it is [contraception and sexual health clinics], and when it is open
- More info on where to find them [contraceptive services]
- Less prejudice [towards Travellers and about sexual health and family planning]
- Advertising services/sex education
- Make sure that an address or lack of it wouldn't be problem in accessing services
- If they took you without postcode or address [would be easier to obtain contraception]
- Knowing where they are/exist, if you're not registered and going through the GP [it's hard]
- Someone from the community as representative
- Just need to be accessible without an address and also a website with addresses on for when you're on the road.

# **Boaters:**

- Specialist nurse/community service for boaters
- Don't know what's out there except have used drop-in centres people need to know what's out there.
- Advertise them more along the canal advertise walk-in services outside of health centres at sanitation points along the canal
- If people know where they are; if they could go to any family planning clinic where they are rather than being registered with one that's too far away.
- Leaflet drops to inform of places to access
- Ease of registering and not losing records when changing doctors, especially if suffering from long term/ongoing illness.
- Towpath Community Nurse

# 2.8.2 Sexual Health Services

38 respondents (58%) reported having access to Sexual Health Services (SHS). However, only 3 respondents (4.5%) reported NOT having access. Many more did not answer this question.

Respondents were asked about their SHS priorities to probe whether such services could be made more accessible / user-friendly for them. The frequency of elements cited by 19 New Travellers, 16 Boaters and 1 Showman were as follows:

Table 14: Sexual Health Services (priorities for use)

	New Traveller	Boater	Showman	TOTAL
Short waiting times	12	6	0	18
Discreet premises (won't be seen by anyone I know)	2	7	0	9
Staff familiar with cultural issues for Travellers/ Gypsies/ Boaters	5	2	1	8
Reassurance service	3	10	0	13
is confidential				
My community don't talk about / aren't aware of the services	1	0	0	1
Knowing you will see staff who are the same sex as you	0	0	0	0
Non-judgmental	1	4	0	5
Other (e.g., leave this decision to my partner)	12	13	1	26

The response 'other' generated few responses - mainly 'I don't need it' 'with a partner' 'don't use them'

Interestingly, New Travellers were less concerned about confidentiality/discretion than were Boaters, favouring short waiting times as a key element in selection of sexual health services. Potentially therefore it might be possible for specialist services to be made available (e.g. testing/advice) on sites or at drop-ins for NTs in a way which would be less acceptable to Boaters. The response 'other'

Respondents were also asked where they would prefer to access Sexual Health Services. 17 New Travellers, 19 Boaters and 1 Showman replied as follows:

Table 15: Preferred location for accessing sexual health services

	New Traveller	Boater	Showman	TOTAL
Chemist	2	5	0	7
Family Planning Clinic	3	2	0	5
GP	4	8	1	13
Hospital	9	7	0	16
Specialist nurse / community services for Travellers / Boaters	3	5	0	8
Other	1	4	0	5

Respondents also made some suggestions as to how Sexual health Services could be made more accessible to Gypsies/Travellers/Boaters etc. Largely these mirrored the responses in relation to contraception/family planning services. Once more, use of culturally competent in-reach services to sites and boaters was proposed by several respondents.

#### New Travellers:

- By letting us register at a GP without an address
- People visiting site
- Specialist community nurses
- Local information. Where it is, when it is open
- · Get rid of prejudice
- Advertising services/education
- There are no cultural reasons for New Travellers not being able to access or use sexual health services if required
- Walk-in, no address needed
- Knowledge of where walk-in services are
- To have someone from the community shared culture, shared references makes the experience much more positive.
- They don't need to be made more accessible to our community as we are generally quite capable.
- Just need to be accessible without an address and also a website with addresses on for when you're on the road.

#### Boaters:

- Specialist boater health care professionals.
- If someone could visit the boat that'd be fantastic.
- Highlighting where they are, opening hours.
- I think GP more accessible. Main problem is where they are, travel/distance if you have to keep going, knowing where they are if you travel a lot, especially if no internet.
- They already are you can self refer and only have to provide NHS number only issue is whether you can get to one.
- It's difficult to get to them as they are too far away; being able to go to the nearest one can be a problem.
- · Community nurse used to Boaters.
- Confidential, no fuss, no need to register to use the facilities.
- Towpath Community Nurse.

#### 2.8.3 Information / advice on domestic violence.

In total the majority of respondents replied to this question. 28 respondents (42%) reported having access to Information / advice on domestic violence.

14 respondents (21%) reported not having access/information or knowledge on DV services.

Those reporting a lack of access to information included 6 New Travellers (29% of respondents) and 7 Boaters (23% of those who replied).

Respondents were also asked what they would do if someone in their family or community were having trouble/experiencing problems as a result of domestic violence. This question was deliberately phrased to avoid a respondent experiencing family violence having to respond to or reflect on their personal experience when replying.

20 New Travellers, 20 Boaters and 1 Showman replied as follows:

Table 16: How to address domestic violence within the community.

	New Traveller	Boater	Showman	TOTAL
Talk to GP	4	2	0	6
Talk to a specialist health worker with experience of Travellers/Gypsies/Boaters	4	6	0	10
Keep quiet about it	11	13	1	25
Ask their family/community to deal with the problem for them	10	7	1	18
Call a specialist helpline	4	9	0	13
Go to a refuge	0	7	0	7

There was a significant (and concerning high) number of respondents who indicated that family violence in their community would not be spoken of/'kept quiet' indicating that potentially a victim of violence may find it difficult to obtain support. The second and third most favoured responses were to seek advice from a trusted health worker or a specialist help line. Problematically, evidence gathered in the ESRC review (Cemlyn et. al., 2009 op. cit.) indicates that very few refuges and advice centres are equipped or have the knowledge to offer support to Gypsies and Travellers. We would therefore suggest that cultural awareness training and knowledge of appropriate specialist support services are made available to health workers who may encounter Gypsy/Traveller/Boater services users who require advice on this subject and other 'sensitive areas' such as substance misuse concerns (see below).

The selection of 'asking family/community' to assist was common in Greenfields (2002) research11 on family and child rearing patterns in New Traveller communities where a large number of respondents (both male and female) indicated that domestic violence would be 'dealt with' by other site members/friends of the person experiencing the violence. In that study it was found that other community members were likely to either 'invite' the perpetrator to leave the site/vehicle or help move the victim to a new location

1

<sup>&</sup>lt;sup>11</sup> Greenfields, M (2002) New Traveller Families and s8 Children Act applications. Unpublished PhD Thesis, University of Bath

if the situation was regarded as unduly volatile. It may be that this pattern still holds true with in New Traveller populations although there is not adequate evidence in this current study to confirm such suppositions.

A number of respondents indicated the reasons why they felt they (or other of their community members) would not go to a refuge/or would 'keep quiet' in the case of domestic violence:

# Male New Travellers:

- Talk to GP but they could cause problems.
- Social pressure
- Keep quiet Some people do same as anyone else in wider community experiencing domestic violence

### Female New Travellers:

- There are other sites, so it is easier to move away, instead of going to a refuge
- This could cause a family split and the women could end up homeless
- Keep quiet Because people going through domestic violence don't tend to talk about it.
- Try and rationalise it.
- If people are in this situation they often won't recognise there is a problem.

# Male Boaters:

- Towpath telegraph would distort
- Keep quiet in the absence of a specialist with experience of boaters
- Refuge Only if absolutely necessary
- Keep quiet There are still people who'll keep quiet rather than speak out. No [to refuge] a live-aboard boater would find a static refuge too alien.
- Community would have word with abuser
- Escalation of violence [might occur]

#### Female Boaters:

- Would go and stay with mother.
- Keep quiet that's the nature of it... Might go to refuge it's 50/50 I don't think people want to leave the life, depends how desperate they are.
- Keep quiet common with domestic violence wherever you are
- Refuge Less likely option, you'd lose so much compared to someone in a house - become instantly isolated from your community at a point where you needed support
- Keep quiet It's a temptation not to talk about it.
- Keep quiet Because they wouldn't know who they could talk to that they could trust
- Refuge No, they wouldn't do that wouldn't want to give up living on a boat.
- People can feel ashamed about it
- Private, shamed, embarrassing.

• Depends on individual - would like to think it wouldn't be tolerated.

#### Female Showman:

 Keep quiet – because of fear and shame. Going to a Refuge – would be shameful.

#### 2.8.4 Substance/alcohol abuse advice/information

Overall 37 respondents answered this question. 56% reported having access to substance/ alcohol abuse advice/information. However, only 5 respondents (7.5%) reported not having access to specialist advice on substance misuse services if required. Many more did not answer this question.

Respondents were also asked what they would do if someone in their family or community were having problems as a result of drugs or alcohol. 19 New Travellers, 21 Boaters and 1 Showman replied as follows:

Table 17: how to address substance misuse within the community

	New Traveller	Boater	Showman	TOTAL
Talk to GP	11	8	0	19
Talk to a specialist health worker with experience of Travellers/Gypsies/Boaters	7	7	0	14
Keep quiet about it	4	14	0	18
Ask their family/community to deal with the problem for them	5	2	1	8
Call a specialist helpline	4	3	0	7
Other	2	7	0	9

Interestingly, New Travellers were somewhat more likely than Boaters to actively seek advice on substance misuse issues for themselves or a family member/friend than were Boaters who most commonly reported that they would 'keep quiet' supporting view emerging in the qualitative data and some other areas of the survey which suggest fairly widespread community tolerance of alcohol misuse and limited engagement with health/prevention services. Specialist outreach services may once again offer an option for reaching community members who may be aware that they wish to seek some help but are unsure of whether their use warrants concern and wish to avoid the stigma of speaking to someone without knowledge of their community, a proposal strongly endorsed in Greenfields (2008) study 'A good job for a Traveller' op. cit. by young Gypsies and Travellers who felt that experienced and trusted community substance workers would be more acceptable to their peers than 'outsiders'.

Again there was a clear recognition that some individuals might not recognize that they had a problem with their substance use.

# Comments made by New Travellers:

- They may not think it is [a problem]. Stigma. Reluctant to go to a doctor as drink and drugs are often part of site life... Rehab maybe... Usually deal with it themselves.
- Talk to friends.
- They may do any of the following [rehab/access services/see GP etc.] they are the same as people in wider community experiencing drug/alcohol problems.
- Because they probably don't think they have a problem. Typical male problem and men don't seek help very easily.
- Try and rationalise it.
- Might not recognise they have a problem.

### Comments made by **Boaters**:

- Talk to other boaters.
- Some members of the community have problems they are ignoring.
- Keeping guiet would depend on the person 'we're all different'
- Maybe keep quiet for years, then do something. Other alcoholics Anonymous.
- Depends if they want help with the problems if want help, would do all of above - drugs or alcohol abuse over rides all other concerns about how else you live your life - more substance misuse within boating community especially alcohol but maybe more obvious as you see people outside more.
- Go to place in Manvers street used to be called Badass; CAB, council.
- Do nothing about it because they don't see it as a problem.
- some people don't like to talk about it.
- People don't always want help.
- Not wanting to be judged.

# Comment made by **Showman**:

 Talk to a specialist health worker especially one with experience of Travellers/Gypsies/Boaters

# 2. 9 Caring and Carers

In Section F of the Questionnaire, all respondents were asked whether they were engaged with caring for an elderly/disabled member of their family/community (or if themselves required assistance and care).

The following definitions were used:

Caring includes cooking, shopping, washing, giving lifts, etc. to someone who could not manage otherwise.

A carer is someone (of any age) who provides unpaid care for an ill, frail or disabled relative, friend or neighbour

Very limited information was received in response to this section of the survey. Only 5 respondents (all Boaters) provided information about their experiences of acting as carers/receiving care in their home. These were two males aged 56-64, two females aged 36-45 and a male aged 46-55.

Four of these respondents said that the person who needed caring for was receiving support from Health/Social Services and that they were satisfied with this care (timing of appointments/service received etc.). One gentleman (aged 56-64) reported not receiving needed support to enable him to maintain his lifestyle as a boater.

One male aged 56-64 and one female aged 36-45 both reported needing help more often, needing home-visiting support, and needing more types of help, e.g., due to ongoing chronic illness.

Comments about extra help required from two Boaters: Help with boat movements [locks and physical effort involved]. Ongoing chronic illness needs more input.

Comments about refusal of support from health/social services (2 cases):

#### Boater (m)

Was not offered any help.

#### Showman

• Have been told can only get help with personal care, not with wood chopping, cleaning etc. "because it's not normal".

Whilst 'ethnic' Gypsies and Travellers in the main did not respond to this question in two cases the subject was 'closed' by respondents

# Romany Gypsies:

- Family will deal with it.
- Don't need it [help/benefits etc.].

The responses in these latter cases suggest (as is typical) a high degree of self-sufficiency and independence on the part of the Romany Gypsy communities

In the main little can be gleaned from this element of the study as we have found (or had reported) far lower levels of 'caring' responsibilities than have been found in some GTAAs and studies pertaining to Gypsy/Traveller health. It might well be, however, that some information on the support available to Gypsy/Traveller/New Traveller populations could be made available and social care staff should be required/reminded of their duty to assess the circumstances of the person in need of assistance rather than basing their judgments on 'normal' [e.g. house-dwelling] behaviours, which can create as a covert pressure to move into 'conventional accommodation' (see further focus group comments amongst Boaters) for service users .

In addition, to be asked about caring responsibilities, respondents were asked how they/their community would (culturally) prefer to care for older/disabled relatives and friends.

Whilst again very few respondents (8) replied to this section there is clear evidence of a wish for older/disabled people to remain living in their own cultural/community environment through the use of carers/support and adaptations where possible.

Table 18: Preferred care options for elderly/disabled community members.

	Romany Gypsy	Irish Traveller	New	Boater	Showman	TOTAL
At home (house)	-	1	-	1	-	2
On site/boat with	-	-	-	1	1	2
adaptations						
Sheltered / adapted housing	-	-	-	-	-	0
Care facilities	-	-	-	-	-	0
Support them to remain living independently in their own home/boat/trailer etc.	2	-	1	4	1	8

# 2.10 Terminal Care amongst Gypsy, Traveller, Showmen and Boater Communities.

This subject was flagged up by the research team as 'sensitive' across all communities and potentially even more so for 'ethnic' Gypsies and Travellers (based on findings from Parry et. al., 2004 and Cemlyn et. al., 2009). It has been noted anecdotally and in the reports cited above, that few Gypsies and Travellers will willingly refer to be eavement or terminal care support needs.

In total however, 52 respondents from a range of ethnic/community groups responded to at least some of the questions in this section of the questionnaire.

Table 19: Preferences for care of household member/friends at 'end of life' by category of respondent

	Romany Gypsy	Irish Travller	New Traveller	Boater	Showman	Other	TOTALS
At home (site/ house/ towpath etc).	5	5	13	18	1	1	43
Hospital	0	0	4	4	0	0	8
Hospice	0	1	3	7	0	0	11
Other	0	0	3	5	0	0	8

15 respondents reported looking after relative/friend at the end of their life, and 13 (87%) said they were given support with this by hospital/medical staff. Whilst answers (above) referred to cultural/community practices; for New Travellers and Boaters, experience of terminal care of friends and relatives or losing a close family member is equally as likely to involve loss of a parent who is not a member of the same 'cultural' community as the respondent (hence comments by two respondents on hearing about the imminent death of a parent).

Two respondents (Boaters) said there was a problem with the way they had been told the person was not going to get better.

14/15 (93%) respondents reported they had been given information in a way they found easy to understand. The only respondent who replied 'No' was a New Traveller. This respondent and 2 Boaters said it would have helped to have a 'mediator' from the Traveller/Boater community to talk to the hospital. However, 15/18 (83%) said that a mediator would not have been helpful in the circumstances.

Comments on finding information about terminal illness hard to understand:

#### Boaters:

 Only regarding the info that was given - but I work in medicine so easy to understand - would have been able to be there sooner if had been given clearer explanation about the deterioration in my Dad's health.

#### New Travellers:

- Medical jargon difficult to understand don't talk plain English.
- Although had to pin the nurse down to give an honest answer about mother's future as doctor's prognosis was very vague.

There is a striking preponderance for caring for a household/community member in their own location as they reach the end of life. This finding indicates a shift away from perceptions of (ethnic) Gypsy/Traveller preferences for death to occur away from home

– recorded historically and amongst anthropologists (e.g. Okely, 1983)12. It is likely that amongst ethnic Gypsies and Travellers the gradual move onto more sedentary authorized sites or housing has had a substantial impact in this shift, as in such circumstances there is at least theoretically greater ability for an individual to die at home with dignity. Moreover, death at home permits the enormously important cultural rites of family support during bereavement, a subject noted in various reports (e.g. Cemlyn et. Al, 2009 Clark and Greenfields, 2006; DGLG, 200813 and cultural awareness training programmes operated by diverse Gypsy and Traveller groups) as leading to high rates of tension between medical staff in hospitals who are unused to dealing with large numbers of visitors during the end of life process.

Jesper et. al. (2008) 14 in the only qualitative study of Gypsy/Traveller bereavement care and end of life experience reported that despite a strong preference for dying at home many 'ethnic' Gypsies and Travellers ended their life in hospitals as a result of lack of acceptance of trailers as suitable locations for death. They reported that this, coupled with lack of cultural knowledge of the communities caused significant levels of distress to families increasing tensions between health care providers and service users. There was significant interest from respondents in providing qualitative responses to the section of the survey which asked what health care providers needed to know in relation to supporting their communities who were facing end of life situations (see further below) indicating that this is a subject which has not been sufficiently aired with populations who wish to be able to care for family and friends at this most difficult of times.

# 2.10.1 Existing capacity to cope/support dying person

Respondents were asked whether, if they were looking after someone reaching the end of their life, they would be able to care for them in the way they wanted to (both personal capacity and practical issues pertaining to access to services. Several New Traveller and Boater respondents in interviews/focus groups made reference to their experiences of supporting terminally ill friends and community members (see Part Four) and there was a strong emphasis amongst respondents that if they were supported in accessing appropriate medical services they would be able to provide care to their terminally ill loved ones at home, on a site or in a boat.

Those answering yes are presented as percentages of those in each ethnicity who responded:

<sup>13</sup> Cemly et. Al, 2009 op. cit, Clark, C & Greenfields, M (2006) *Here to Stay: the Gypsies and Travellers of Britain,* Hatfield: UHP. Derbyshire Gypsy Liaison Group (DGLG) (2007) *A Better Road: an information booklet for health care and other professionals* Matlock: DGLG

Okely, J (1983) The Traveller-Gypsies, Cambridge: CUP

<sup>&</sup>lt;sup>14</sup> Jesper, E, Griffiths, F. & Smith, L. (2008) *A qualitative study of the health experience of Gypsy Travellers in the UK with a focus on terminal illness*. Primary Health Care Research & Development,

Table 20: Capacity to support death at home by ethnicity/community group

	Romany Gypsy	Irish Traveller	New Traveller	Boater	Showman	Other
Yes	100%	100%	50%	38.90%	0%	100%
No	0%	0%	43.80%	55.60%	100%	0%
Don't know	0%	0%	6.20%	5.50%	0%	0%

Where respondents were asked why they might not be able to provide care/or to provide further qualitative responses, references were made (particularly amongst Boaters) to the difficulties of providing terminal care for someone living on a boat (e.g. access to beds, equipment etc.). Other responses are provided below under 'what hospitals and medical staff need to know'

If people ask to go home to die - if boater and still need palliative care, to do that on a boat could be difficult.

Respondents were also asked, if they or someone in their family is currently having to cope with grief about the death of a relative, whether they have enough support right now.

Of the 34 respondents (52% of the sample) who answered this question, 28 (83%) replied 'Yes' and 6 (18%) replied 'No'. The latter consisted of two New Travellers and 4 Boaters – all other populations/ethnicities felt adequately supported by their existing networks.

# 2.10.2 What hospitals need to know about terminal care of Travellers/ Gypsies/ Boaters etc.

To the best of our knowledge this is the first data ever gathered on New Traveller/Boater terminal care needs. The issues of support to allow a person to die with dignity at home excited considerable attention amongst respondents and Boaters in particular (within interviews, phone conversations and casual chats on hearing about this study) were hugely exercised at the need for the dying person and their family to remain moving unless the hospital could liaise appropriately with the Canals and Rivers Trust. Several respondents advised the IDRICS team during phone calls or the focus group or when visiting along towpaths of heartbreaking examples of dying people or newly bereaved partners having to negotiate a short stop in a single location, or argue with enforcement officers that they wished to die on their boats rather than move into a house. Equally some examples were given of compassionate enforcement officers doing all they could to support families but the issue of individual discretion and lack of a key policy across the canal network coupled with limited mooring places near to roads/accessible medical services is problematic in the extreme for this group. With an ageing population (some of whom have significant health needs) this will inevitably be an issue which arises intermittently and we would urge that some form of policy agreement/statement is negotiated between health, water and local authorities in such circumstances.

Whilst New Travellers did not provide such explicit evidence, referring more to terminal care in hospital settings (and in the main they are a younger group so may not have encountered this issue so frequently) it is likely that similar circumstances will apply although local authorities are likely to be more familiar with circumstances of toleration arising from ill-health and related conditions than are waterways enforcement officers who do not appear to be bound by existing court rulings/statements with regard to considerations prior to eviction.

Comments which explicitly referred however to the <u>levels of understanding/knowledge</u> which respondents felt were required in hospital/hospice settings are as follows:

# Comments made by Romany Gypsies:

- They need to understand if one of our family members is in hospital ill they will get a lot of family visiting from all over.
- They need to let family members see the person after they pass away before they take them to the morgue and let us have time with them.

# Comments made by Irish Travellers:

- We are a private people and need respect
- We are a private people.
- To let family take care of them.

# Comments made by New Travellers:

- We are a bit different. We won't be that solemn. We might be rowdy; we might need a different room because of this.
- In hospital, they have no time for anybody. In a hospice I think they adapt the treatment to whatever you want within the law.
- Respect their wishes and their visitors' cultural behaviour. More visiting room [large numbers of visitors].
- Aware that we don't want conventional funerals e.g. Knows of somebody whose body as 'stolen' from morgue to be taken back to site and burnt on pyre. Interviewee would like to be buried under tree somewhere.
- Not liking being indoors and separated from friends/pets on site
- To try and facilitate people being cared for at home on site.
- Need to be aware that people on site are often closer to others on site, whom they regard as family, than those blood relatives.
- We're a tricky bunch... [need to be alert to cultural preferences]
- That they have a lot of visitors and they're all 'family'
- Out of hours visiting times and rowdy visits lots of laughing and joking.
- Might be more anxious/distrustful of being in the 'system/in hospital not so comfortable with being institutionalized [rather than on site].
- Just being accepting of lots of visitors restriction of visiting could be a problem

- They might like a drink [whilst with the person]
- The cultural need to be outside, in the air. Respect for lack of medical intervention, especially if there are not living wills written. Our differences should be celebrated and respected. The difficulty we have with concrete, cement, electricity. Lack of fresh air - all very hard for us.
- Possibly that Travellers have a large social network therefore lots of visitors
- Just that they should have the same rights as others in that if they want to die at home they should be able to, as the Traveller community look after each other.

# Comments made by **Boaters**:

- Boaters aren't used to being indoors, on solid ground, without buoyancy beneath you, no community around you - absolutely nothing normal about it [being indoors to die].
- Need to appreciate that it's [boat] a person's home even if not a conventional base and not dismiss it, and also be aware of challenges/logistics of living on a boat. A visit [to assess] would be useful.
- Specific beliefs good communication, everyone is different.
- Any itinerant boater, especially at time of impending death, finds it difficult to be penned in; the family member is also obliged to move the boat [regularly even if someone is dying unless special permission is granted to remain in a single location for a period] and this has a range of complications - it's important for the hospital support staff try to liaise with British Waterway.
- If the families need to stay in one place while they are visiting the hospital they will get hassle from CRT so the hospital needs to intervene.
- The same as they treat any other patient, understanding their beliefs and wishes.
- · Respect of cultural needs.
- Lack of accessibility to health care. i.e. Friend had to move off boat for end of life care.
- Really different problems and communities.
- Lack of facilities, money/savings and lack of transport.

#### Comment made by **Showman**:

• They should be aware of our culture and beliefs.

# 2.10.3 Use of bereavement support services (voluntary sector agencies/professional services)

Respondents were asked if their family had ever used bereavement support services such as CRUSE or the Childhood Bereavement Trust. Of the 56 respondents who replied to this question, 3 (5%) replied that they had used such organizations (all Boaters and New Travellers); 52 (93%) said 'No' and one did not know.

When asked if their family would use such services if they felt the organisations understood the culture and community structures of Gypsies/Travellers/Boaters or there was someone from their own community they could talk to if they contacted the agency,

there was a resoundingly positive response, with 32 of the 50 who replied (64%) saying 'Yes' they would call/access bereavement services in such circumstances. Whilst less than half of Boaters responded that they would make use of such services (potentially reflective of the circumstances re: access difficulties as well as a higher percentage of male respondents (see further below under gender and bereavement), the only group who were markedly less likely to make use of such services even if their own community were involved in delivery of support were New Travellers. This may potentially be reflective of apparent trends which indicate that the report their tight knit community offers adequate support to them, as well as the more noticeable reluctance to access external services found elsewhere in this survey.

Of those who <u>would use</u> such services if culturally competent/own community staff were available the ethnic breakdown is as follows:

60% of the total Romany Gypsy sample (3/5)

84% of the total Irish Traveller sample (5/6)

100% of the Showman Sample (2 persons)

43% of Boaters (13/30)

38% of New Travellers (8/21)

And the one individual who classified their ethnicity as 'other'

Fifteen respondents (30%) said 'No' they would not use them regardless of the cultural/ethnic background of support staff whilst 3 (6%, two NTs and a Boater) were unsure.

This noteworthy finding provides a clear endorsement of the need for agencies to access and train support workers/staff in the needs of these communities and in particular to provide training to community bereavement supporters from within Gypsy/Traveller/Boater communities. The Childhood Bereavement Trust is currently working with Buckinghamshire New University to explore the support needs of Gypsy/Traveller communities who have lost close family members (bereaved parents as well as children who have lost a parent) and preliminary findings of this study as well as early stage development of training for community members are under development. We would recommend that other agencies consider adopting similar models to ensure appropriate outreach is available to Gypsy/Traveller populations, particularly given the size/spread of the ethnic Gypsy/Traveller community across the UK.

#### 2.10.4 Gender differences in coping with bereavement

The survey set out to explore whether respondents considered that gender impact on ways of 'coping' with bereavement (e.g. support seeking behaviours and/or use of substances to deal with depression/grief see Cemlyn et. al., 2009; Parry et. al., 2004). 29 respondents (58%) felt that bereavement affects men and women differently, whilst 19 (38%) did not think so, and 2 (4%) did not know.

More women than men answered this question (overwhelmingly from New Traveller and Boater communities), but the perceived difference in reactions to grief by gender, was

reported as slightly greater amongst the male sample, 61% of whom thought that men and women cope differently with bereavement, compared with 58% of women.

Table 21: Respondents conception of gender differences in reactions to grief/bereavement

	Yes, there's a difference	No, there's no difference	I don't know	TOTAL
Male respondents	14	8	1	23
Female respondents	15	11	1	26
Total	29	19	2	49

# 2.10.5 Comments made about gender differences in bereavement (by community/ethnic group)

Whilst Boaters and New Travellers were more likely to speak about individual behaviours rather than gendered practices (as did 'ethnic' Gypsies/Travellers) there was in the main a recognition that males and females tend to behave differently as a result of cultural expectations in relation to bereavement/grief. Only one NT respondent explicitly referred to alcohol use as a coping mechanism although Parry et. al. (2004) and Cemlyn et. al. (2009) cite evidence from Gypsies/Travellers of increased use of alcohol as a mechanism during periods of grief with a strongly gendered dimension to such practices.

#### Comment made by male Romany Gypsy:

• Men can cope better than women

# Comments made by female Irish Travellers:

- Men don't show their feelings.
- Women go to family [for support]

#### Comments made by male New Travellers:

- Women find it easier to cry about things though.
- Men are more guarded about talking about things.
- Different for individuals regardless of gender
- Generally speaking yes but really don't know as it's a real generalisation.
- Women more open with emotions.
- Men don't open up as easily can't show grief.

# Comments made by <u>female New Travellers</u>:

- But this depends on the person [rather than gender although generally feels there is a gender difference in ways of coping with grief]
- Women are more likely to ask for help.

- Don't think men can outwardly express their feelings.
- Depends on the individual.
- She thinks it is different for individuals not necessarily a male/female thing.
- Thinks it's more based on the individual
- Women need to cry and men need to drink/party and release it to say farewell.
- Men and women deal with it in different ways but it's not necessarily different.
- Possibly easier for women to cry and be vulnerable.
- Men tend to hide their feelings a lot more and push themselves to get on and get over bereavement quicker. Women more emotional.

# Comments made by <u>male Boaters</u>:

- Unable to verbalize grief as a man.
- Men pretend it is alright
- I think men don't talk enough.
- Men conditionally find it harder to talk and have less strong social support true of Boaters as well as settled community.
- Men are much less equipped to talk about their bereavement than women
- Women are better at talking (in general)
- I think women find it easier to show feelings.

# Comments made by female Boaters:

- Don't know more difficult for each PERSON than gender divide.
- Only insofar as men can't cry and have to be strong apart from that no different.
- Men and women cope differently manifestly differently.
- It's an individual thing rather than gender based.
- Women find it easier to cry
- Depends on the individual
- Male pride inhibits dealing with death/emotions.
- Bereavement is different for everyone depends on many things, not just gender

# Comment made by female Showman:

• Women are more open about their emotions, men tend to internalise more - they need more support, women support each other, men don't.

The above section (gender approaches to grief/bereavement) whilst only offering a subjective view of gendered styles of grieving may however, prove of use in terms of background service planning for populations by health authorities as well as voluntary sector agencies.

# 2.11 Living Environment

With the aim of assisting health agencies and the local authority to consider the impact of environmental health/quality of accommodation on wellbeing. Both housed and sited/boater respondents are included in this category.

Respondents were asked to rate their physical environment on a number of variables. It was particularly noteworthy that the general physical environment was rated as being of a lower quality amongst English Gypsies (both sited and housed) than amongst New Travellers despite the generally lower availability of services for NTs and Boaters. Table 23 (below) should be read in conjunction with Table 24 (social/emotional environment) to enable fuller consideration of general levels of wellbeing amongst respondents across a number of communities. Additional questions on residence in housing (for those in such circumstances) are included below. In total 57 individuals (86%) responded to this question. One Gypsy (public sector housing); all Irish Travellers; 19 New Travellers; all Showmen, the person self-identified as 'other' and 29 Boaters.

Average ratings (out of 7) given by each ethnicity/community groups were as follows:

Table 22: Physical Environment of current place of residence by category of respondent

	Access to sanitation	Access to water	Access to electricity	Access to wood/coal	Ability to light a fire on site	General physical environment
Romany Gypsy	7	7	7	-	2	4.33
Irish Traveller	6.8	7	6.8	-	1.5	5.5
New Traveller	4.84	4.63	5.26	6.39	1	5.47
Boater	3.48	4.1	3.96	4.68	2.06	5.44
Showman.	5.5	6	4.5	7	1.5	5
Other	5	7	7	-	-	5

Unsurprisingly physical environment was lower for Boaters/Travellers than other populations overall given their residence (overwhelmingly) at unauthorized locations. There was a low ability across all groups for access to open fires (themes which have emerged in some GTAAs as of quite significance importance to respondents on site) presumably site regulations or safety issues re: density of accommodation/residence in a boat/towpath environment have impacted to some extent on this category of environmental issues. Access to wood/coal is relatively low for boaters and given their dependence in the main on solid fuel for warmth this may be an issue in terms of bronchial health/arthritis etc. if there is intermittent ability to remain warm or carry adequate fuel for burners. It is noteworthy that no single category of respondent reports being extremely pleased with their physical environment with most responses remaining around the low upper median.

Respondents were asked to rate their social environment on a number of variables (Table 24 below).

Once again levels of satisfaction with the social/community environment are broadly similar to those for physical environment.

Significantly, all respondents again report low upper median degrees of satisfaction. New Travellers express the lowest level of satisfaction with regard to their neighbours attitudes towards them although all classifications under 4 (found in relation to relationships with local communities for a number of groups) may potentially give cause for concern over community cohesion. New Travellers and Boaters reported feeling generally safe from crime and this may in part pertain to density of residence and the belief that their community 'looks out for each other'.

Average ratings (out of 7) given by each ethnicity were as follows:

Table 23: Social (community cohesion) Environment of current place of residence by category of respondent.

	Relationship with neighbours	Safe from crime	Neighbours' Attitudes to Travellers etc.	Relationship with local community	Community look out for one another
Romany Gypsy	5.2	4.4	4.2	4	4.2
Irish	5.5	5.17	4.67	4.5	4.33
Traveller					
New	5.56	6.63	3.88	4.35	5.72
Traveller					
Boater	5.93	5.97	4	4.69	6.17
Showman.	6	5.5	4.5	5	5.5
Other	5	5	5	5.5	4

# 2.12 Impact of Residence in Housing (previously sited respondents).

A small number of questions were asked specifically of those house-dwelling respondents (Gypsies/Irish/Scottish-Welsh and New Travellers) to explore how they perceived residence in housing impacted on their health and wellbeing.

In total eleven respondents (4 NTs, one 'other' 2 Gypsies and 4 Irish Travellers) answered these questions.

Nine individuals (2 NTs, one 'other', 2 Gypsies and 4 Irish Travellers responded that in their present circumstances living in housing was 'better' for them. Four NTs and one Gypsy stated that living in a house had an impact on their physical health Only two (both NTs provided comments, in both cases indicating they weren't 'as fit' as when

living a more active life on site, and in one case referring to issues of isolation: "You are not as mobile. You don't keep fit by wooding. You are more isolated". The other respondent indicated that she and family were not as physically active and in addition did not eat as well in housing but no further information was provided: "Not as fit and eating was healthier when on site".

When questioned about the impact on mental health/wellbeing of living in housing, whilst four New Travellers, One Gypsy and One Irish Traveller indicated that living in housing had had a negative impact on their mental health/well-being, only two qualitative comments were recorded.

One Irish Traveller woman stated that the main problem is "Isolation from your own people" whilst the New Traveller (female) respondent similarly commented on her loneliness/isolation whilst acknowledging the practical benefits of living in bricks and mortar" Better for pressures of being/keeping clean etc., for work but [can] too easily isolate yourself - don't see people in the morning [way do on site]...."

No other qualitative comments were provided in this section of the survey.

#### 2.13 Social Networks

As part of attempting to assess degree of community engagement/community strengths/social support, respondents were asked how often they speak to people (extended family, friends and neighbours) who are not members of their immediate household. Contact was measured across a number of domains. All but 11 (male) Boaters responded to at least some question in this sub-set of the survey

Frequency with which respondents speak with family members other than those they live with:

It is relatively unsurprising that 'ethnic' Gypsies and Travellers report having contact with family members at least several times a week, and often on a daily basis. The 'other' respondent and Scottish/Welsh Traveller also reported high levels of contact with family members who are not co-resident in their household.

Whilst New Travellers and Boaters reported marginally lower levels/patterns of contact in the main the respondents indicated strong bonds existed with their family. It is worth noting that New Travellers indicated in a number of places in the survey that 'family by choice/close friends' would be included in the category of 'family' and thus co-site residents might also be counted within daily/weekly contacts as well as birth/adopted families. In the main however, the findings from this section are positive in terms of demonstrating networks of contact although we did not seek to identify how close in geographical distance families reside from the respondent.

Table 24: frequency of contact with non co-resident family by community/ethnicity

	Romany Gypsy	Irish Traveller	New Traveller	Boater	Showman	Other	Scottish/ Welsh Traveller
Every day	3	2	4	2	-	1	1
5 or 6 times p/wk	1	1	2	3	1	ı	-
3 or 4 times p/wk	-	2	4	6	-	1	-
Once or twice p/wk	1	1	5	5	1	-	-
Once or twice p/mth	-		4	2	-	-	-
Every few months	-	-	-	-	-	-	-
Once or twice p/yr	-	-	-	-	-	-	-
Not at all in the last year	-	-	2	1	-	-	-

Frequency with which respondents speak with friends who are not neighbours and do not live in the respondent's household:

Table 25: frequency of contact with non co-resident friends by community/ethnicity

	Romany Gypsy	Irish Travelle r	New Travelle r	Boater	Showman	Scottish/ Welsh Traveller	Other
Every day	-	-	9	6	-	-	-
5 or 6 times p/wk	1	2	4	1	-	2	1
3 or 4 times p/wk	2	1	3	6	-	-	1
Once or twice p/wk	-	1	5	5	1	1	-
Once or twice p/mth	1	1	1	1	1	1	-
Every few months	-	2	1	-	1	-	-
Once or twice p/yr	1	1	1	-	-	-	-
Not at all in the last year	-	-	-	-	-	-	-

Other than for New Travellers/Boaters (see points above re: structure of these households) there is slightly decreased contact with friends when compared to family members. This pattern is reversed for Boaters/NTs. Again, when contrasted to mainstream studies of degree of social contact/isolation the findings are remarkably high, consistent in terms of levels of contact and indicative of communities who are well

integrated into their local areas and able (in the main) to access high levels of social capital.

Contact with relatives and friends at a rate less than weekly is remarkably unusual for these respondents. However, the age range/demographics of the cohort may also have an impact on these findings (with regard to non-ethnic 'Gypsy/Traveller' populations) given that older (particularly post-retirement age and 'oldest-old') people and particularly urban dwellers are less likely to report regular social contact outside of their immediate household. The European Social Survey (2002) cited in Huijts and Kraaykamp (201215) found that reduced rates of social contact are directly related to levels of reported ill-health.

Overall, in the UK the average number of contacts with friends/families/neighbours as reported in the 2002 survey were 4.13 per week. Our sample is thus substantially above the national average in terms of social network/contacts with potentially positive health impacts accruing as a result of this density of contact (and conversely bearing out discussions presented in Cemlyn et. al. 2009 and others on the detrimental effect for Gypsies/Travellers of moving into housing when community and social contacts are lost)

Table 26: Frequency of contact (speaking with) neighbours who are neither friends or family:

	Romany Gypsy	Irish Traveller	New Travelle r	Boater	Showman	Other	Scottish/ Welsh Traveller
Every day	3	-	5	6	1	1	-
5 or 6 times p/wk	-	1	-	3	1	-	-
3 or 4 times p/wk	-	2	2	5	-	-	1
Once or twice p/wk	2	2	8	5	-	1	-
Once or twice p/mth	-	-	4	1	-	1	-
Every few months	-	1	-	-	-	-	-
Once or twice p/yr	-	-	-	-	-	-	-
Not at all in the last year	-	-	1	-	-	-	-

Whilst the table above does not seek to establish 'quality' of contact it does provide some indication of basic levels of social contact. For New Travellers/Boaters it is likely that many of these contacts are other site/towpath residents given their relatively homogenous communities and indicated relatively low trust of neighbours/relationships with external populations. Housed Gypsies and Travellers however (given that the

<sup>&</sup>lt;sup>15</sup> Huijts T & Kraaykamp G (2012) Formal and informal social capital and self-rated health in Europe*Acta Sociologica* 55 (2) pp 143-158

respondents are housed) are in main indicating likely contact with people outside of their ethnic groupings who live locally. Overall, as with the other categories of social contact detailed above, respondents to the survey indicate highly active levels of social capital/network contacts, in excess of that found amongst mainstream populations, a finding also prominent in the Hull health survey of 200716 which found that Gypsies and Travellers reported contact with non-family and friends on several occasions each week, a finding on average three times higher than amongst surrounding populations.

#### 2.14 Access to close social networks/size of network

In order to ascertain the degree of social support available to respondents if they were unwell (specifically 'ill in bed') or required care, we questioned the sample about the size of their close social network – specifically, how many relatives/friends they feel emotionally 'close to' live within a 10-minute drive or 20-minute walk of them (not counting fellow co-resident householders).

All but one respondent (Boater) replied, and of these 65 respondents, nine stated that had one close friend/relative living nearby, with the other 56 (86%) reporting more than one person they felt 'close' to who would be available if they were in need.

Table 27: Average numbers of 'close network' contacts by ethnicity/community of respondent

Romany Gypsy	Irish Traveller	New Traveller	Boater	Showman	Other
2.8	2.5	3.2	2.9	3.5	1.5

Whilst the New Travellers reported the highest number of close network members (excluding the small sample of Showmen), Boaters also had access to a close knit community in the immediate vicinity. The percentage of housed Gypsies and Travellers in the sample potentially diminished access to numbers of close individuals in the immediate vicinity when comparing findings to 'sited' Gypsies and Travellers in one or two other studies which have found an average of 5 'close network' members within a 15-20 minute walk/10 minute drive (e.g. the Hull survey, 2007 op. cit.) It is still noteworthy that despite this slight variant from some other localities, no respondent remains completely isolated and without access to carers/friends in time of emergencies. Some very limited evidence from mainstream studies (e.g. 2002 European Surveys op. cit.) suggest that as many as 20% of members of 'mainstream' British society do not have any friends or relatives within a 20 minute walk or 10 minute drive of their home.

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<sup>&</sup>lt;sup>16</sup> Iddenden et. Al. (2008) *Hull's Gypsy Traveller health and lifestyle* survey (2007) available at: http://www.hullpublichealth.org/Surveys/GypsyTravellerHLSurvey.pdf

All 65 who replied, also confirmed that if they were ill in bed and needed help, there would be someone they could turn to for help.

Overall the findings from this section of the survey indicate that respondents across all communities surveyed have access to thick levels of social capital and strong networks of support in times of need/crisis.

# 2.15 Other comments pertaining to health care/needs

The final question in the service user survey (other than those which asked if respondents wished to be kept informed of the outcome of the study/receive a report/participate in follow-up interviews) invited participants to provide any other qualitative information which they wished to share with the research team/health care providers.

In total 8 Boaters, one Showman-Boater and four New Travellers expressed an interest in remaining in contact with forthcoming health promotion initiatives or being invited to participate in engagement with health care providers over tailoring services/designing materials for use by their community (and see too Section 4 – qualitative comments).

One Romany Gypsy, ten New Travellers and 18 Boaters indicated that they wished to receive a copy of the final report of this study, indicating a significant degree of interest in on-going engagement with health care issues amongst some groups of respondents.

Although in total these responses amounted to an impressive 20% of respondents wishing to engage further with the study/participate in future consultations and 44% wanting to read the results of the survey; perhaps the greatest interest lay in ensuring that 'final comments' (overwhelmingly positive) were drawn to the attention of the commissioning health care providers.

These issues are listed here by ethnicity/community (all by NTs, Boaters and Showmen) of respondent as follows:

# Comments made by New Travellers:

- Talking on 'phones is not good for me. I prefer to see someone face to face.
- There are a lot of people in the community (New Travellers) who need help with drug, alcohol and mental health issues. There is a low life expectancy, especially for men because of drink and drugs. I don't think that the right treatment is there though.
- I think lots of members of these communities feel they would be judged too much and this prevents them from seeking help.
- A health care bus like the school bus could visit the site once in a while.
- Had positive experiences [health] in B&NES
- No complaints all generally good.

- More communication with patients in all aspects of health care i.e. About what your options are, what is going on with your health care you're receiving.
- I am satisfied that my health needs are being met in B&NES. However, sometimes receptionists in GP practices can come across as being judgmental and rude. Do they get equalities training?? Most health professionals are non-judgmental yet this area of health workers seem to fall down in being respectful to clients from New Traveller backgrounds.
- It would be refreshing to not have opinion on views of health professionals in general. People hear the word 'Traveller' and immediately expect us to be either illiterate or unable to look after ourselves adequately and also to stop thinking it is impossible to live comfortably in anything other than a house.
- The New Traveller community would benefit from people from their community acting as mediator or specialist health worker to help provide non-judgmental care and to have someone that understands our life style better.
- He would like to say the GP in Tiverton has been very amenable. They let interviewee register with them despite him explaining that he isn't really living at the site address given. (This was about five years ago, and despite having settled on site 12 miles away for previous two years - he hasn't re-registered at local GP as Tiverton Surgery have been so friendly and helpful) Thumbs up for Tiverton Surgery!!
- Not really as experiences are generally good and we hardly ever use the doctors.
   The NHS is a great service and we're fortunate in this country to have it.
- When the baby was born they wrote the c/o address down wrongly the problem
  is persisting and she has tried to get the local authority to change it but having no
  luck. She doesn't know what else to do. She is not receiving any of the letters
  she should regarding her son's health care and vaccinations.
- Be more open to the more holistic views of health and offer it on the NHS
- He feels that he pays his taxes like everyone else in this country and therefore should receive the same treatment as others. His choice of lifestyle or what he chooses to live in shouldn't make a difference to the health care professionals and shouldn't be an issue when receiving treatment.
- Main concern is respect for different medical practices of herbal medicine. Also importance of being able to be seen at home on site if you live in an isolated area and unable to get out. Also for health professionals to be more culturally aware and sensitive to the fact we fear being judged about our lifestyle, especially when children are involved. If there were more community representatives it would help.
- Think the NHS is great and provides a great service. Only occasionally meet people that are bigoted but that is the same anywhere in life.
- Don't think there is anything to separate the Traveller community from people in houses in terms of health needs. Have found doctors and nurses in B&NES nothing but helpful and friendly. Think there is a lot of suspicion from Traveller community towards health care professionals which is unfounded.

# Comments made by **Boaters**:

Impractical to access medical services whilst mobile.

- I've noticed the difference between different areas and what treatment is available. Waiting lists are different; so much depends on one's luck of where you are at the time. We have to go by what Wilts have in their budget 'cos registered with GP in Wilts but may end up getting range of treatments if in hospital in Bath or Bristol.
- If anyone had a heart attack on the tow path, no defibrillators could have them at waterpoints and in pubs applies to all users not just boaters otherwise hard to get one. Since arriving in this community, especially since started getting to know people been able to overcome my fear of going outside and being seen, because the community is so accepting of you just as you are. Supportive [in nature of community] without making any effort. Another way improved my quality of life when lived in cities, towns didn't feel that at all. Would rather starve than go out sometimes [respondent has some visible (non-ethnicity related) 'differences']. Feel more confident due to building self-esteem at least partly because accepted as I am. Not a judgmental community, feel safe and supported enough to flourish. If only I could work on the canal too! ..but need some challenges in life to push boundaries!
- I think a specific health care visitor would be a huge benefit because they'd be approachable, would understand the boating community and there'd be a good uptake and could be a good advocate for the community and individuals.
- I've worked in London and in a hospice where have provided hospice outreach services to people living in boats.
- It's being exposed to the weather, cold, damp can be a problem; risk of accidents; strain on the body joints, muscles; risk of fire if happens, can be really bad.
- Living on a boat is a way of life that subjects you to more physical stress and is higher maintenance. To be ill in such a situation presents with great challenges whereas being itinerant makes health care harder to access.
- The most important thing is that you should be able to go to the nearest GP/clinic etc., rather than having to travel to the one you're registered with, and still have continuity of treatment.
- The Royal United Hospital (RUH) is a really good hospital. Feels lucky to have it.
- There is a need for better GPs more time spent with patients, more advice rather than medications.
- Would be nice if it was more widely accepted that people live on boats.
- [Need for] Community health and psychiatric health support for Boaters.
- A noticeboard with local contact numbers/information might be useful; i.e. What the walk-in centre can do/location. Being able to register with a 'post restante' address.
- Should be a focus on mental health as well as physical, sexual and substance abuse.

### Comment made by **Boater/Showman**:

 Although my GP is not in B&NES, my X [specialism deleted as would potentially reveal identity of respondent] and xx are. Because of my complex health needs I have to get help from outside the area.

# PART THREE Findings from the 'Professionals' e-survey

Part One of this report discusses the methods used to access the sample of health care professionals. Responses could be anonymised and as such we have not analysed by gender/age as these variables were not obvious, other than when respondents elected to reveal this information of agreed to be approached for further interview and provided their name/contact details.

# 3.1 Sample Size/Characteristics

In total there were 40 respondents to the PCT/Professional survey. Professional designations were as follows:

- 9 GPs
- 5 Practice Managers
- 7 Health Visitors
- 6 Pharmacists
- 7 Dentists
- 1 Nurses.
- 2 School Nurses
- 1 Children's Continence Nurse
- 1 Emergency Care Consultant
- 1 Receptionist

# 3.2 Levels of professional contact with different populations of Gypsies/Travellers/Boaters etc.

13 respondents reported currently being in contact with Gypsy, Roma or Traveller patients in their daily duties.

This represents 32.5% of the sample. (25 reported having no current contact and 2 were unsure whether they were supporting housed Gypsy/Traveller patients.)

### 3.3 Ethnicity/Community membership of service-users

Thirteen respondents specified the ethnicity/categories of service users they work with, with the majority supporting members of more than one group:

7 are working with Boaters, 3 with Showmen and 1 'Roadside Travellers'

- 4 are working with Irish Travellers.
- 1 is working with Romany Gypsies and 1 with Roma/Sinti populations.
- 6 are working with New Travellers.
- 1 is working with Scottish/Welsh Traveller populations.

Five respondents have (or have recently had) contact with housed Gypsies and Travellers. This included 3 cases of housed Boaters (not identified in our service-user survey which has no 'housed boater' respondents) and one family of housed New Travellers.

An additional two respondents were unsure if they had worked with housed Gypsies and Travellers or not.

There appears however to be some lack of clarity over the definition of a housed Gypsy/Traveller. Thus when asked how many Gypsy/Traveller families are known to be housed in their area, one GP responded, "Not sure, but several people live on boats and at caravan site" suggesting that the term 'housed' is understood by some respondents to mean 'accommodated' (i.e., not homeless/itinerant).

# 3.4 Contact throughout career with Gypsies/Travellers/Roma and Boater

When asked if they had ever had contact with Gypsies/Travellers in their professional role, 26 individuals responded 'Yes' (65%). 10 (25%) responded 'No', and 4 (10%) were unsure. Of those respondents who replied that they had had contact with Traveller/Gypsy/Boater populations in the past, 16 had worked with these groups whilst employed in their current job, with 4 of these having additionally had previous contact whilst working in a different locality (those being the Psychiatric Nurse, the Dental Nurse, the Midwife and a GP) as well as a further GP who indicated that they had been employed in a different field of work (hospital medicine?).

In total 11 respondents reported having gained experience of Gypsy/Traveller/Boater/Roma populations whilst working in a different locality.

e.g. One Health Visitor gained previous experience of Gypsies/Travellers in the following way:

"working as a community midwife in [neighbouring county]"

# 3.5 Methods used to identify patients as Gypsies/Travellers/Boaters etc.

Respondents were asked how they identify (or have in the past identified) that the patients are members of Gypsy/Traveller/Roma/Boater communities. Amongst the 22 respondents who reported ways in which identification takes place, most highlighted more than one process (e.g. attending from a site, or with known Travellers who identify an individual as a relative/co-resident). Most commonly however was self-identification of the service user as a Gypsy/Traveller/Boater/Roma, reported by 13 respondents in total (59% of the sample).

In addition, 11 (50%) respondents reported that they identify/identified Travellers/Gypsies by their address (e.g. a known site), and 2 (9%) by their attendance for care with other known Travellers/Gypsies/Boaters etc.

Four respondents (18%) reported that they knew the patients to be Gypsies/Travellers/Boaters etc. from previous contact with them at other locations or previous visits to clinic/community settings.

One Practice Manager explained, "It's more often they are identified by particular needs (e.g. literacy) but some self identify - others can be objects of abuse from other patients in the waiting room. READ codes for ethnic categories are used only if patient wants to give them - otherwise can be seen very much as a barrier to registration/possible used for 'denial of services'."

Respondents were asked if they routinely use READ codes to record the ethnic status of their patients. Of the 37 respondents who replied, 14 said 'Yes' (31%), 10 said 'No' (27%) and 11 (28%) replied that READ Codes are not used in their field of work (for example, Dentists), and 2 respondents were unsure if utilised. This finding pertaining to the lack of continuity of use of READ codes and the problems caused in monitoring for equality of access which results, mirrors the findings of the Irish Traveller Movement Britain (ITMB) (2012) study of ethnic monitoring across Health Services (op. cit.). In addition, Boaters and New Travellers would not routinely be 'caught' by such codes which overwhelmingly focus on ethnic Gypsies and Travellers, although at least one interview (see further Part Four, Qualitative data) noted that additional READ codes can be added at the discretion of a practice to ensure that monitoring opportunities exist for particular populations.

Looking more closely at the 31% of respondents who reported using READ Codes to highlight their patients' medical records, these respondents consisted of 8 GPs, 3 Practice Managers, one Pharmacist, one Health Visitor, a School Nurse and a Continence Nurse. A somewhat anomalous response was received from a Surgery Practice Manager who reported that READ Codes were not used in his/her field of work although this may be an error when they responded to the e-survey).

### 3.6 Numbers of Gypsies/Travellers/Boaters etc. registered with service provider

The data pertaining to the number of Gypsies/Travellers that respondents have registered with the service they provide is very varied and hence largely meaningless in terms of measuring population size (particularly in the light of non-standardised use of READ codes and that Boaters/New Travellers are unlikely to be included in many data sets. , In total, 34 respondents answered this question (85% of respondents) and of these, 28 (82%) replied that they had no Gypsies/Travellers registered to their service.

Of the six respondents who reported that Gypsies/Travellers were registered with them, all provided figures for service-users. In total respondents reported that there were 25 Gypsies/Travellers registered in B&NES, 14 as permanent patients and 11 as temporary patients.

One GP reported 4 temporary and 4 permanent patients. Three Health Visitors reported (respectively) 2 temporary and 3 permanent registered patients, (One temporary and One permanent patient) and 5 permanent registrations. Of two nurses reporting that they had contact with Gypsies/Travellers, one noted 4 temporary registrations in her setting, and the other that one permanent registered patient was known to them.

In itself, how 'temporary' or 'permanent' registration is defined may be problematic given the varying numbers of patients detailed in responses. We are unsure in all cases of the practice location at which respondents work, and hence if a hospital nurse refers to someone as a 'permanent' patient they may be indicating that the patient is permanently registered with a single GP (for example this may involve double counting of an individual listed by a GP if they responded to the above survey) or the nurse may work in a GP surgery setting. It is simply not possible in all cases to make these calculations. In any event, based purely upon the numbers of respondents accessed during the service-user survey it is clear that the data/state of knowledge which exists pertaining to the ethnicity/community membership of Gypsies/Travellers in B&NES is patchy, and does not 'capture' all members of the communities.

We would suggest that as a minimum recommendation that all services should be encouraged to use READ codes and that coding should be entered to ensure that New Travellers and Boaters as well as Gypsies/Travellers and Showmen are entered as subcategories of a particular code to enable monitoring of prevalent health conditions/awareness of potential environmental health dangers.

<u>Qualitative Comments</u> (from e-survey) pertaining to identification of GRT/Boater communities.

Nine respondents referred to fluctuating numbers of registered Gypsy/Traveller patients. In particular, GPs noted that this was because:

- Some move in and out of area
- Fairground people register only as temporary patients at the practice

### Health Visitor comments:

- Because the Travellers move around
- Occasional move ins/out
- [Permanent patients 'comers and goers' ] Only if they move on but most stay around on a permanent mooring or have to move a bit away every two weeks [see comments in Part Two from Boaters]

Comments by 'other' practitioners (lumped to avoid individual identification):

- Depends on referrals [specialist continence nurse]
- Travellers move in and out of the area
- Because they are Travellers [reason for fluctuating numbers]
- Depending on how many times the fair is held in Bath

# 3.7 Perceptions of specific clinical and practical challenges to working the Gypsy/Traveller/Boater communities.

Thirty two responded to the question on whether they had experienced any specific clinical or practical challenges when working with Gypsies/Travellers/Boaters etc.

Of these, 12 (37.5%) said 'Yes' and 20 (62.5%) said 'No'.

Those who said 'Yes' were mostly GPs and Health Visitors (the categories most likely to have contact with service-users and need to negotiate provision of care for them) whilst those saying 'No' were predominantly Pharmacists and Dentists who were likely to see patients in a 'walk-in' setting and were not likely to have on-going health responsible for patients (see Table 29 below):

Table 28: 'Are there [in your opinion] any specific clinical or practical challenges that you face when working with Gypsies. Travellers and communities listed above?

	GPs	Practice Managers	Health Visitors	Pharmacists	Dentists	Nurses	Others
Yes	4	0	5	1	0	1	1
No	3	1	2	4	7	2	1

Of those respondents who provided further details of the specific challenges they face with different communities of Gypsies/Travellers the highest number of responses showed that the greatest challenge (across all populations) is achieving continuity of care.

When asked specifically to identify the populations with whom they experienced most challenges to delivering care, Irish Travellers and New Travellers were the groups most often identified (See Table 30).

Table 29: Specific challenges/clinical issues by 'category' of Gypsy/Traveller:

	Boater	Scottish/W elsh Traveller	Romany Gypsy	Irish Traveller	Showman	New Traveller	Roma/S inti	TOTAL
Continuity of care	3	0	0	3	0	4	0	10
Fixed health beliefs	1	0	0	2	0	2	0	5
Illiteracy	0	0	0	3	0	2	0	5
Understanding Traveller culture	2	0	0	3	0	2	0	7
TOTAL	6	0	0	11	0	10	0	27

It is worth noting however, that one explanation for frequency of some responses within Table 30 represents health professionals' differing levels of contact with particular groups rather than intrinsic characteristics of the groups themselves. For example, it may be that respondents have had higher levels of contact with highly mobile Irish Travellers than Showmen, increasing the response rate re Irish Travellers and giving a false impression that this group is beset by difficulties, when compared with Showmen who in any event are more likely to be at a pre-arranged location for a Fair whilst in B&NES and have continuity of health care at a location near to their home 'yard'. In addition, no responses were received in relation to Roma whilst anecdotal evidence suggests that in locations with relatively high numbers of Roma patients, language, culture and continuity of care barriers are relatively high in terms of delivering high quality health services. Accordingly, the data is presented again below (at Table 31) as a percentages of respondent replies, so that the relative importance of issues within different groups can be illustrated more clearly.

Table 30: Challenges to delivering care represented as percentage of responses (by 'category of Traveller':

	Boater	Scottish/Welsh/T raveller	Romany Gypsy	Irish Traveller	Showman	New Traveller	Roma/Sinti
Continuity of care	50	0	0	27.3	0	40	0
Fixed health beliefs	16.7	0	0	18.2	0	20	0
Illiteracy	0	0	0	27.3	0	20	0
Understanding Traveller culture	33.3	0	0	27.3	0	20	0

Accordingly, when viewed in this format it can be seen that continuity of care is regarded as a particularly major issue for Boaters and New Travellers (both highly

mobile/insecurely accommodated groups), while illiteracy is seen to be a significant barrier for Irish Travellers in particular. Fixed health beliefs were regarded as more of an issue when dealing New Travellers (although in practice as is demonstrated in Part Two only a small minority of service users from these communities were loathe to engage with GP services or use allelopathic medicine), and understanding of culture is seen to be more of an issue when dealing with Boaters (despite Boater's own perceptions that they were broadly similar to mainstream populations other than in terms of wishing to remain water-borne even during times of terminal illness).

Qualitative comments (from e-survey): challenges faced when dealing with Gypsies/Travellers/Boaters etc.) by profession:

### GPs:

- Attending/ communicating with multiple family members acting as Next of Kin
- Different health beliefs [e.g. belief in herbal or 'alternative' medicines].

# Health visitors:

- Reluctance to engage with some health professionals
- Potential difficulty accessing a site. Behind electric gate
- Lack of fridges and safety issues with wood fires usually chosen lifestyle or for cheap housing

### Community Nurse:

• Fear of dogs on site [potentially impacting on willingness to attend for 'home visits']

### 3.8 Challenges and Concerns by different professionals

The frequency with which a concern/challenge to delivering health care has been raised (in relation to any Traveller groups) has also been analysed by profession. This reveals that it is mainly Health Visitors and GPs who report concerns about continuity of care.

GPs also seem equally concerned about understanding Traveller culture and Health Visitors about the impacts of fixed health beliefs (see below Table 32).

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Table 31: Challenges/concerns by profession of Respondent?

	GPs	Health Visitors	Pharmacists
Continuity of care	4	5	1
Fixed health beliefs	1	4	0
Illiteracy	1	2	2
Understanding Traveller culture	4	3	0

The inclusion of pharmacists in this table is indicative of their awareness that patients may misuse or fail to understand medication as a result of illiteracy and/or have noted that mobile families may not be able to ensure that they are able to access repeat prescriptions or that dressings etc. are changed as frequently as required (see under Part Four – qualitative comments, information provided by community pharmacist).

# 3.9 Contacting Gypsies/Travellers/Boaters for routine health checks, vaccinations, appointments, etc.

Although this question was included as routine in the e-survey, seventeen respondents noted that this question was not relevant to the service they provide (mostly Pharmacists and Dentists). However, for those who found the question relevant to their practice, sending a letter [problematic in the case of individuals without a postcode or who were illiterate/highly mobile] or calling in person or by phone were the most popular methods of contact with GRT/Boater communities. Given the difficulties articulated by a number of service-users in relation to receiving post, or even having a mobile phone signal, and ensuring that they were aware of appointment dates etc. it is unsurprising that there is a mismatch of experience and preference between health professionals and GRT/Boater populations in this field.

In total seven respondents reported that they sent letters to GRT/Boater service users and a further seven called by phone. Six respondents reported that they will visit the site/towpath to make contact whilst four use a drop-in clinic to see their clients. In addition, three professionals reported sending texts to patients in relation to appointments and check-up reminders.

### Qualitative comments (contact with patients) by profession:

# GPs:

- Letters often not delivered so problems with hospital appointments do not attends (DNA) and recalls
- [GRT/Boaters] Often give alternative address to use for mail
- Don't know. [They] probably aren't contacted. Some boat dwellers do have PO Boxes or receive mail from friends

### Two school nurses reported that contact is made:

- At school
- Letters/information sent through the child's school. Home visits

### The Receptionist stated that:

• [contact] Would not be done as [Travellers/Showmen are] very short term temporary patients

Thirty Four respondents answered the question on whether they provide any 'reminder' services for routine health checks, vaccinations, appointments, etc.

Of these, 17 (50%) said 'Yes' and only 5 (15%) said 'No'. The remaining 12 (35%) said this was not applicable to the service they provide (including 5 Pharmacists).

Reminders are mainly given by telephone (10 respondents), letter (11) and text (9).

All 4 nurses who responded said that they visit the site/towpath and 2 use their drop-in clinic to remind patients. A School Nurse said reminders are given through the school.

In addition, seventeen said reminders were irrelevant to the particular service they provide (e.g. GP/dentist etc.).

#### Qualitative Comments:

### One GP commented:

 We have just started to use text service for messages appointment reminders and [to provide] results

#### 3.10 Issues around Non-attendance at clinics/for services

Interestingly, most health professionals did not identify any specific issues of non-attendance (DNAs) for appointments with Gypsies / Travellers / Boaters, despite the fact that anecdotally this is regarded as a fairly large problem when working with this population.

Only 5 respondents (16.7% of the 35 who responded) identified this as a problem (4 Health Visitors and 1 GP). Where DNAs was identified as an issue, eviction was cited as a causal factor twice, literacy issues 3 times, and moving on / travelling for the summer on 4 occasions.

#### **Qualitative Comments:**

### 2 x <u>Health Visitors</u> stated:

- Often family unable to register for GP services as they don't have a postcode/secure postal address
- [Results from families] moving to other family sites

# 3.11 Whether help with form filling is provided to GRT/Boater communities

Thirty three respondents provided information on whether they or their employer provide Gypsy/Traveller and other communities with help to fill in forms. Of these, 15 (45%) said 'Yes' and 10 (30%) said 'No', help was not offered.

As is clear from the data gathered in relation to the service users, literacy issues are not particularly problematic for the majority of NTs and Boaters and existing data (e.g. Cemlyn et. al., 2009) suggests that Romany Gypsies/Irish Travellers are more likely to require assistance with literacy/completing forms than other populations (apart from Roma). Given however the demographic changes in the B&NES area in recent years and in-coming migrant populations as well as general levels of illiteracy found nationwide amongst mainstream populations it would be a simple solution to this issue if a routine enquiry was made within all health services as to the need for assistance in completing forms.

Looking more closely at which professionals do and do not provide assistance, there is a clear distinction between Practice Managers, Health Visitors and Nurses who tended to reply 'Yes', vs. GPs, Pharmacists and Dentists who tended to say that they personally do not help with form filling (see Table 33).

(40% of those who said 'No' were GPs and 30% Pharmacists.) Eight respondents (24%) did not know if their staff/employer offered such assistance.

Table 32: Health professionals providing Gypsy / Travellers and other communities with help to fill in forms:

	GP	Practice Manager	HV	Pharmacist	Dentist	Nurse	Other	TOTAL
Yes	2	2	3	1	2	3	2	15
No	4	0	0	3	3	0	0	10
Don't know	1	0	3	2	1	1	0	8
No response	2	3	1	0	1	0	0	7

### **Qualitative Comments:**

# <u>GP:</u>

• [assistance with forms] Via receptionists.

# **Practice Managers:**

- Offered by reception staff.
- Routinely offered.

# **Health Visitors** commented:

- Routinely offered.
- Provided by Health Visiting team as appropriate.
- Offered at visit.
- I would if they needed but they [individuals she has contact with] are all literate.

#### Pharmacist:

• Offered though not had to [provide assistance] in present location.

### Dentist:

As deemed necessary.

### Nurses:

- When requested [nb: placing the emphasis on the service user may result in lower use of service even if required]
- I would speak to the parent/carer or child to find out if help is needed.

# 'Other' categories of professionals:

- Reception or nursing staff [provide assistance].
- Help from front desk receptionist if look as needed.

# 3.12 Confidentiality

We have seen above that guarantees of confidentiality was regarded as a significant issue in relation to (some forms of) health care by service-user respondents.

When professionals were asked about whether they make their professional confidentiality duties clear to their Gypsy/Traveller patients during their contact with them, 22 individuals replied.

Of these, 14 (64%) replied 'Yes' they do assure service users of confidentiality [subject to legal requirements] whilst 8 (36%) replied that they did not [in some cases because it was irrelevant to their practice area].

Categories of respondent indicating they did highlight confidentially included Health Visitors, Nurses and Practice Managers as well as one GP, a Pharmacist and one dentist.

In contrast, (presumably because patient confidentiality is taken as a given in their profession) 75% of the GPs who responded said they do not make their confidentiality duties clear to patients.

Those who do make their confidentiality duties clear explained how they achieve this in the following free text section.

#### Qualitative Comments:

# **Practice Managers:**

- [make clear] with all patients.
- Paperwork provided [nb: against literacy issues may raise barriers for some patients in these circumstances. We would propose that verbal information is provided re: confidentiality as well as written information]

### Health Visitors:

- Verbally, also provide information on how and where any information re their or their child's health needs is recorded and stored.
- This is routinely shared as part of the conversation but also includes information that if there is a safeguarding concern this [confidentiality expectations] would change. This would be done in a way that the client could understand.
- Ask on completing a form. Explain signing means certain information can be shared with certain agencies.
- Verbally.
- Verbally.

#### A Pharmacist commented:

 Explaining to them when dispensing meds and they ask what things are for. Also issuing coloured sticker charts for poly-pharmacy to make sure they understand when to take medications throughout the day – [discussion] conducted in consultation room.

# Nurses reported:

- By telling them. . . . not been an issue [to date].
- Verbally face to face.
- By verbal explanation at the start of any contact and by written information.

# 3.13 Professionals perceptions of prevalence of health conditions by Gypsy/Traveller/Boater category

Health professionals were asked to highlight, based on their own experience, which health conditions are most relevant to the Gypsies /Travellers and other communities they have treated/treat (see below Table 34).

The most significant health issues indicated by respondents were alcohol misuse (cited 12 times), followed by smoking and substance use (9 times each). Mental health issues and low uptake rates for screening were also key issues based upon practitioner experience (8 times each).

The community with the highest number of health issues cited was New Traveller, accounting for 40% of all problematic factors detailed.

Practitioners indicated (mirroring certain concerns of New Travellers themselves albeit smoking was not identified by professionals as being as problematic as NTs perceived it to be) that substance and alcohol misuse were of concern amongst this group.

Boat dwellers as a category were accounted as experiencing 29% of all health issues cited. The greatest issue for this group perceived of as low screening uptake, followed by low immunisation rates. Smoking and alcohol misuse were also significant again mirroring findings from our survey users sample. (See Part Two, section 2.5/ Table 7)

Stress and Anxiety (specifically) was afforded a significantly lower prevalence rate by practitioners than our service user data would appear to indicate, although mental health issues (undifferentiated) were specified by 8 respondents suggesting a mismatch in reporting and level of such conditions. Physical injuries, rated as a relatively important issue for Boaters were also not regarded as problematic (and perhaps not seen in general practice if emergency treatment was utilized via A&E services) by practitioners in our survey. The three populations referred to by practitioner accurately reflect the local populations in our survey as well as the small and intermittent number of Irish Travellers who traverse B&NES. Interestingly, despite the known health risk factors for Gypsies, as a community they do not feature in practitioners' narratives/experiences in this survey.

Table 33: Practitioner's perceptions of health conditions experienced by Gypsy/Traveller Boater communities

Health condition	Boater	Scottish Welsh Traveller	Romany/ Gypsy	Irish Traveller	Showman	New Traveller	Roma	TOTAL
Alcohol misuse	3	1	0	2	1	5	0	12
Anxiety	2	0	0	0	0	2	0	4
Asthma	1	0	0	1	0	1	0	3
Cancer	1	0	0	1	0	1	0	3
Domestic violence	0	0	0	0	0	1	0	1
Excessive cardio- vascular and heart conditions	0	0	0	1	0	1	0	2
High rates of diabetes	0	0	0	2	0	1	0	3
Injuries	0	0	0	1	0	1	0	2
Lack of breast feeding	0	0	0	0	0	0	0	0
Low screening uptake	4	0	0	1	1	2	0	8
Mental health issues	2	0	0	2	1	3	0	8
Obesity	0	0	0	0	0	0	0	0
Low immunisation uptake rates	3	0	0	0	1	3	0	7
Sexual health	1	0	0	1	0	1	0	3
Smoking	3	0	0	2	1	3	0	9
Stress	1	0	0	1	0	2	0	4
Substance misuse	2	1	0	1	1	4	0	9
TOTAL	23	2	0	16	6	31	0	

# Qualitative Comments re 'other' health issues for GRT/Boater populations

- Not different from the [mainstream] populations around [B&NES]?
- Unable to specify. The [Emergency Care Consultant] sees all aspects of health care presenting from all parts of the community

### 3.14 Measures to increase uptake rates for immunisation etc.

Respondents were asked if they/their areas of service have any special measures in place to increase the uptake rate of immunisations, health checks and screening by Gypsies, Travellers and related communities.

A number of respondents reported this item as not relevant to the service they provide [e.g. dentistry, pharmacy, etc.], but of those who responded and felt it to be a relevant question, 73% replied that 'no' special measures were in place.

Only three practitioners (two Health Visitors and one Nurse) reported they were actively engaged with seeking to increase the uptake of health checks, immunisations and screening (see below Table 35).

It is to be recommended that in line with Health Inclusion priorities practices which are known to have Gypsy/Traveller/Boater populations on their books in either a temporary or permanent basis should take the opportunity to undertake 'outreach' work and encourage health checks/screening, immunisations for a number of standardized conditions (e.g. cardio-vascular, BP, weight, diabetes etc.) as well as engaging (where possible) with communities/conditions outlined elsewhere in this report and discussing with community members whether they require referrals/monitoring of other conditions.

Table 34: Measures to increase uptake of checks, immunisations and screening:

	Health checks	Immunisations	Screening	TOTAL
Yes	3	3	3	9
No	9	7	8	24

### **Qualitative Comments** (by profession):

# GP:

It is just too small a number and an ever changing population.

### **Health Visitors:**

- Gypsies and Traveller families would fall into the targeted work that Health Visitors (do so would receive an enhanced service to improve all health needs.
- Not a problem [this is the individual who felt the target group is no different from the general surrounding population see comment above].
- There is a Specialist Health Visitor role to coordinate care for this group Rachel Howell.
- Nurses:
- All children immunised
- We follow up all families who do not consent to immunisation for HPV and DTP
- If we were aware of the situation [Traveller/Gypsy/Boater family] we would make increased effort to make contact and offer help.

# 3.15 Receiving Gypsies/Travellers/Boaters via referrals from non-health professionals (e.g., sign-posting).

Respondents were also asked if they have any non-health professionals who sign-post or refer Gypsies, Travellers and related communities to them regarding health issues (e.g. education services, Traveller/Boater community projects.

Whilst 23 respondents indicated that this did not occur, one Health Visitor and a School Nurse replied that they did receive referrals in this way.

### **Qualitative Comments:**

A <u>Health Visitor</u> indicated that the following groups referred Gypsies/Travellers and Boaters to her service:

• Ethnic Minority/Traveller Education Service, The Children's Society, B&NES Environmental Health Department

### The School Nurse said:

LEA Children Missing Education Officers for Travelling families

Another <u>Nurse</u> commented that GRT/Boater 'Patients go to Julian House' [specialist service for homeless people]'

# 3.16 Degree of awareness of Specialist Health Visitor Service for Gypsies and Travellers

Professionals were asked about their awareness of any Specialist Health Visitor service for Gypsies and Travellers in their locality.

Rather concerningly (indicated fairly significant lack of contact/knowledge sharing between services) 27 respondents were unaware that such a service existed, compared with only 10 individuals who had awareness of such specialist practitioners within B&NES. The limited knowledge of local facilities is also suggestive of the fact that little is known amongst practitioner networks about the West of England Strategic Partnership for Travellers Health and Wellbeing whose Annual report for 2010/11 clearly specifies which services are available across the region.

Those who were unaware of the existence of specialist HV services included all GPs who responded (nb: one GP did not answer this question) all pharmacists, all dentists and all of the Practice Managers who answered this question.

Unsurprisingly, all but one Health Visitor (6/7) were alert to this service and all Nurses who replied had knowledge of the Specialist Health Visitor (4/4).

The professionals who were aware of the Specialist Health Visitor were asked to give details of the type of contact they have had, if any with that service.

### Qualitative Comments:

### Health Visitors:

- I am the link Health Visitor lead for Sirona and have regular contact with the specialist leads in Bristol and North Somerset
- Specialist is also my manager no contact re Travellers [potentially indicating this individual only works with Boaters?]

# Nurses:

- Email [contact]
- Telephone and face to face to discuss particular families/young people
- [Attended] a lecture on a study day from her explaining her role and responsibilities

Recommendation that a concerted effort is made to ensure that a wider range of services are alert to the existence of this expert/specialist resource and encouraged to liaise/work with the practitioner to improve the health of Gypsy/Traveller/Boater community members with whom they come into contact.

# 3.17 Whether practitioners have 'concerns' about working with Gypsies, Travellers and related communities

Two thirds of the respondents -21 of 32 – who responded to this question reported having no particular concerns over working with this population.

Amongst those who did express worries, the most significant concerns raised were the difficulties involved in working on sites / towpaths (especially amongst Health Visitors), a problem which seems to be compounded by a fear of dogs in some cases.

The other main concern retaining contact with Gypsy/Traveller/Boater patients, mostly raised by GPs. Fear/poor communication were also concerns for some respondents, (see below Table 36).

Table 35: Any 'concerns' over working with GRT/Boater populations - by profession:

Nature of concern	Total Number expressing Concern	Professionals expressing concern
Difficulties of working on sites/ towpaths	5	4 Health Visitors 1 Child Continence Nurse
Ensuring targets are met	2	2 GPs
Fear / poor communication	4	1 GP 1 Health Visitor 1 School Nurse 1 Continence Nurse
Problems retaining contact with itinerant population	5	2 GPs 1 Practice Manager 1 Dentist 1 School Nurse
Fear of dogs	2	1 Health Visitor 1 Continence Nurse
Lack of experience with these groups	1	1 GP

# 3.18 Possible improvements to working practices

Health professionals were asked how things could potentially be improved in relation to delivery of services within their practice field when working with Gypsy/Traveller/Boater and other related communities in their local area (see below Table 37).

Most commonly, staff awareness training was the most popular option for respondents (particularly favoured by Health Visitors).

Health Visitors were also very interested in accessing culturally specific resources pertaining to health.

Significant interest was also recorded in the introduction of hand-held records (particularly by GPs – see in relation to their concerns about ensuring continuity of care highlighted in Table 32).

Table 36: Suggestions for improving service delivery by professional discipline.

	GPs	Practice Managers	HVs	Pharmacists	Dentists	School Nurse	Others	TOTAL
Access to Gypsy, Roma & Traveller Health Consultants	1	0	1	1	1	2	0	7
Awareness training for staff	1	1	4	3	2	1	1	13
Culturally specific resources / information	0	0	5	3	1	0	1	10
Hand-held records for Gypsies, Travellers etc.	4	0	3	0	3	1	1	12

Of the 'Other' professionals who highlighted suggestions for service delivery improvements,

Overall – whilst staff are generally interested in working with these populations and concerned about their state of health (and see further Qualitative data gained from one-to-one interviews/focus groups presented in Part Four) there appears to be (other than amongst a small group of experienced Professionals) limited knowledge of the populations, lack of confidence in dealing with Gypsies/Traveller/Boater populations and poor knowledge of where and how to access specialist advice. Accordingly this leads to lost opportunities to make positive impacts on the health and wellbeing of members of these populations.

Immediate (and relatively cost-effective) changes which could be brought into force are delivery of specialist training (including the results of this report) to a range of health professionals, access to specialist resources (drawn up potentially with local Boaters/Travellers as well as utilizing pre-existing health resources from agencies such as Derbyshire Gypsy Liaison Group; Leeds GATE and Friends, Families and Traveller and those under development via Inclusion Health projects, as well as enhanced awareness of the existence of specialist Traveller health visitors in the B&NES locality.

Further suggestions and comments detailed in Part Four (Qualitative findings) include the suggestion from a Pharmacist that in-reach is undertaken to sites by a range of professionals, and that an advisory group of Boaters and New Travellers is convened to work with health professionals to deliver training and specialist materials to practitioners in the absence to date of any targeted resources available on these populations.

#### **PART FOUR**

# Qualitative Data (interview and focus group) themes and findings

This section of the report focuses on the findings from the single focus group and depth findings gleaned from individual interviews in this study.

As detailed in part one we had anticipated holding focus groups for both professionals and service users in the study area. Initially we had indications from six professionals in B&NES (various disciplines) that they would be interested in participating in a focus group, as well as six boaters and four New Travellers.

In practice organizing focus groups proved highly problematic and time consuming as a result of the time constraints imposed by professional's workloads and difficulties in getting New Travellers and Boaters together at one time.

We were able to achieve one focus group with 3 Boaters but after continued difficulties with convening the other two groups we liaised with New Travellers and Professionals and undertook individual phone interviews with the following participants (2 New Travellers and 3 Health Professionals: one Pharmacist, One Health Visitor and one Head Receptionist at a GP practice). One further (very experienced) Health Visitor had wanted to participate in this study but we were unable to find a mutually convenient date for interview and unfortunately the lady was then on holiday during the key interviewing period. On her return the very limited dates which the research team could offer for interview (as the project was at the writing up stage at that point) were inconvenient so unfortunately we were unable to obtain/include her responses.

Individual interview all followed the format of the Focus Group topic guide (Appendix D) with probing for additional details/thematic development as appropriate. Phone interviews lasted between 10 and 45 minutes and the focus group with Boaters (held at community venue in Bath) lasted for approximately 1.5 hours.

Given the low number of participants and to preserve anonymity (both for service users for professionals) as guaranteed we have sought to only include relatively minimal details which might potentially reveal the identity of any individual participant, using this section predominantly to paint broad themes and raise pertinent suggestions for service delivery/barriers to engagement.

Findings are grouped into 'professional' respondents and 'service users' with (where appropriate) indications of the professional/community affiliation of participants. Quotations are used for illustrative purposes within the summary of the thematic discussions.

### 4.1 Findings from Professionals.

Core level of experience with working with the communities. One Health Visitor with in excess of 20 years of experience in that capacity reported that whilst she had only limited contact with GRT families/service users in B&NES when working in other locations she had higher rates of contact with these populations (including working in a specialist role as well as undertaking management responsibilities elsewhere which included GRT services). The Head receptionist indicated that to the best of her knowledge in her practice there were no registered GRT/Boater patients

• "we don't get that many, but we have a fair that comes to Bath about three times a year – that would be the main time we dealt with [Showmen]".

The pharmacist (five years qualified) has been working in the local area for a relatively short period of time and over that period, as a result of the location of his pharmacy has had fairly significant levels of contact with New Travellers over a period of some months.

### 4.1.1 Use of READ codes for identification of service users in practice area

The Head Receptionist was not aware of the use of READ codes in her practice although indicated that other staff/practitioners may deal with them.

The <u>Pharmacist</u> noted that whilst his access to NHS databases would permit the identification of GRT populations by ethnicity where recorded he and his team do not utilize ethnic coding. Identification of GRT/Boaters for pharmacy staff would take place where someone self-identified or gave a known site address.

 "I don't assume that because someone dresses in such a way that they are a Traveller or not – most of the it comes from the address on the script"

The <u>Health Visitor</u> indicated that levels of knowledge of an individual's ethnicity depended upon access to certain parts of the IT system - whilst GPs would make use of READ codes, HVs in her practice make use of paper records however information per ethnicity:

• "would be in the [paper] records".

On being asked whether they felt it would be possible to identify GRT/Boater populations within their area of practice (for example to assist in targeting information on immunization uptake or to monitor particular health conditions) it was clear that this information is not routinely accessible and levels of record keeping (as well as physical effort involved) would vary substantially. In addition, New Travellers and Boaters would not be picked up by this method of monitoring/review.

HV:

"would need to audit the records....all audits on our records would have to be manual tasks because we only have paper records... we record ethnicity and anything specific and relevant about a family would be recorded on the front of the notes." With regard to New Travellers and Boaters, as they would not be recorded under ethnicity coding the only way of monitoring for need would be if "someone was from a travelling family [or other 'unusual' circumstances such as living on a boat] it would be noted"

Whether would be helpful to be able to identify GRT/Boaters via READ codes?

The Receptionist wasn't able to comment on this strategic question.

The other professionals were concerned however on the impact on community relations/'labelling' of groups if READ codes were routinely used to identify GRT/Boater populations.

# HV:

 "not really... we generally assess any individual needs on a family or individual basis. You might have issues that come up about accessing services and willingness to use services if [service users] felt judged [monitored] – but I don't think we would treat them any differently from any other group".

### Pharmacist:

 "if it's for tailored services might be worth but then you need to think about people feeling a bit negated if they are given a particular ... say for example, [identify] someone taking methadone, and then giving them a section [ethnicity/READ] code. If it is for good tailored services it might be worth it... if the point is to give them a much better service and they do get the better of it..."

# 4.1.2 Questions on whether they had contact with/thoughts on how to access/contact housed Gypsies/Travellers/Roma/Boaters and other 'hidden' populations.

Neither the Pharmacist not the Receptionist were aware of a housed GRT/population in the locality or how best to contact them. The <u>HV</u> (based on her experience with the groups in different settings) commented "my experience has been in how they access services when not registered with the GP when they are mobile. So we see them in walk in centres a lot, ad hoc services, those different kinds of settings".

### 4.1.3 Cultural Variations in Need between different GRT/Boater populations

Both the pharmacist and the HV were able to comment under this theme as a result of their clinical contact with service users:

# HV:

"depends historically on what their cultural background is – diet, how they access services. Again you tend to see men access services less than women. Women tend to be exposed more to the health sector because of pregnancy and because of children. You tend to see children less if they are mobile or not in school routinely, or they change schools frequently. Then they often miss opportunities to be picked up on conditions, but particularly men [have needs], maybe around substance misuse, but also the culture means that they don't access healthcare routinely." On being asked if she could differentiate more in terms of ethnicity/community and particular needs the respondent was loathe to do so as she felt she didn't have enough experience of working with the particular communities in her current location of work and didn't wish to generalise.

# Pharmacist:

"I've got a lot of patients who have alcohol misuse issues – some are like ordinary [non-Travellers] and I've also come across a number of Travellers who have alcohol problems and take prescribed drugs to help with that – but I wouldn't say it is out of proportion as a percentage in terms of the overall population of Bath... I've seen a lot of asthma, people with lots of dressings [from injuries and infections], secondary infections, stuff like that – that I think is a big problem, lots of wounds which cause all sorts of problems. They come to the pharmacy with a prescription so I guess they've already seen a nurse or GP and I've seen a lot of dressings issued to them, but I don't [can't] know if there are other underlying conditions such as diabetes – however, whatever it is, they are not healing. It might be the environment in which they live which doesn't help".

On probing re: potential role for pharmacists in terms of advice on wound care/hygiene etc. the <u>pharmacist</u> stressed that there could be a role for greater outreach for pharmacists to build up relations with local site residents and act as a source of initial advice on health promotion:

• "I think there is room for this – these are not people that are a community that we don't pay much attention to and they are seen to be on the other side [of society] and just passing through. If there is a community with Travellers it is worth us, as healthcare professionals going out and finding out more about their health needs and how we can help them. It is will raise awareness I think it is worth it... I would be happy to do that – even if it was my day off or to take half a day to go out and talk to them about simple things like scabies, how to improve medicine [compliance], what they taking etc. I do think it would be worth it"

# 4.1.4 Particular challenges experienced/encountered in working with GRT/Boater groups e.g. fixed health beliefs etc. – and how to improve engagement with service users / culturally specific materials.

The <u>Chief Receptionist</u> indicated that some individuals may have literacy difficulties but:

• "we do our best to help – it wouldn't be a problem... if when they start [e.g. completing forms etc] we see they are struggling we ask if they need any help". She didn't felt that there was a particular need for culturally appropriate resources and felt that in her experience the Showmen/Travellers who did make use of her surgery were "just like any other group". With regard to accessibility she indicated that "regulars, fairground people always know and come back – our surgery is signposted very well and it's not far, within walking distance of the fair" [regular site used for fairs].

For practitioners more engaged with delivery of clinical services the responses were rather more detailed:

### HV:

• literacy can be an issue as people tend to leave school early – they don't tend to be hooked into systems that pick up [health issues] and there is a natural wariness with some families about accessing statutory services, either because of non-attendance at school or because girls are out of school very early, or they don't want to access, say immunization, so lots of issues around this in the past but may not be so much recently... culturally too [re immunizations] people say.. I never them it didn't do me any harm – that sort of parental and family influence...

The discussion then moved into exploring screening take-up:

[Cancer] there is certainly a sense of you seek help only when you need it, you
don't have any outside intervention in your community voluntarily, so that picks
up on screening/immunizations, all those things which they regard as not part of
their cultural background and therefore not necessary – particularly around
traditional gender roles and ways of life

# 4.1.5 How to improve/deliver Health Care Services

### Pharmacist:

• It all boils down to...find[ing] out what their needs are - finding out if there is a cultural fear that we need to know about to provide care. I don't know a lot about Travellers - I do know that move around but if they have any particular faith or how they approach things, life - those things we'd really need to know in detail as health care professionals it is better to go out and meet them and find out their health needs, how things work... but what I'd suggest, I guess if one has Travellers in an area that would love to register with a surgery - what comes to mind is basically that [based on own experience of patients] if someone has drug and alcohol problems - there has to be a walk-in centre where they can simply

register and have a whole health screen and be diverted non-judgmentally to the right services for them, but to be able to link them up to surgeries in Bath too - so if it is - a walk-in that specializes in drugs and alcohol - could point out their speciality and say but 'this is the best place to go for ..' sort of a walk-in becomes a something like a one-stop shop.

This discussion continued with a conversation about the services available at Julian House (homeless health centre). The Pharmacist wasn't sure if Travellers accessed Julian House but in fact discussions with interviewers, Big Issue staff, some service users and Traveller interviewees (see below) has raised indications that whilst some New Travellers and Boaters make use of Julian House that they don't feel it is necessarily appropriate for their needs and that they would prefer a service/access point more suitable/dedicated to their lifestyles.

<u>Inter-disciplinary in-reach teams</u>: continuing the theme of personalised engagement with Traveller communities introduced by the Pharmacist (above) the <u>HV</u> recommended that the model utilized in an area where she had previously worked could be effective in B&NES:

• where I worked before we had specific health visiting teams who built up relationships with the community – working with the sites and working with a team of say outreach teachers, GPs with a specific interest etc. I have known of other two-tier services developed [elsewhere in England] around supporting whole families... GP with special interest, working with health visiting staff with a teacher and others... therapists – speech and language – so people very much worked with Traveller children under 5 from a health visiting perspective and also had access – specific staff who develop and build relationships with a number of key individuals in those communities.

Although this interviewee has not had contact with Boaters in her current work feels that specialist HVs could work effectively with Boaters as well as Gypsies/Travellers/Showmen.

The <u>Pharmacist</u> reiterated the value of specialist tailored services in engaging with communities, using as an example sexual health services where he had worked with a team who

• 'raised awareness of it.. going to freshers week that sort of thing, giving out leaflets, letting them know where to get the services they need in a nonstigmatising way... it all boils down to health care services going in to meet the needs of the local people.. if it's hard for people to out and meet the healthcare service, we the professionals need to be out there to say we are here to help, we don't have an agenda, we just want to make sure they get the best healthcare help:

The <u>Receptionist</u> indicated that to the best of her knowledge her practice would really only engage in health/promotion and delivery of services with registered patients. As a practice they were committed to ensuring ease of registration for temporary patients and

they would then contact patients in the usual way – letter and messaging in relation to appointments.

### 4.1.6 Use of culturally specific health promotion materials:

# HV:

• well you can't leave leaflets if someone is not literate- and it doesn't just go for those communities. In terms of the setting, you would need to work out ways and interventions that people will access, language and format they understand – so perhaps using things like apps now that smart phones are so useful - but generally I'd say look at the individual community and what they as a group are likely to access.... [images in leaflets etc.]. images that reflect [populations] but which also say 'look your Mum might not have done this but is something can offer you this and may be something you want to consider' but doing it in a culturally sensitive way but also in a way which appeals to particular generations. So mobile phones are still around, but also need to specifically target certain groups within populations so being very targeted at women v men, culturally within the community they will have separate and very set roles.

This respondent (HV) also indicated the great value of talking to service users in an open non-culturally specific way, citing:

• materials produced by the Kings Health Partners and Centre for Parent and Child support 'based on open questions asking things like 'how do you feel about the baby'; 'what might it be if..." have you thought what baby may be thinking.' Then other things come up – but those are not [materials] which we give out automatically. Those [standardized materials] are not culturally sensitive but those [items discussed above] and the resources which go with them could be adapted because then you can use them in an open way... those things are very open and tend not to make people feel judged whereas an immunization leaflet is [aimed at a] very middle and white population.

She was also able to identify good practice examples used with other minority or 'hard to reach' communities in different locations:

• things like Twitter, Facebook, websites, pop-ups – those sort of things, use people's emails, images, culturally and age appropriate imaging. I know that Barking and Dagenham had a campaign for teenagers around cervical cancer which was cartoon based... Wigan's Breast Feeding team use... a website that focuses on thinking about it from a child's perspective – so getting people to step outside of their own thought patterns - generally it's about being able to offer a place that people are comfortable with – you need to be able to ask them what that place is, to be able to offer services at home too... mobile unit, people attend on a certain day – building relationships, trusting relationships and not moving [professional healthcare staff] around frequently [so trust is lost and needs to be rebuilt].

[nb: This respondent's comments pertain mainly to experience of working in previous roles with Gypsies/Irish Travellers, and as such are highly relevant to 'ethnic' GRT communities as well as core values in relation to communication and valuing patients as individuals across all groups.]

The <u>Pharmacist</u> indicated that pharmacy companies were all run differently so it might be difficult to ensure that reminders re medication use or tailored materials were available or sent out to patients

 "we don't have the facilities to do that... because all pharmacy companies have different IT systems it is something which would need to be addressed nationally or in a certain area and dealt with by the PCT or the NHS as a whole – then it could happen"

He suggested however that specialist services or pharmacist willingness to come onto sites or have special times when they could meet with Traveller patients could be publicized by:

• "finding out where the Travellers tend to gather and approaching it that way – try using the supermarket or where a lot of people do their shopping or go to a Travellers advice point and leave leaflets. You can also leave [culturally appropriate] leaflets at a GP surgery as that is where they will go - or at entertainment centres [cinemas etc.].

# 4.1.7 Improving continuity of care for Travellers/Gypsies/Boaters and Showmen

As noted above the <u>receptionist</u> indicated that phone messaging would be used for registered patients. Enlighteningly, she was able to discuss the process by which patient records are transferred and data stored, flagging up some of the reason for lack of continuity of care for highly mobile patients:

 "for a temporary patient, the information is then sent back to the central office every three months – the forms goes back with copies of the consultations and everything that we have dealt with here for them. That all goes back to the central office and then onto the GP they name as their full time registered GP – where they spend the majority of their time – and hopefully that would then be available on their return"

She noted (see further below re hand-held records) that

• "depending upon how responsible the patient is" that hand-held records would be useful to ensure that there is no delay in receipt of information and that continuity of care is maintained.

### The HV reported that

• it is difficult as you are not going to have people followed all over the place geographically as it is not practical, but trying to have some core standards in terms of care, shared literature, mobile records for patients, making sure that 'red books' for children and maternity records actually go on with people... there is

already a hand-held record for under 5s for child protection purposes – we hold those in the office..[phone] apps [for other health records] would be good.

The Pharmacist also proposed the use of text messages and phone calls to remind of appointments or medication checks

# 4.1.8 Hand held records (and see above for earlier comments by HV)

### Receptionist:

• I suppose you could put the onus on the patient and say they should be carrying the medical information themselves to a certain extent. I think it is a general thought that patients' health is part of their responsibility.... [usefulness of handheld records for her role?] would want records to show if they were diabetic, asthmatic, cardiac problems, mental health issues, maybe any regular medication they were on, learning difficulties and any disabilities of any sort. They would have to have it intact and up to date, and obviously if they were a minor you would expect the parent or guardian to hold that information.

The <u>pharmacist</u> was very enthusiastic about the concept of hand held records for highly mobile patients/GRT and Boaters without a regular GP:

• that would be fantastic, because not only are you then able to supply them with the medicines they have got but you then have the chance to talk to them about all the other medication they are on and how they are getting on with them, have they got any queries or issues at all – so in that way we're taking the first step and meeting them halfway. That is something to talk about in a general way – access to patient records means that we can give a much better services – if they have it to hand would be a blessing... something like pregnant women do with maternity notes which has everything they need because of moving between surgery and hospital for test – something like that can work.. all the notes, medications and history – everything you need to know and you just walk into a surgery or healthcare notes, give them the notes, they read it and there is continuity of service and then they just write down the outcome.

[Degree of detail required in hand-held notes?]

 as much as possible – there has to be a central point so that... it could be got to the GP who would have access to the notes later on, but the patient then would have a copy of it to carry around.

### 4.1.9 Cross-boundary working

Few comments were received on this question however all recognized that delivering higher quality services would be improved if. The <u>receptionist</u> however indicated "oh yes definitely" that there was a strong need for greater degrees of inter-area/cross-boundary working around "children and young people", with particular reference to any child health/protection concerns which might occur – favouring the employment of specialist

staff who could be contacted to liaise with Traveller/Gypsy/Boater populations as required.

### The pharmacist noted that

• "there needs to be the will – for everyone to knock the walls down [in practice/area boundaries] if we want to improve services – and work together to find a framework which is effective for everyone."

The <u>HV</u> however indicated that significant strategic thought would need to go into devising the role of specialist cross-border services as although she felt

"cross boundary teams would be fine... it all does depend on who commissions
what, how it is commissioned and for what – it could be very problematic given
the boundaries in the South West .. if you are jointly commissioned you can track
people [for health care] but at the moment we work to GP registered population
so in any given day I could be working in Somerset, Wiltshire, Bristol or Bath"

# 4.1.10 Cultural Awareness Training/Encouraging Attendance

The pharmacist was generally positive about the idea of cultural awareness training

• "the more awareness - the more it is in the front of people's minds" suggesting that any training programmes should include "the health needs of these people, the benefit to society – they are part of society, but again because they are moving around and living in obscure places – generally the sense from watching Gypsies on TV is no wants them to live around their houses because of affecting house prices and the community and things like that but they are part of community and we must support them and raise awareness of common issues that could crop up – how healthcare professionals can help – for example if I get a prescription for a dressing and I know about certain common ailments which happen to Gypsies then I can ask about any issues, common problems they might have..."

He noted too that in terms of scheduling training or encouraging staff to attend the greater the notice the better as he and other professionals tend to be booked up months in advance [an issue we discovered when seeking to convene focus groups] he also stressed the need for people to be encouraged to attend by senior line managers and commissioners:

 "once this is raised at PCT level – you need to know to make sure that people know these are real issues being tackled from above, not just tick the box but that [commissioners] want something real to come out of this"

On probing this respondent also felt that it would be important to offer some sort of information/awareness raising for Gypsies/Travellers/Boaters "leaflets, some sort of thing, left at sites or in places they gather" to become aware of their healthcare rights and health literacy issues.

The <u>receptionist</u> felt that whilst she had every confidence in her own reception staff, that front line staff could sometimes benefit from

 "training .. [where there is] contact with young people on site... perhaps not to show anything – [surprise/shock] if for want of a better word they were perhaps 'scruffy' – which obviously they could be if they were travelling – to not show shock or surprise - I'm sure none of my ladies would – but the same as if working with the homeless or something".

On probing about whether she would encourage her own staff to attend such training she indicated that the relevant time commitment would need to be weighed up and hence depended on the likelihood of contact with service users on a regular basis:

• "I don't know [what option would be best for teams such as her own] a training day with [information on] lots of groups but with one bit on Gypsies so if someone doesn't deal with them much they would have that bit of information but learn about other communities.. having someone from that group present would be helpful".

She noted too that (on probing) that issues raised by some reception staff re concerns over large groups of Travellers attending together or 'fear' about perceived aggressiveness/loud voices etc. had never been drawn to her attention or considered to be an issue in her practice.

This respondent also indicated that she would like to receive feedback on any planned training events in the future.

Finally the <u>HV</u> (probably resulting from her own level of expertise) favoured fairly tightly drawn definitions of training courses and what would be provided

• "needs to be very specific in terms of what training needs to happen – where there is a service, what is going to happen... in terms of commissioning and health awareness resources available and key training messages. It needs to have a point to it – and to be focused cos otherwise it is bound to simply raise more questions than answers for staff... [training should include] what resources are out there, raising awareness generally on how to approach the issues, are there likely to be particularly sensitive issues, picking up on language, literacy, key messages, available people and resources to support [the specialist role of the professional]".

To encourage professional attendance she recommended that

"target it specifically at staff who work with those communities, so in Bath you
would need to start off with GP practices that would cover the official and
tolerated sites".

On probing in relation to the feasibility/desirability of offering training on health literacy/rights to GRT/Boater populations she indicated that it would need to be handled very sensitively so that community members didn't feel that they were being told how to use services

• "something about having a conversation with the community... listening as well as training – but I'm not sure how people would respond the response might be to say 'hang on these are our services and they should be there to respond to our need – it would have to be a two way process and involve key people within communities who have influence.. like site managers who are part of communities [referring mainly here to Irish Travellers/English Gypsies residing on authorized sites] who hold a lot of sway but it does depend on what people think so accessing them [is important].. we did a lot of work on a site [in another role] with a grandmother who had a lot of connections and she had influence and was able to get the younger members interested [in health care].

This respondent also approved of the idea (when suggested) of training health advocates from communities to engage with professionals and their own networks in disseminating health information and advice.

### 4.1.11 Summary discussion:

Given the very different disciplines of the three professionals interviewed for this study it is not especially easy to identify over-arching themes. There is general agreement however that it would prove beneficial to offer training on working with Gypsies/Travellers/Roma/Boaters to GPs and other practitioners engaged with the communities (potentially offered as part of a training day involving outreach to various diverse groups/populations) and incorporating clear information on available local resources and individuals with expertise.

The theme of outreach to communities was emphasized by both front-line health practitioners and the interest expressed in particular by the pharmacist in going out to deliver information/meet with populations supports the data provided by the experienced HV on the success of multi-disciplinary teams who develop trust over time by working closely with particular populations.

Whilst there are clear commissioning/boundary difficulties to be overcome there is a consensus that inter-area working would be useful for both professionals and community members.

The oft-cited anecdotal barriers to engagement with GRT/Boater communities had not been experienced by the professionals interviewed for this section of the report.

Overall the effectiveness of READ codes in identifying patients would appear to be low and two professionals expressed some unease over perceived targeting of populations. There was little knowledge over how to undertake in-reach to housed populations of GRTs in the local area.

The use of tailored materials on health literacy/promotion for GRT/Boaters and diverse mechanisms for delivering these was regarded as a step to be welcomed, with

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participants offering a range of ideas which are known to have worked for other populations or in different areas.

Hand held records (either by app or in paper format) to be retained by patient with a copy at a central location were regarded by all respondents as of use in their particular areas of expertise and a positive step towards ensuring continuity of care for mobile patients.

The pharmacist in particular would welcome the opportunity to engage in outreach practice on sites, assisting in health promotion activities and developing his expertise in working with this population.

The theme of 'talking to' local communities whilst largely common sense and good practice emerged in several places in the interviews and we would therefore emphasise the importance of including diverse GRT/Boater community members in any new health promotion fora which may be set up, particularly given that a number of respondents to Part Two of this study (see above) would be interested in attending/or assisting in developing training and health promotion materials for their own communities as well as for health care professionals.

# Qualitative Interviews from Service Users:

In this section we explore the themes which emerged within the Boaters focus group as well as the individual interviews with New Travellers. No 'ethnic' Gypsies/Showmen or (Irish) Travellers accepted the opportunity to participate in a focus group or one-to-one interview. See Appendix D for the full topic guide used in all interviews/focus groups.

Interviewees/focus group participants (all categories) consisted of one female and two male Boaters and two female and one male Travellers. All were resident at different locations within B&NES.

Duration of residence on sites/boats varied between 2+ to 20 years. Two respondents (one male and one female New Traveller one at a tolerated unauthorized sites the other 'under the radar') had co-resident children (aged between 15 and 4 years of age). All of the Boaters lived alone on their boat, although one was travelled with her partner who retained a separate boat. All boaters are 'continuous cruisers' (individuals without access to a regular mooring place).

The boaters were particularly keen to discuss the impact of the continuous cruising regulations on the health of their community and the immense difficulties which could occur for people with poor health/terminal health care needs (see further below).

# 4.2 Discussion on why health workers might find it difficult to contact GRT/Boaters (issues of disguising identity).

Site and Boat dwellers were unanimous that in some circumstances GRT/Boaters might wish to hide their identities/living arrangements in certain circumstances although this did vary depending on individual situations.

- It is hard to get a doctor because you don't have an address you can't get a doctor if you don't have a post code... people do disguise their identities and [sometimes] use a silly name, over they years they've often learnt to do it (female Traveller nb uses care of address for GP services 'as I live in a caravan'
- I've always been upfront I go in and hopefully make a decent enough impression but I know a lot of other people don't want to identify in any kind of semi-official situation where they don't have to as there is still a stigma attached [to being a Traveller].. where we are living [location explained]... you don't want to draw attention to yourself the ideal situation is a site no body knew about, if you can manage that it's what you would be doing so you really don't want to advertise that fact that there is a site there (male Traveller).

# Boaters (within focus group):

- it's a completely different world [living on a boat from being on a site]... we are sometimes a bit under the radar... more likely to be registered with a GP some distance away...
- "A lot of people I know on site don't necessarily want to identify themselves as a Traveller although is what they are from the point of view of the law and Traveller status is what they have there can be a stigma attached to the word Traveller and New Travellers to a lot of people the whole conception of it is still early 1990s, the medieaval [brigands] thing [quote by a the Cabinet Minister Douglas Hurd in the 1980s in relation to New Travellers]. A lot of people are other things, have other identities outside of the site... in my case I'm a care worker, when I go to work that is my main identity and it is a professional one, although I'm open to the fact that I live on a site, that is not just who I am" [male Traveller]

Boaters indicated that less likely to disguise their identity other than use of 'care of' addresses to remain registered with a GP. Their main issues were around accessing health care whilst transient (see further below)

### Particular health issues associated with living in boats/sites

The boaters were particularly eloquent both in the individual interview and within the focus group on the range of health issues which faced members of their community, expanding upon the data from the surveys:

Environmental health factors were cited far more frequently by Boaters than by Travellers as causing significant problems in terms of retaining a healthy life-style.

- The facilities aren't frightfully good for people living on boats in terms of access to water and sanitary arrangements/rubbish and lavatory pump-outs along canals where continuous cruisers reside.
- "rubbish points are few and far between and are infested with rats that isn't the end of the world as we don't mind a bit of rough and ready but I just don't think they empty the bins quite enough... notwithstanding the logistical problems they have, in Bath the Canals and Rivers Trust replaced all the big wheelie bins at refuse points with small domestic ones completely overused and they complained about the rubbish spilling out over the top... there has also been a problem with fly-tipping in the vicinity it was done in such a way it was bound to fail ... now we have to keep our rubbish store it on the boat [creating huge environmental risks].
- Access to water not such a problem it is less of an issue, but it is still reasonably sparse, (named points for taking on water on boats) that is ok as most people have large tanks but then if you haven't go that, then you need more water points so that is one thing sewage is much worse there is one [pumpout] at Dundas and one in Buckhampton (paying) and a paying one in Bath.. and often the standard of those isn't good Dundas is like a hose so it can be cleaned up but I can't help feeling cynical, why a hose in some places and not provided in others is it to say that 'those people aren't cleaning out toilets properly'?.. if you don't provide services then people really can't manage.
- Well we live on a little site just a heap of mud... (New Traveller woman)

Key health problems faced by Boaters which were exacerbated by lack of CRT clarity over policies re: enforcing continuous cruising were identified in a helpful, lengthy discussion within the focus group and also by the individual who was interviewed:

• [Boater who participated in focus group and was also an interviewer for the study] I interviewed one man who had just had an operation on his leg and was in plaster – he was expected to move on... people obviously needed to look after him, he couldn't get dressed on his own, couldn't do his own shopping, bring in his own coal, make his own fire so he had to have a team of people to support him whilst he recovered... they [CRT] were ok for one boat to support him but not two so they expected one couple to do 24 hour care which wasn't realistic as they work and have children.. I helped out myself but they [CRT] never actually acknowledged that I needed to or could stay in the mooring

Considerable discussion on other examples of people being required to move on by CRT officers although

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• [decisions can be] sometimes under the radar... this is fairly common that there is an acknowledgement that someone has a health problem then can be an unofficial policy depending on who is looking after that area.

The discussion in the focus group turned to the impacts of enforced movement on health conditions and enumeration so of other common health effects of being a Boater:

- Breathing difficulties, chest difficulties cos you are actually living in a tube and you have a fire and most of the people I interviewed are smokers so you are actually getting twice the amount of smoke being confined into that tube (male Boater)
- Quite a few people have had various injuries some of which were directly from accidents on the boat or maybe having cycling accidents as well but they all expressed concern about 'what if I couldn't do the things I need to do because I got this or I get some sort of long-term physical injury which stops me lifting, boating or walking.. the other thing people all talked about was the distance from any health care facilities... it's all very well to be registered with a doctor at Bath that's great when you are actually there but if you're somewhere else it is really difficult to get there if you are in the same place for ongoing treatment for all appointments but if you have to travel from Devizes or Trowbridge or somewhere it is really difficult (female Boater who undertook interviews for the study).
- If you have got a health problem which needs to use a lot of water for instance you might have a wound which needs to be regularly cleaned (see the comments by the pharmacist above) or you need to take a lot of care with washing or anything it can be quite a problem as you usually only fill up the tanks every week or two depending on family needs and a lot of people don't have that amount of water in their tanks.. so if you need to kept up that sort of regime to get well then you need to keep on stopping to take on water [or be] almost constantly moored where there is a water tank and then you are crossing the line where you get enforcement action taken against you.

Discussion on sometimes minor but very typical injuries commonly found on sites and boats (all participants).

- Cuts.... Injuries with chopping wood...using saws.... chainsaws and power tools... cycling along a towpath, a lot of the time it is good to cycle but there are places where you cycle in the winter and it is very slippy and you risk falling off or falling into the canal.. Gang-planks - difficult to manoeuvre when you're pregnant or with young children
- Weil's disease it's not just a risk if you fall in [Boater] but that's the time you are
  most at risk and the thing to do is take your clothes off and have a shower which
  is fine if you have enough water in your tank and the shower is working

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- Rats...sometimes... infections, cuts getting oil in them (Traveller)
- Parked up near sewage works (Traveller)
- Slipping on site when you're pregnant
- Bad backs... working on engines... [all]
- One of the things is boat design, almost designed for wrecking your back people who design boats should be forced to repair them take my starting
  motor, I had to be a contortionist by the end of the day I had a badly bruised arm
  and couldn't move my back and that is just trying to remove one bolt [male
  Boater]
- One of the most common injuries is sprained ankles jumping off boats when you come in to moor – depending on the season and the quality of the ground you jump onto sometimes it is a bit hard, or soft or uneven or the vegetation is such that you can't see what you are jumping onto (male Boater)
- My partner had to take someone to hospital A&E because he sliced his hand with a chainsaw (Traveller)
- I've personally had two different injuries on two different boats where I've cracked or bruised badly my ribs through falling and landing on the gunnel of the boat both times I've actually taken a long time to recover which has stopped me from moving on. The first time I told the enforcement officer and said I've been told it might take this long to recover and I might be able to move my boat if I get help but otherwise I won't be able to that was fine but if it had gone on longer, things get nastier. They're fine if you say straight away it is going to take me 6 weeks to recover and then you move the boat but if after 6 weeks you say it is going to take longer then they get progressively worse and harass you (female boater).

## Access to healthcare

As a result of their relatively stability of sites (at the point of interview) whilst New Travellers were most likely to report difficulties in accessing registration to GP services (see also above at Part Two), once they had achieved this goal, in the main they identified access to services as relatively unproblematic, other than when they encountered practitioners who were either unsympathetic or perceived of as prejudiced or unduly curious about their lifestyles:

"if your life in the middle of a soggy boggy land like I am you can't get a
postcode. If you can't get a postcode you can't get a doctor or a dentist or
anyone official to do anything – and a field doesn't have a postcode" (female
New Traveller). This respondent indicated that her search to access a GP who

would register her and her family was of some duration, with one surgery explaining that:

• "they will not do it – apparently ...there is some clause that if you put down an address they have got to visit you in an emergency" [refused even temporary registration by two separate B&NES surgeries] Eventually this respondent was able to access the Julian House homeless healthcare team "brilliant – eventually I've managed to get a doctor ..only a couple of hundred yards away from me but they would not register me to start with because I didn't have a postcode. Eventually after lots of letters from the homeless healthcare they started to look after me... it took me nearly two years to be able to get an appointment at the doctors where I am."

This respondent reported that prior to the intervention of the Julian House staff she had made use of A&E services with her two (junior and infant) school age children and that accordingly she had not managed to access routine care which would have been helpful for one child with a fairly common but persistent health care issue. Although the child has since been referred to hospital she indicated too that not having a driving license means that getting to and from hospital appointments can at times be problematic

• "I can't keep appointments at hospitals [easily]... because we can't get into town and back because we're not on a bus route and I can't drive".

Whilst the male NT and his family were registered with a surgery

• "we do use the GP occasionally but [X resident on site] is a nurse and in an emergency there is a Minor Injuries Unit [from where they live in B&NES easier to cross the health authority border to access a particular MIU] – I've taken my son there once when he burnt himself on a burner once and had a bad fever – and if people injure themselves worse then we'll take them to A&E [RUH]... but we're all [on that site] – well the oldest is 45 so we don't engage with the GP much but we all are registered.. that we've been here for a few years now means we can easily access healthcare – but it is very different if you're being evicted all the time cos you might be 30 miles up the road when your appointment comes around.

The theme of inadequate access to services and being 'pushed' along repeatedly were constantly reiterated by the Boaters who participated in depth interviews with very clear evidence provided of the potentially devastating impacts on their community's life/health and well-being of lack of clarity amongst Canal and River Trust staff on the rights of Boaters, the reduction in mooring places as a result of policies to encourage more 'leisure' boaters, and strict enforcement.

"You may be registered with a doctor... but if you are not near where the doctor
is it is just hugely complicated to make an appointment, to get there, and how
predict how you are going to get there on the day you have an appointment – so I
really don't bother a lot of the time unless I'm really on the spot and know I'm
going to be there on the day of the appointment as well – you usually have to

wait for a few days so I don't both.. if you aren't registered it can sometimes be easier as long as you know you can go as a temporary patient – you know you can just walk into any doctors but a lot don't [know of that right].. but you might get somewhere... [new area] and not know where the surgery is and can't be bother [or feel too ill] to find out" (Female Boater)

- Male Boater: "it also depends on how well you feel just thinking about when my back went – just getting 300 yards was mega and I had to get a friend to take me – so if you are along a towpath and...
- Female boater: "that's why a lot of people don't go to the doctor much and if they
  do go it's because of an emergency and then they'll just ring an ambulance or get
  someone to take them to A&E or someone will be discovered [on a boat] in a
  really bad way and [person will say to them] you need to go to A&E, you're
  coming with me I'll drive you there or we'll get an ambulance"

One way of dealing with concerns over rejection of registration (as reiterated at some length in the service user survey) was to remain registered with a sympathetic doctor. The male Traveller explained how a friend now living outside of B&NES but still in the Somerset area remains

 "on the books of a GP in Bath – signed up when he was on the site in Bath and been living [x] for a while but anything which involves a GP he travels back to Bath because he likes the GP and trusts him"

Boaters (perhaps because of their more precarious situation in the current sample) gave explanations of access problems which involved more significant risk to life, health and well-being. Predominantly, these examples of injuries where co-resident site members/boaters had to escort someone to hospital seemed to focus mainly on axe and chain-saw injuries where the injured party failed to realise the seriousness of their injury. In these cases a culture of 'male self-sufficiency' could combine with a sense that it would not be easy to access health care could coincide leading to reluctance to seek assistance:

- Had to wrap his hand [finger badly damaged in a chain saw accident] in a towel and walk him a mile up the towpath – I took him to A&E – they [ambulance] couldn't get down to the towpath..."[male Boater]
- "The person who had a chainsaw accident my partner walked him to A&E the bloke said 'no I'm alright' he was trying to sew his injury up and my partner said 'no you're not... you're coming with me to A&E now' (female Boater)
- 'on site... someone refusing to go and see people and needing to be stitched up on site by someone handing them a needle [and thread]" (female Traveller)

One boater indicated that lack of knowledge about the right to register as a temporary patient could also limit an individual's ability to argue for appropriate healthcare access:

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• "in my first year on the boat [approximately 18 months prior to interview], partially through ignorance I kept registered with my family doctor in Calne so I only had access to emergency things here [B&NES].. it wasn't particularly clear to me that I didn't need an address to register with a doctor... that potential for access to health care when you don't have a postcode could be better communicated [to itinerant people]..

### Attitudes of Health Staff to Boaters/Travellers

Whilst in the main respondents indicated that having managed to become registered for services health care professionals "can be good... or bad – but generally work on quite a professional level" (Traveller) some complaints were raised about attitudes of staff towards an individual perceived of as itinerant.

One Traveller noted that receptionists could act as a barrier to receipt of good quality healthcare for people with no fixed abode:

- "I just spoke to somebody who said they were turned away and told they couldn't even register because they lived on a site the receptionist said 'you're not allowed' [person said] 'but we want to' [told] 'no we're not having you'
- "you just don't know what you are going to get especially in a small village... the
  receptionist could be quite hostile to everyone whoever they are which can be
  quite intimidating or you could have a bit of paranoia that you are going to be
  judged" (Traveller)
- 'The midwives were great (when interviewee's youngest child was born) it wasn't
  an issue... the site we're on is incredibly tidy and together but some are less
  tidy... it doesn't mean that the trailer isn't going to be incredibly time. I'm actually
  a bit sympathetic to people when they come on site as you get a nice middleaged, middle-class lad and it can be quite intimidating we don't realize it cos
  we're used to it but if you're not its quite intimidating when dogs come up and
  bark at you' (Traveller)

The Boater female respondent indicated that staff's understandable concerns about health and safety (see further too professionals worries about delivering care at towpaths/sites as well as regulations pertaining to accessing patients) could also potentially impact on care):

• 'from my general knowledge of boaters with children... healthcare staff generally won't walk across a plank – so it means that to have visits you have to be somewhere with a hard edge so that generally means visitor moorings.. there are other places with hard edges but for midwives and health visitors they generally prefer to be somewhere they can park their car and walk a short distance and get onto the boat easily – I know some people say they've had midwives who will put on their hiking boots and walk down a towpath and it's not been a problem but other people I've been told have been told – by health care professionals – that they have to be somewhere with easy access for health staff" at which there was

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general agreement that it is remarkably difficult to access 24 hour moorings as a results of CRT changes and charges.

"We had our son at Clandown.. the midwives didn't like to visit – I don't think they would come on site... where we are now – it's much smaller and more rural and a bit more twee – the midwives to came to deliver our daughter last year they got stuck down some track and lost but had no problem coming around. They were surprised we've got a tap and sink in the trailer but we don't have running water, it's just there and we never got rid of it so the midwife was trying to wash her hands but we hadn't got running water – but they were really really friendly and nice" [Traveller]

The male New Traveller, whilst feeling that overwhelming cultural awareness training pertained to Gypsies and Irish Travellers suggested that for health care professionals

• "just if someone knows they are going onto a site, having a little booklet in their pocket, something to read, just to put people's minds at rest cos they'll be sent somewhere and they may be intimidated or they may be fascinated..."

One service on which there was general agreement from boaters and travelers above (and see above under section two re ambulance crew) was that despite their major difficulties sometimes in accessing towpaths or finding the locations of bridges:

- "ambulances, paramedics will pretty much come out anywhere even if it means climbing a fence"
- "they aren't judgmental ambulance crews are pretty good"
- 'fire service when X put a trailer alight they come out and they were great' (Traveller)

One respondent (who has health and social care employment experience/qualifications) indicated that despite the generally high level of approval of paramedics reported by interviewees, when living at *another* location

• "they were pretty offensive... jokes about mental health and very judgmental. Once there was a guy I was parked up with and he overdosed in his truck – he was a lovely guy and my mate and the other people were really upset and the paramedics called out were joking and going 'blimey gents you've got a great life' very sarcastic - it's not only people on sites – I've had similar experiences when working in a homeless hostel actually [poor attitudes of health staff to service users].. quite interesting the cross over as sometimes people I knew [Travellers] would end up at the hostel..."

In contrast, (although still providing proof of the belief that indeed paramedics are perceived of as reaching anyone regardless of circumstances) the Boater who took part in an individual interview recounted two unexpected examples of perceived prejudice towards his community which he (and a friend) experienced when seeking to access

A&E care. He indicated that he believed that some medics could assume that Travellers/Boaters because of their 'unconventional' lifestyle were automatically seeking controlled substances rather than genuinely experiencing significant pain, and moreover had no understanding of the genuine difficulties associated with living on a boat with a skeletal-muscular injury:

• 'one of the issues, I had a friend, [attended walk-in clinic]... I wanted to go in with him [respondent has professional health qualifications] but he preferred to do it himself, he had slipped a disc and he was in real pain... they gave him co-codamol... because he is of no fixed abode in a walk in clinic they wouldn't give him codeine on it's own. As a result he was in real danger – he was literally at risk of overdosing on paracetamol when I saw him [later] because they refused to give him an adequate dose of codeine' [and he was self-medicating to assist the extreme pain].

Probed if any reason given for ineffective pain relief:

• "they said that's your lot – try and stand up better... they were very dismissive once they knew he lived on a boat – they weren't even thinking of how he would manage the sheer physical labour of it – it was like we can't give out pain killers for this – we're not your doctor, pop off – which I felt was really indefensible because there was a significantly greater risk of him overdosing on paracetemol. People aren't really very savvy if you're in great pain"

Asked if the interviewee assisted his friend in obtaining access to a GP or stronger pain relief:

"he just tried to get on with it... we had tried to get him something better and that
was when we went back to the walk-in clinic and were dismissed so he thought
blow this and just went back to the boat"

The same respondent was critical of the care received when some months prior to that incident he had an accident on an icy towpath (see notes above re common accidents) and recounted a lengthy but very telling incident where CRT regulations and lack of medical awareness of his circumstances combined to create a critical situation which his health was at significant risk of long-term damage:

"I broke my hip coming down the canal – fell off the bike – the paramedic decided to take me in [to hospital] it was impossible (to move properly) so they took me into A&E. She apologized on three occasions to staff for presenting with a 39 year old male who had falled off his bike and couldn't stand up – they left me with no pain relief for 4 hours then the consultant came eventually, saw me, did a physical, rushed me off to x-ray and it was consistent with a broken femur - next thing I've got the physio saying come on we need to get you up and walking – I said you'll need to get me some pain relief to do that I can't walk on it – I only managed to get along to the ambulance with the paramedics because of the gas and air – I told them I live on a boat and she [physio] said 'that's why we need to get you moving, you'll have to pretend you're on the boat now'... needed pain

relief and she got me two paracetamol and an ibuprofen, she said she didn't want to give me any relief and when I asked why she said you may be back on your boat and wake up in the night and need to get to the toilet when the painkillers will have worn off so we need to see what you can do without them. Eventually after insistence the consultant attended and on being asked for at least gas and air as analgesia the interviewee was told "I can't discharge you with gas and air - it isn't consistent with the long term plan'.... she said some shocking things, sent me off for more x-rays and said the next day 'you've got to go' ...another doctor came in, also said I'm not prescribing high dose pain relief as you still wouldn't be able to stand on your feet.... The main thing was that they couldn't see the fracture clearly on the X-ray the next day sensitive MRI showed up the fracture and eventually all the standard of care became better but I think it was a combination of things, how I look [somewhat 'travellerish/boaterish'] inconsistency of age with fracture, how I live [boat] or combination of these things but if I was to put my social awareness head on I have to say that it was very likely that they were discriminating against me".

The interviewee was eventually discharged home to his boat several days later on crutches with some pain relief

"they really didn't know what to do with me, but I eventually said I can do this, if I can get my leg over there I can do that, and then I think I can get back home onto my boat". No follow up services were provided and he was not visited "nobody came out to the boat... I'd had to be moved on by then [re CRT regulations] and was in limbo and then it [injury site] became infected... some of the internal sutures and staples and some were poking out, it was a very bad service, nobody told me if you see any signs of infection come in, it was very much just that it looked angry and I thought about going to a GP. This isn't really a complaint but you do wonder if it is discrimination or simply the state of the NHS...

# 4.2.5 CRT regulations and the impact on health/long-term conditions

• "the next aspect was how could I get myself a nice place to moor up comfortably... somewhere for a bit of a winter mooring ... just wanted British Waterways to cut me some slack, [told them] I have a legitimate reason to stay but after a couple of weeks the enforcement officer told me 'I can't cover for you any more you'll have to start moving again'.. luckily it coincided with my six week follow up and the consultant wrote a letter to say that 'this man shouldn't have to move too far along from where his car is parked'....the enforcement officer however still said 'you've got to move on'... I thought if I was a person who was vulnerable in certain ways I would have been in a real pickle... so I said I will move on if you insist but this is under duress and against my doctor's orders... fortunately, I am quite popular so I had help and people moored up to help while I was recuperating.. if there had been no one else staying by me... but fortunately people were able to cycle back and help" [male boater – individual interview above]

Other Boater respondents (during the focus group) also referred to the problem of enforced movement on individuals experiencing health problems:

- "there is a lady here with cancer she had a lot of trouble with the CRT in terms of her needs and them wanting her to move on etc... She's on her own and has a Macmillan Nurse who acts as an advocate for her and has worked wonders... the CRT local area enforcement officer has eventually agreed that as she is a blue badge holder she can stay for 28 days not 14 whether or not that is adequate is another thing...."
- "another guy, got a lung problem, can't walk far and suffers recurrent chest infections and then he's really stuck, he's been given slack for so long and then they start – he must be about 60 – and he's got doctors letters coming out of his ears and they're sending him letters about how they've successfully evicted people off the canal for non-compliance and he needs to start moving... perhaps they are concerned about him or something but now they've started making suggestions to him that he should go into care"

The pressures which can occur for chronically sick boaters and Travellers (more particularly boaters given their generally older age range) to move on or ultimately to transfer from a boat into housing attracted some considerable attention within the focus group (and should be read in conjunction with the discussion on terminal care in Part Two).

Thus comments were made in relation to individuals being misunderstood or subjected to misplaced pressures by professional and agency staff:

- "there is one particular enforcement officer who seems to have a habit of bullying boaters who are injured or disabled in some way... saying wouldn't [they] be better living in a flat. things like that are really upsetting and it makes me really angry that people are being subjected to things like that"
- "told he should go into care"
- "as soon as I got ill people [health staff] said are you going to move off the site and into a house now
- "asked why she wouldn't want to move into a house"
- "suggested to her that she should go to a hospice" by both health care and CRT staff rather than respecting individual's wishes to remain on a boat or site for the duration of their life.

During the focus group probing took place with regard to what could potentially happen to an individual who was concerned about accessing health care. The discussion arose from flagging up a number of comments around who may live on sites/canals and a culture of ignoring health concerns:

 "the lads on site – too hard to think about health and that... people taking ketamine and that" (Traveller)

- "I'm a bloke and none of us go to the doctor unless we're really dying" (Traveller)
- "people under the radar bit cautious... maybe don't want to engage too much with health staff or other officials" (Boater)
- "perhaps 90% of the [males] I interviewed had moved on because of relationship disputes, marital breakdown and some have already had a poor mental health state - may have increased their use of chemicals, be it alcohol, cocaine, cannabis – which are the primary ones ...one of the other things, people can sometimes move onto the canal for is to evade the banks or big brother so they don't want to see anybody or say anything that might alert the state to where they live" (Boater interviewer)

MG (interviewer): let's say hypothetically – what if someone is moderately isolated... if they get ill, they may be in late middle-aged....

Boater - they could die

MG: are you telling me that you have literally come across cases of people dying through not receiving medical care or having care plans?

• Boater – and refusing medical care

MG: do you mean someone saying 'I'm not going to have a doctor come out to me'?

Boater: well not wanting to go to the doctor – or make a fuss – saying I'll be alright I'm going to get better then the next day they were dead

MG (to other participants) is this something you've ever experienced?

Boater 2: not so much but X has more experience [been a boater for considerably longer]... there was one boater who was quite old who died recently

 he had had to move off his boat, not sure how old he was – he was perhaps 70 and he got ill and ended up having to move into a nursing home, someone else lived on his boat.. for a lot of people that was a blow... he was really capable of looking after the boat and himself right up until a year before he died

MG: if there had been practical medical and social care support could he have lived on this boat until he died?

- Boater 1: my understanding is that he was so riddled with arthritis it just wasn't possible any more...
- Boater 2: but there are people I know who say the only way you'll get me off this boat is in a box there are people I know who are quite elderly and have no

intention of moving off... they can be worried over how health care providers might react to them

Nb: this does raise significant questions over how best to ensure that suitable health and social care services are made available to an ageing population or one where cultural barriers lead to self-neglect of conditions through fear of lack of understanding from service providers.

# Access to long-term moorings for individuals who are elderly or sick

Part of the focus group discussion hinged upon whether older boaters would be able to remain living on a boat as they aged and the long-term implications of access to permanent residential mooring for policy makers:

"I think a lot of boaters think 'when I get older I'll just get a mooring' and that
means if my health gets bad I won't have to move the boat and it will be easier,,
that is how my mind works – much as I don't want to get a permanent mooring,
people do see that as a solution"

# 4.2.6 Good Practice in Service Delivery/Cultural Outreach to GRT/Boaters

Respondents were all asked to identify previous and current experiences of good practice or suggestions for outreach medical care which could be relevant to their communities:

One Traveller raised the point that barriers to engagement with external health services could related to previous experiences with 'officials':

 'if your whole experience of officialdom and authorities comes from evictions and enforcement officers coming to see you then it makes you less comfortable in those environments.. when I go to work I have to take people to doctors appointments [interviewee is a care worker] so I'm used to that type of thing but if I didn't.. I would find it hard to do..."

All respondents indicated that there is a dearth of experienced professionals with a good awareness of their community employed in mainstream services. However, a number of respondents were able to report that they had had contact with, or were familiar with/had heard of certain professionals who were known to be able to assist or make referrals to support GRT/Boater communities.

• There is a retired social worker, very experienced, who does social advocacy if you like, privately if needed, so he is willing to do an assessment but there is no formal route of access – it is just by chance – he is someone who can help to place people in contact with social legislation - who can say – you've got no business saying when someone's been on a canal for 12 years that you [CRT] can say 'we've had enough of you and your chest complaint, start moving or go into a care home' [Boater]

Another boater highlighted the spiritual/emotional/mental health support available via the Canal Ministries and Boaters Christian Fellowship – sometimes even those without a recognized religious adherence would make use of these services because of the degree of trust which existed. It was proposed that they could potentially be approached to work with health staff as conduit of information and support:

- "it's the same as with prison chaplains they do everything [for boaters] from going to hospital to negotiating with social workers... the Reverend Peter Atwell does all the funerals for boaters.. they will help if someone's parents are dying, or if a boat burns down"
- "It would be a good idea to have several nurses who work with people on sites" (Traveller)
- "actually just about making services accessible to everybody emphasizing the equality and dignity which we all expect in the 21st Century "(Boater)
- "This is actually the best site I've ever been on for [environmental health] services, we have portaloos, bins taken away and had water within a year and a couple of months" (Traveller)

In-reach services were regarded as severely lacking by all interviewees with all respondents (in common with those who participated in the survey) indicating that specialist materials and experienced staff coming to the site and towpath would offer the most accessible and culturally friendly way of ensuring that services reached those in most need:

- "More midwives to come out to the site would be really nice... the Travelling Doctor used to come out to us in Herefordshire and that was really good, if you have a doctor a health bus like Herefordshire that covers say four areas it would be good... outreach health". (Traveller)
- "For people on sites anywhere we stay is usually in the middle of nowhere, it's a nightmare getting to appointments but whether it is me with kids or someone older or with a disability, it's a nightmare to get anywhere so perhaps they could have a health bus to come and pick us up basic care and to pick us up and take us to the doctor or hospital?" (Traveller)
- 'Community health team I want them to be familiar with working with boaters and Travellers maybe Boaters themselves? There are nurses and people on the canals I've spoken to several people who are health professionals to have them employed would make such a difference' (Boater)
- 'If you have good and accessible moorings... in some places there is a community boat, a café boat if there were spaces which could be used say once a month or 3 or 4 times a year, some sort of floating surgery in different places that could be looked at or held in a riverside pub somewhere away

from other eyes – people to keep an eye on sanitation, sexual health information, drugs and alcohol awareness that sort of thing – I'm not saying there aren't any problems in any demographic but maybe – well people can get left out in our community, slip through the net, get divorced, got no money or whatever, become an alcoholic but here on the water they can get some quality of life or acceptance (Boater – not the same individual who commented on substance use above)

**Nb:** this latter point linked to a discussion within the focus group on the work of a 19th Century-early 20th Century nurse who was the daughter of canal side pub-owner. She ran an entirely self-funded clinic from the pub for much of her life (Sister Mary Ward) and this model was regarded

- "trusted health care workers who is able to liaise with social care... that would be helpful (Boaters)
- 'One of things Travellers would probably like a health visitor who they can know is in a certain place at a certain time who knows our community' (Traveller)
- 'Psychiatric nurses experienced with our community not judgmental part of
  the reason people with mental health needs are on the canal because of the care
  in the community thing works better here because there is a community...
  perhaps also an advocate for sexual health and hygiene sometimes there are
  young children you see on the canals and whether or not they get the care they
  deserve it is all down to the parent so perhaps you could use outreach better to
  them ... immunizations there are illnesses in the water I don't think we've
  been targeted, I wouldn't be surprised it there are people who haven't had
  immunisations' (Boater)
- 'Overwhelmingly, what people are saying would be helpful is to have access to a community psychiatric nurse on the towpath ... the enforcement and harassment that you get makes it much worse for some people'(Boater)
- 'I'd love a travelling dentist to come out —nobody on the site would go to the
  dentist and then my daughter went when she had a bad toothache and they
  were lovely so everyone started going to them ... get people [health care
  professionals] to come out to the site for a couple of days, visit along with the
  doctor for a week they'll get the hang of it alright then.. but they'd need to be
  open-minded... and get more Travellers working in health as well" (female
  Traveller)
- 'At the moment there are quite a lot of nurses living on the canal so someone needs a dressing changed every day one of the other boaters who is trained as a nurse will hop on a bike and come along and change it.. informally' (Boater)

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 "things such as electricity [discourse on an individual who had access to a nebulizer for a while on a boat] if the NHS were aware of the problem and had a generator for emergency use to cover whatever area is needed in case someone's engine isn't working to save them going into hospital – it would be a lot cheaper" (discussion during Boater focus group)

4.2.7 Use of <u>hand held records for itinerant Boaters/Travellers</u> and Text reminders for follow-up care.

This subject was considered in some detail within the survey but revisited for individual interviews and focus groups.

Hand held records met with limited interest and there was a mixed reaction to the use of text reminders depending upon the circumstances of individual respondents:

### Hand-held records

- "we've not used or needed them but might be useful for some" (Traveller)
- "most people don't move that far really but they might be useful" (Boater)
- "hand held records might get trashed with the mud... and there isn't much room
  in a trailer to keep records I've always managed to get doctors to hang onto them
  but it can take a couple of weeks for them to pass them on, but now it's all been
  computerized nobody has a clue about anything (Traveller)
- "maybe use on laptop or something" (Boater)

### Text-reminders

- "well it does depend if I'm in the area, and can find the place and remember... it could be stepping into a whole different world..." (Boater)
- "text reminders would be a blinding idea and would help because living down here we are on a different time scale doing different stuff so lose track of time, so keeping track of everything outside is difficult text reminders from doctors and dentist appointments is a really handy thing" (Female Traveller)

# 4.2.8 Suggestions for Health Promotion with GRT/Boater communities

To a large extent the topic of health promotion was covered in the discussions cited above re outreach health work.

Access to trusted health staff and confidential advice services (e.g. at floating clinics or on a health bus) were regarded as the most likely routes for accessing individuals with regard to health promotion.

Core areas (outlined above) for consideration included substance use, smoking, sexual health, hygiene and immunizations.

• "hhm have to try it – probably the kind of thing with a lot of resistance" (boater)

Travellers and Boaters alike commented on male resistance to health promotion – one Traveller female suggested that a magazine which utilized [men's/soft-core porn magazine] format might appeal to 'blokey' men... sexual health, testicular cancer, substance issues etc. could be dealt with within the format – rather similar to some Dutch health promotion initiatives.

'ketamine... wearing a condom... eating properly and smoking'

She was also a firm advocate for general safety awareness training praising highly the fire brigade who had attended at her site and ensured that people were aware of, and had access to carbon monoxide detectors

- "for in the winter when you're burning a lot of shit stuff comes out of it you need one"
- "there are sometimes people out there with quite chronic health problems...
  multiple health problems and it is quite a hard way to live. If you neglect yourself
  for any reason you can become quite seriously ill quite quickly and you do see
  people that get themselves in a proper state.... People who forget to put their
  burner on and freeze to death, a lot of mental health problems... it's hard it's all
  out there in the community and sometimes you see sites it's sad they all
  cluster together in groups on untogether sites which basically exasperates
  existing health problems..... [targeted health promotion advice] respiratory
  problems for kids you need to target that, how to make sure it's not too damp
  in a trailers actually if you are seeing clusters of things [conditions] then it
  should be targeted the same as with any other communities" (Traveller male)

Ultimately all boaters interviewed and both Travellers indicated very strongly that health promotion materials and training advice for health care professionals needed to be devised in partnership with community members:

- "you could get a group of us together to work with the PCT and put together the sort of booklet [outlined above] ...something which says if you are looking at Gypsies and Travellers then you need to look at particular health and cultural needs – such as different washing bowls, and anything about a community which needs to be mentioned.." (Traveller)
- "magazine for lads like I said... lots of ideas" (Traveller)
- "they need to know that it's different for people who've lived on a boat most of their life – and there are children now who have grown up on boats – it is very difficult living in a house ... it can cause real psychological distress" (Boater)
- "if you go into hospital, it is only just about all right in the summer with the windows open but I was in the in winter and kept going out to get a breath of air... one of the things about being on a boat you can be solitary... and the movement

- hard to sleep without it... even coming into an urban area it can be scarey"
   (Boater)
- "part of the distinct boater culture comes from the days when it was a really closed community... like asking before you'd step onto someone's boat or across their boat... all sorts of courtesies and habits like so I suppose if someone is visiting they need to know about those things" (Boater)
- "materials need to be created by and with boaters so that we have ownership –
  that would give the project credibility not just health people coming in and telling
  us what we need if we're involved from the beginning it is us creating "our
  materials" or "our outreach clinic" for us... not sure there is anything culturally
  specific or different from the mainstream really but you need to work with a
  boaters to consider these things" (Boater)

#### **PART FIVE: Recommendations for Practice**

This concluding section draws together a range of themes from across the findings of all three elements of the study and summarises suggestions for health improvement/good practice across B&NES and the wider locality.

# 5.1 Recommendations for Commissioners targeted at 'professional' staff

# Registration with GP surgeries and access to primary care

There is an urgent need to engage with surgeries over promoting the issue of registration of GRT/Boater/Showmen populations as both temporary and permanent patients. (potentially through emphasizing Duty of Care responsibilities).

Use of READ codes (for all services in contact with the populations) should be urgently reviewed to include flagging for cases of members of the above communities. We would suggest that as a minimum recommendation that all coding should be entered to ensure that New Travellers and Boaters as well as Gypsies/Travellers and Showmen are entered as sub-categories of a particular code to enable monitoring of prevalent health conditions/awareness of potential environmental health dangers.

DH guidance on fast-tracking Gypsies/Travellers (Primary care service framework: Gypsy and Traveller communities, 19th May 2009) should be emphasized to all primary care and front-line staff (including receptionists)

http://www.pcc-

cic.org.uk/sites/default/files/articles/attachments/ehrg\_gypsies\_and\_travellers\_pcsf\_190509.pdf

It may be that particular practices wish to apply for 'enhanced service' status in relation to Gypsy and Traveller (and Boater) groups following discussion with CCGs – a model utilized with great success in Leicestershire where levels of trust have been enhanced, immunization rates increased and rates of A&E use and emergency hospital admissions

for these populations have decreased. <u>See further Annex 3 of the DH guidance 19/5/09 (above).</u>

It is to be recommended that in line with Health Inclusion priorities practices which are known to have Gypsy/Traveller/Boater populations on their books in either a temporary or permanent basis should take the opportunity to undertake 'outreach' work and encourage health checks/screening, immunisations for a number of standardized conditions (e.g. cardio-vascular, BP, weight, diabetes etc.) as well as engaging (where possible) with communities/conditions outlined elsewhere in this report (see Table 7) and discussing with community members whether they require referrals/monitoring of other conditions.

Where possible continuity of care (ability to see the same GP) and an automatic offer of 'same gender' practitioners should be offered to all patients. 'Ethnic' Gypsies and Travellers are however particularly likely to require access to same gender physicians for cultural reasons.

Midwifery services should be encouraged to review home birth policies and consider if these are flexible enough to offer home births to Travellers/Boaters where circumstances are safe.

Guidance on the 'postcode' issue should be provided to surgeries (as well as other practitioners required to attend call-outs to site dwellers/boaters) to ensure that reliance on sat-navs and IT technology does not result in vulnerable individuals and families being denied care.

Guidance is also required on the use of 'bridge numbers' for attending/accessing patients on boats as well as open discussions on whether staff feel able to 'cross gangplanks' or enter onto sites – e.g. training on hazards and fears for professional staff.

Assistance should be routinely offered in regard to form-filling/literacy. We would recommend that this takes place for all patients to avoid stigmatizing particular groups.

It is recommended that rather than rely on letters to contact patients which may be sent to 'care of' addresses, greater use is made of phone calls/personal visits and texts to contact GRT/Boaters (following discussion with service users re: practicality of various methods of contact). Nb: at section 4.2.7 (Use of <a href="https://hand.neld.records.org/letters/">hand held records for itinerant Boaters/Travellers</a>) a discussion occurs re immunization follow-ups and use of letters – phone or text would potentially ensure that all children received such follow-up care.

Care should be taken to ensure that follow-up care (e.g. post hospital discharge) is provided to residents of sites/boaters and that awareness of 'danger signs' are understood as well as what actions should be taken (cf. example of infected wound for Boater – Part Four)

# Hand-Held Records

It is recommended that trials of use of hand-held records are undertaken in B&NES (as well potentially as surrounding areas) to see how effectively they can be used/how feasible they are for different communities and ensuring continuity of care during cross-boundary movement. In the longer-term there may be some scope for use of Apps on mobile phones or remote access to records via lap-tops to allow patients to retain at least some crucial health records pertaining to on-going care.

# Cultural/Health Awareness Training

Commissioners and all healthcare staff should be made aware of the sense of 'difference' articulated by Boaters and GRT people with regard to their health care needs, cultural practices and the evidence on increased rates of health needs amongst particular communities (see above Table 7).

Training materials should be devised (in partnership with community members where possible – perhaps through the auspices of creating health fora for potentially vulnerable groups) which a) highlight health conditions and cultural factors pertaining to different communities and b) include wherever possible active participation of members of the communities in question to deliver training on their culture and health care preferences, as well as permitting consideration of devising information which challenges common practices (e.g. information on low take up of screening during pregnancy amongst pregnant NTs) in an acceptable manner to service-users.

Practitioners from a range of disciplines should be strongly encouraged to attend cultural/health awareness training in relation to GRT/Boater/Showmen. CPD points could be offered as part of the incentives for attending such training. Training may potentially be delivered as part of a wider training day (see comments above from reception staff) or as stand-alone modules.

That consideration should be given to training and employing (perhaps on a sessional basis) 'community health advocates' from local service-user groups given the very high level of interest in engaging with local GRT/Boaters employed in such roles.

Health Care providers should be alerted to the potential strengths of membership of GRT/Boater communities (see findings re: support when ill) as well as receive training on the potential tensions/discrimination experienced by housed GRT people, as well as the risk of isolation/impact on community members of movement into housing.

Showing Dignity and Respect – participants need to receive information on the practical difficulties which may pertain for GRT/Boater/Showmen in terms of muddy sites, physical space on boats/in trailers or evictions during training. Practitioners should be encouraged to consider both practical challenges faced by service-users as well as to reflect on stereotypes they may hold – e.g. attitudes cited by a number of respondents pertaining to provision of adequate analgesia for New Travellers/Boaters treated at walk

in and A&E clinics; assumptions of high risk of substance misuse, or 'fixed' health beliefs; receptionists objecting to 'mud on floor' when someone comes in from a site etc.

### Other

It may thus be, that there is some scope for benefits advice outreach work to be undertaken by local advice agencies/CAB etc. (potentially through 'site drop in'/floating clinics etc. if these are utilised) with Romany Gypsies and Boaters given the percentage of these populations with no knowledge of benefits rights reporting caring for household members had a range of conditions including mobility problems, cardiac difficulties, depression etc.

Where service users have indicated that they require information on particular health care topics this information should be provided (confidentially) to those who made such an approach.

There may be scope to wider information dissemination on walk in confidential services in relation to contraception, sexual health and sources of advice on Domestic Violence assistance within the communities. This may be targeted (e.g. through leaflets etc.) or take place at special 'drop-in' services in accessible locations e.g. Julian House etc.

Inter-agency training and close liaison with a range of agencies (including Avon Consortium Traveller Education Service: ACTES who will already have contacts with housed Gypsy and Traveller populations) as well as local authority social care should be carried out to ensure service users are alerted to specialist health care initiatives and practitioners/agencies receive materials on/have increased awareness of a) greater prevalence of some health conditions including common stress/mental health issues, substance misuse amongst some communities and b) that for individuals in need of a social care assessment for support, chopping wood, carrying water and moving boats are not 'unusual' and hence should be included in assessments of need as standard if detailed by clients as part of their lifestyle.

Terminal/Palliative care services – delivery of information and advice on GRT/Boater preferences for palliative care should be shared with care providers. Liaison and shared policy approaches should where possible be devised with agencies such as hospitals, hospices and the CRT in relation to delivery of care, and for boaters access to longer-term moorings and support for boaters with health conditions and long-term/terminal illness to support them in remaining at home or dying with dignity in their preferred environment.

# In-Reach and Specialist/Shared Services

We strongly recommend that consideration is given to commissioning cross-border/shared practice inter-disciplinary teams to undertake work with Boaters and New Travellers/nomadic Gypsies and Travellers (including the church/spiritual groups working with Boaters).

Professionals from a range of disciplines should be encouraged to liaise with health specialists and 'meet communities' (e.g. through liaising with local site residents and being introduced as health care professional with an interest in working a particular population - see comments under Part Four by Pharmacist) or as an option during training/refresher courses.

Pharmacists/Dentists and Opticians with a particular knowledge of or interest in working GRT/Boater/Showman populations could apply for a logo/sticker (similar to a quality mark) which could be displayed subject to training/service-user review of services indicating 'enhanced services' (including willingness to provide 'walk-in' services/medicine reviews etc.) as possible. Such practices (as well as GP surgeries and experienced HVs etc.) should be made known to specialist websites/community groups for recommendation to callers/website users. Julian House (Bath homeless unit) could also retain a list of experienced/enhanced service providers in B&NES and neighbouring areas.

Based upon best practice and community/expert practitioner experience we would suggest that an identified GP or HV lead (a 'health champion') should be appointed (perhaps attached to an enhanced service GP practice if this is the preferred/selected model) and the coordinating practitioner is able to call upon the services of pharmacists, dentists, psychiatric nurse and other specialists such as sexual health and smoking cessation teams as required to offer 'on site'/towpath clinics on occasion (e.g. 3 x a year at specified locations), as well as being the designated first point of contact for newly arrived GRT/Show/Boater populations who prefer to access a specialist rather than utilize standard community/primary health care facilities. The lead practitioner would also operate as a referral point and liaise closely with Julian House and/or practices known to be used by relatively high numbers of Travellers/Boaters.

Practitioners embedded within communities (e.g. nurses living on boats) should be encouraged to self-identify and be offered the opportunity to take on a designated liaison role or 'health champion' post for their population.

We would encourage commissioners to consider developing/commissioning programmes such as the Buckinghamshire New University/Buckinghamshire PCT/One Voice for Travellers 'smoking cessation' course delivered to Gypsies/Travellers by trained members of their community which included the use of culturally tailored materials and was perceived of as 'not patronising' by recipients

As READ codes become used more commonly for these communities it will be easier to map patterns of service use and numbers of GRT/Boater/Showmen registered with practitioners across B&NES and neighbouring areas assisting in health intelligence and targeting of resources.

Sources of information/health promotion materials

A variety of health promotion and health rights materials (e.g. cartoon, DVD, leaflets, apps. etc. as detailed within the report) should be devised in conjunction with community members (to enable 'ownership') and health professionals with experience of working with these groups of service users to promote healthy lifestyles, eating, and enhanced awareness of gendered approaches to health promotion/symptoms.

There should be a targeted drive to reduce use of A&E by service users other than when urgent, by improving awareness of and access to preventative care/ minor injury units as well as active encouragement of GPs to register patients.

Materials should be developed for distribution in conjunction with local service users and GRT specialist community groups (preferred route of health advice for some survey participants) in relation to common conditions, as well to encourage take-up of pharmacist services; increased access to dental and optical services and screening for common health conditions. Materials aimed specifically at male GRT/Boaters should be considered a priority given findings in relation to attitudes to health care and service use.

Specialist materials (health promotion, rights to temporary registration and information on the availability of services designed in partnership with community service-users) could be disseminated at locations where GRT/Boaters are known to use services (e.g. Julian House, markets, community centres etc. as well as made available via specialist website and community agencies such as the K&A boaters group, Friends, Families and Travellers, as well as distributed to residents of new unauthorized encampments and made available to health professionals resident on canals for distribution to fellow Boaters.

See above for recommendation on the training of health advocates within particular communities who are linked to specific communities/locations (e.g. tolerated sites) in addition, 'help lines' where GRT/Boater communities know that on particular dates or times they could speak confidentially to a 'health champion' with regard to particular health issues/conditions etc. could be promoted in conjunction with other 'out-reach activities'.

#### 5.2 Recommendations for engagement with service-users

# Registration with GP surgeries and access to primary care

Given that one third of New Travellers and 20% of Boaters were unaware of the right to register as a temporary patient (although most 'ethnic' Gypsies/Travellers and Showmen were) there is an urgent need of health rights information campaigns for these particular categories of respondent.

As noted above there is an urgent need to liaise with health and social care professionals living on sites/in boats and engaging them along with other community members (e.g. Showmen, Gypsies, Irish Travellers) in health fora/reference group to

work closely with CCGs in devising and planning outreach services, involvement in training and the preparation of relevant information and health promotion materials for dissemination to their communities.

Materials developed – e.g. gendered health promotion, information on inoculations, rights to follow-up care, information on particular conditions etc. should be reviewed and disseminated via community groups and forum members wherever possible.

Work with Boaters in particular should be undertaken which enables consideration of forward planning for suitable health and social care services to be delivered to an ageing population/where cultural barriers may lead to self-neglect of conditions through fear of lack of understanding from service providers. For Boaters in particular this will involve potentially setting up and convening space for working with CRT over supporting older boaters and access to moorings for health requirements or the equivalent of 'floating retirement moorings'.

If health advocates are to be trained/appointed there is a need for 'ground work' to be undertaken with community members in advance of such programmes being put into action. We would recommend that such outreach commences as soon as possible whilst there is a momentum and interest in the findings of this project.

#### Conclusion

This complex and multi-method study has proved both exciting to work upon and has also generated a number of potential possibilities for enhanced commissioning and improved delivery of care to potentially vulnerable groups.

The concluding words however, must belong to the community members who participated so freely in this study and without whom it could not have taken place:

"look the present government is stuck somewhere with an idea about what this community is – stuck somewhere a long time ago - where we are now is very different... we're not all involved in festivals by any means but a lot of us are and festivals have been tied up and made legit and a lot of us have been made legit as well – but we want to live on sites.. that doesn't seem to be recognized. People don't recognize you for what you are – they have a label and say 'it's like that' and that is why so many people don't want to identify themselves as Travellers – we need to be called by a new name... itinerant entertainment workers of something..." (Male Traveller)

I think it is fantastic what you people are doing – listening and trying to make things happen" (female NT)

"I hope they do do something – not just ticking the box and saying that's it – we've done it now ... We do need something because there's a lot of us out there and it's going to grow" (Boater)"

# Appendix A: Service Users' Questionnaire

Tick boxes				
Bath and North East Somerset				
North Somerset				
Interviewers Initials				
Boat	Housed	Site		
Postcode of location or Bridge Number				

# North Somerset and B&NES Gypsy, Traveller, Boater, Showman and Roma Health Survey 2012



# **INTRODUCTION**

Thanks the participant for taking part and explain reasons for this interview.

Reassure about confidentiality
Explain will take about 40 minutes

Person interviewed	_ Date	
SECTION A: DEMOGRAPHICS Please tick boxes from selection. Male	Female	
Site locationNS	3) Trust Area B&NES	

4) Ethnicity	5) Age
Romany Gypsy	Under 18
Irish Traveller	18-25
Scottish/Welsh Traveller	25-35
Roma/Sinti *	36-45
New Traveller	46-55
Showman	56-64
Boater	65-74
Other (please specify)	Older (Ask age if possible):
* Please identify country of origin if Roma (e.g. Czech/Polish etc)	

# 6) Type of accommodation (tick as applicable)

Housed owner occupied rented (private) rented (public sector e.g. local authority/housing association)

staying with relatives/friend in their house

(please identify tenure e.g. local authority/private rented/owner occupied)
Boat
(please specify size/type where possible)

Showman's Yard someone else) Local authority site (authorised) Roadside (unauthorised) Private site (authorised) Other (please specify – e.g. family land 'lying low') 7) How long have you lived there? Years \_\_\_\_\_ and Months \_\_\_\_ 8) How many times have you been evicted/moved on (not by choice) in the past 3 years? For boaters, includes being told overstayed/not moved far enough, mooring agreement terminated, Section 8 notice, boat seized, etc. Evicted/moved on times (if at all) (Comment) FOR THOSE ON A SITE: 9) Have you lived in housing in the past five years? Yes/No (If yes) **10)** Why did you move onto a site? *Please tick any that apply:* Couldn't settle To join friends and family Cost of living R
Other (please specify) Racial/lifestyle harassment (Comment) FOR THOSE IN HOUSING: 11) How many times have you moved in the past three years\_\_\_\_ (If at all) **12)** Please can you tell us your reasons for moving? *Please tick any that apply:* Racial harassment Couldn't settle in housing Offered a council house Overcrowded Other (please specify)

13) Do you have moorings? Yes / No\_\_\_\_\_\_

Private site (unauthorised) (owned by self or

Bender/temporary structure

(Comment)

FOR BOATERS:

14) How often do you move usually?				
(boater without moorings/CC/or by choice)				
15) If you are a Continuous Cruiser/Boater without moorings where do you move?				
(e.g. remain in B&NES or to Wiltshire then back etc)				
16) Have you lived in housing in the past five years?	Yes / No if Yes,			
17) Why did you move onto a boat? Please tick any Couldn't settle Cost of living To join friends and family	that apply: Racial/lifestyle harassment? Other (please specify)			
18) How many children live with you?				
Please give their ages and genders				
Child 1: Age M / F Child 2: Age M / Child 4: Age M / F Child 5: Age M /	F Child 3: Age M / F F			
Other children:				
19) How many adults are part of your household? (e	even if in a different trailer/boat)			
Please give their age, gender & relationship to you:				
Adult 1: RelationAgeAdult 2: RelationAgeAdult 3: RelationAgeAdult 4: RelationAge	Male / Female Male / Female			
Other adults				

REASSURE <u>SECTION B</u> IS TO FIND OUT ABOUT HEALTH NEEDS

AND IF EVERYONE IS GETTING FAIR ACCESS AND SUPPORT

# SECTION B: BASIC ACCESS – If 'no to all' go to question 23

Are you and all members of your family who live with you registered with a GP?

You: Yes / No Partner: Yes / No Children: Yes / No Other relatives: Yes / No

### (Comment)

Is your registered doctor within 5 miles of where you live? Yes / No

Or if a boater, what is furthest distance you travel away from your registered doctor? \_\_\_\_\_ miles

Is your Doctor in North Somerset/B&NES? Yes / No

If not, why?

(e.g. good doctor prefer to travel to see them – registered at my Mum's address etc.)

Do you and all members of your family have an NHS number?

You: Yes / No Partner: Yes / No Children: Yes / No Other relatives: Yes / No

# (Comment)

Do you or your family have any hand-held medical records?

You: Yes / No Partner: Yes / No Children: Yes / No Other relatives: Yes / No

# (Comment)

Did you know that you can register with a GP as a Temporary Resident? Yes / No

Are you and all members of your family who live with you registered with a DENTIST? You: Yes / No Partner: Yes / No Other relatives: Yes / No

# Comment)

If registered with a dentist, are they NHS? Yes / No

If private, would you want an NHS dentist if could get one? Yes / No

# Comment)

Are you and all members of your family who live with you registered with an OPTICIAN?

You: Yes / No Partner: Yes / No Children: Yes / No Other relatives: Yes / No

Comment)	
Do you and your family <b>see</b> an optician at least annual	ually? Yes / No
Please explain:	
(e.g. only go if break glasses or if seeing optician for an ar	nnual check-up)
Do you and your family <b>see</b> a GP at least annually? <b>Please explain:</b>	
Tiodoo oxpidiiii.	
(e.g. on going medical issues require regular treatment)	
	W 0 M (A)
Do you and your family <b>see</b> a dentist at least annua <b>Please explain</b> :	
If you have dental problems do you /have you ever treated with over-the counter or herbal medicine Yes	• • • • • • • • • • • • • • • • • • • •
Please explain:	
(e.g. on going medical issues require regular treatment)	
Do you or your household ever use any of the follow	ving to treat ill health?
Please tick any that apply: Herbal/traditional medicines	Massage
Homeopathy	Reiki
Infusions Acupuncture	Other (please specify):
Acupuncture	
If you have used any of the above therapies, do you	u(tick all that apply):
Use 'alternative' medicine first before seeing a	Only see a doctor/hospital as a last resort if
GP Use any of the above at the same time as GP /	someone has a very serious injury / illness Other (please specify):
hospital medicines / services	
Always use instead of GP / hospital medicines / services	
If there was a health scare in your area/site/communwould you or your family contact for who information	, -
Please tick any that apply: GP	Chemist / pharmacy
Specialist health visitor	Call a helpline

Wait and see if anyone in your family got ill A Traveller advice group etc General media (TV / radio / newspaper) Wouldn't bother/don't believe in inoculations etc. [please delete as applicable]	Other (please specify):
Do you prefer to see the same GP every time you a) Please explain:	<u>——</u>
<b>b)</b> How easy is it for you to see the same person? Comment:	
Do you mind whether the GP you see is male or for a) Please explain:	
(How does the interviewee feel about hospital doctors?)	)
<b>b)</b> How easy is it for you to see a GP of your preference ⊕ DIFFICULT <b>1 - 2 - 3 - 4 - 5 - 6 - 7</b> EASY ⊕ Comment:	
When you see a GP, do you feel you have enough	n time to speak with him/her? Yes / No
When you see a GP, how easy is it to get the trea 'pills' when you would prefer another option, like 'ta ⊗ DIFFICULT 1 - 2 - 3 - 4 - 5 - 6 - 7 EASY © Comment:	alking therapy' if you felt low/had nerves)
As a <i>Traveller/Roma/'Boater</i> , do you feel that you way from other people's? Yes / No Please explain:	r family's healthcare needs differ in any
Do you feel that there are any particular health co more likely to get than if they weren't a Traveller/S conditions, asthma etc. Yes / No	
Please explain:	
Do you you feel that your healthcare providers (do No	octors, nurses etc.) understand your needs? Yes /
Please explain:	

Do feel the NHS fully provides for your needs as a Traveller/Boater/Roma/Showman? Yes / No

Please explain:
•
Do your family experience any language or cultural barriers to receiving health care? Yes / No If there are language barriers, a) Please explain:
b) How do you access translators?
(e.g. hospital calls for translator, children help)

# **SECTION B: EXPERIENCE AT DOCTORS' SURGERIES**

Have you or your family **had any problems** with any of these things since you've been living in / travelling through B&NES/North Somerset? **Please** <u>rate</u> your experiences of:

<b>46)</b> Finding a GP surgery who will take you Please explain:	
47) GP Surgery opening hours Please explain:	⊗ POOR <b>1 − 2 − 3 − 4 − 5 − 6 − 7</b> GOOD ©
48) Getting / making an appointment with a GP? Please explain:	
<b>49)</b> Quality of GP Reception staff (attitude, helpfulne Please explain:	·
<b>50)</b> Quality of GP Reception area (e.g., space availa Comments:	able)? $\otimes$ 1 – 2 – 3 – 4 – 5 – 6 – 7 $\otimes$
<b>51)</b> Waiting time in GP surgery? Comments:	⊗ 1 - 2 - 3 - 4 - 5 - 6 - 7 ⊚
<b>52)</b> Quality of consultation with GP? Please explain:	<b>⊗</b> 1 − 2 − 3 − 4 − 5 − 6 − 7 <b>©</b>
53) Getting your prescriptions? Please explain:	⊗ 1 - 2 - 3 - 4 - 5 - 6 - 7 ©
54) Follow-up treatment / after-care? Please explain:	<b>⊗</b> 1 − 2 − 3 − 4 − 5 − 6 − 7 <b>©</b>

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# **SECTION C: OUT OF HOURS / EMERGENCY ILLNESS**

<b>55)</b> If you need medical treatment in the evening or weekends where do you go? <b>Please tick all that apply:</b>				
Hospital A & E	Emergency dental clinic			
Walk-In Clinic	(where?)			
Phone NHS Direct	Other (please specify):			
56) Which do you prefer?				
Why?				
	_			
<b>57)</b> Do you have any problems with using A & E? Yes Please explain:				
<b>58)</b> Are you able to use a telephone helpline e.g. NHS Direct? Yes / No <u>if No</u> , Why not?				
<b>59)</b> Are you able to get home/ site/ stopping place /mooring/towpath visits from Doctors/ Midwives/ Health Visitors?				
Yes / No <u>if Yes</u> , Which services will come to visit you?				
60) Do you ever call an ambulance in an emergency / if someone has had an accident? Yes / No				
<b>61)</b> Will ambulances come to your site/ stopping place/ mooring/ towpath? Yes / No / Don't know Comments / examples:				

# SECTION D: ANTE-NATAL / MATERNITY CARE

Is anyone in your family who lives with you having a baby? Yes / No Or had a baby in the last five years? Yes / No

If Yes – Do you mind if we ask about treatment during pregnancy?

If No - Please move on to SECTION E

were you/the person offered regular appointments to see the Midwife/Doctors? Yes / No			
63) If yes, were they taken up? Yes / No if No,			
Please explain:			
64) Were you/they offered scans? Yes / No			
<b>65)</b> If yes, were they taken up? Yes / No <u>if No,</u> Please explain:			
66) Were you/they offered screening for conditions such as Spina Bifida/Down's Syndrome? Yes / No			
<b>67)</b> If yes, was this taken up? Yes / No <u>if No,</u> Please explain:			
(e.g. thought would be pushed to have a termination if condition found/ don't believe in screening etc.)			
71) If you/they wanted a home birth, was that option offered? Yes / No <u>if No</u> ,			
a) Please explain:			
(e.g. home conditions regarded as unsuitable)			
b) How did you/they feel about being refused a home birth?			
73) Did the hospital and midwife understand about Gypsy & Traveller/Roma/Showman/Boater culture and childbirth? Yes / No			
Comments: 74) Did you/they have Health Visitors? Yes / No Comments:			
<b>75)</b> If so, did the <b>Health Visitors</b> understand about Gypsy & Traveller/Roma/Boater/Showman culture and childbirth? Yes / No Comments:			
<b>76)</b> Overall, how happy were you/they with the treatment received during pregnancy? ⊗ 1 − 2 − 3 − 4 − 5 − 6 − 7 ©  Comments:			
77) Overall, how happy were you/they with the treatment received during childbirth?  ⊗ 1 − 2 − 3 − 4 − 5 − 6 − 7 ⊚  Comments:			

<b>78)</b> Overall, how happy were you/they with the follow-up treatment received after childbirth? ⊗ 1 - 2 - 3 - 4 - 5 - 6 - 7 ©  Comments:
68) Were you/they offered information about vaccinations? Yes / No
69) Were you/they offered /advised to have baby vaccinations? Yes / No
<b>70)</b> If yes, were they taken up? Yes / No <u>if No</u> , Please explain
(e.g. scared about risk of jabs; moved on; couldn't get an appointment, etc.)
72) Were you/they offered information about breast feeding Yes / No
79) What more would you want from health and social care staff?
□ Jnder 18 □ 18-25 □ 25-35 □ 36-45 □ 46-55 □ 56-64 □ 65-74 □ Older (Ask age if possible)

# **SECTION E: OTHER SPECIFIC HEALTH NEEDS**

80) Do you, or any of your family you live with, have any of the following health problems?

Nature of health problem	Enter Age Group	Gender	Which Family Member?	Health/social care professionals who've been most helpful	Any extra help wanted	Sought help before	Notes
A - ADHD/Autism							
<b>B</b> - Alcohol dependency							
C - Cancer							
<b>D</b> - Dementia							
E - Diabetes							
F - Eating disorders							
<b>G</b> - Epilepsy							
H - Eye sight problems (short-sightedness, Glaucoma, etc.)							
I - Hearing problems							

J - Heart problems			
K - High Blood pressure			
L - High Cholesterol			
M - Mobility (walking/standing up, etc.)			
N - Nerves, depression, stress			
O - Respiratory problems			
P - Non-prescribed drug use			
<b>Q</b> - Does anyone in the family smoke?			
R - Stroke			
S - Have you previously sought help?			

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If YES to question 80) N):
<b>81)</b> Were you/they offered 'talking treatment'/therapy? Yes / No <u>if yes</u> ,
82) Did you/they feel it worked? Yes / No Comments:
83) Did you/they want this sort of treatment or did they prefer to take pills? Yes / No Comments:
If YES to question 80) B) or P):
84) Have you/they been offered or able to access help through specialist services Yes / No Comments:
e.g. moved on from site/moorings before able to access services/stigma of acknowledging need
Has anyone in your household been told they have a 'dual diagnosis' e.g. substance use + mental health or learning disability? Yes / No <u>If yes</u> ,
Check that question 80 is answered correctly

Are they getting enough help do you think? Yes / No Comments:

(e.g. can get help with mental health needs but not substance abuse, physical disability treated but staff we see not sure how to deal with learning disability as well)

Are there any other health needs in your family? Yes / No if Yes,	
a) Who has the problem?	
b) What is the nature of the problem	
c) What support/treatment is being received, if any?	
d) What extra help is needed?	
<u></u>	

Thinking about yourself, the relatives who live with you, other site residents nearby and other boaters you know, is there anything that makes it difficult for you/them to get the help you/they need with your/their health care? Yes / No Comments:

(e.g. filling in forms, being a boater, being moved on from sites)

Are you aware of any benefits entitlement you might be able to claim to help care for the person with the health needs/disability? Yes / No Comments:

#### DIRECT TO INFORMATION/CONTACTS SHEETS FOR REFERRALS FOR ADVICE

Have you/your family who live with you ever been refused the support you need by health care staff? Yes / No *if Yes*, Please explain:

### **SECTION F: CARERS AND CARED-FOR ADULTS (and Older People)**

Caring includes cooking, shopping, washing, giving lifts, etc. to someone who could not manage otherwise. A carer is someone (of any age) who provides unpaid care for an ill, frail or disabled relative, friend or neighbour.

Are you or anyone you live with a CARER? **Yes / No** 

Does anyone in your household depend on being CARED FOR by another person? **Yes / No** 

<u>If No</u> to both questions Please move on to SECTION G

Who is the carer in your home?
Who is cared for?
Why do they need a carer?
In what way do you/members of your family/friends look after the person who needs care?
(a.g. My sisters help me and we take turns to look after our Mam and do the channing.
(e.g. My sisters help me and we take turns to look after our Mam and do the shopping; person on site is ill so we help with their care etc.)
Do you/the person you are caring for get any support from Health / Social Services? Yes / No ( <u>if No, go to Q99</u> ) <u>if Yes,</u> a) Please describe:
(e.g. health visitor, district nurse; hospital or social work support)
b) Are you satisfied with this help (e.g. timing of appointments/service received etc.)? Yes / No
Is help needed more often? Yes / No
Is more home-visiting support needed? Yes / No
Is any different help needed? Yes / No
If you don't get help - why not?
(e.g. we want to look after our own family; we were refused, moved on; language barriers etc.)

How would you/your community prefer to care for old <i>Please tick:</i> At home (house) On Site/Boat with adaptations Access to sheltered/adapted housing	er/disabled relatives and friends?  Care facilities Support them to remain living independently in their own home/boat/trailer etc.		
Do you think that there is anything 'different' or 'specknow about how Gypsy/Traveller/Roma/Showmen/Bocommunity members?	aters prefer to care for older/disabled people		
e.g. cultural issues, etc.			
How do you think you/family members will best be ab needs to live as a Roma/Gypsy/Traveller/Boater/Show become disabled)?			
Are you aware of the range of disability/illness relate help you to care for a family member/friend? Yes / No	•		
(Refer to contacts/advice sheet if more information	n required)		
Would you like us to pass on your name/contact deta benefits advice/assessments? If yes –	ils to someone who might be able to help with		
Contact details	number / email)		
Signature			
Ask if interviewee minds talking about 'difficult' subjects and explain this next section is about end of life / bereavement – skip questions if necessary and go to Section H (Healthy Living) commencing at Q118			
SECTION G: END OF LIFE			
Terminal illness			
How do you and your family prefer to care for relative Please tick all that apply: At home (site/house/stopping place/moorings) Hospital Hospice	s/friends who are reaching the end of their life?  Other (please specify):		
1 loopiloo			

What would you like in the way of support (if anything)?

Have you ever cared for a relative/friend/ family member at the end of their life? Yes / No

<u>If No,</u>	please	go	to	Q	<u>1</u>	1	1
---------------	--------	----	----	---	----------	---	---

How and when were you told they weren't going to get better?
e.g. a few days before they died, Doctor took me aside at the hospital,
Where there any problems with how you were told? Yes / No Please explain:
Were you given support with looking after them by hospital / medical staff? Yes / No Please describe:
Did they give you information in a way you found easy to understand? Yes / No Any problems?
(e.g. written materials, told badly, left to cope alone, etc.) Would it have helped to have a 'mediator' from the Gypsy/Traveller/Showmen/Boater/Roma community to talk to the hospital about your family's needs? Yes / No
What do you think hospitals need to know about helping Gypsy/ Travellers/ Showman/ Boater/ Roma families who have someone reaching the end of their life in hospital?
If you were looking after someone reaching the end of their life, would you be able to care for your relative how you want to? Yes / No Please explain:
(e.g. no medical support for terminal care at home if on a site, boat etc.)
Loss and Bereavement
Who would you go to for help and support if you had lost someone close to you?
e.g. family; doctor; friends; etc.
Do you think bereavement is different for men and women? Yes / No
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(e.g. men don't talk to anyone or pretend it is alright; or women go to their sisters/daughters for support)
If you or someone in your family are having to cope with grief about the death of a relative or family member, do you/they have enough support right now? Yes / No
Comments:
Has your family ever used services like CRUSE (bereavement charity) or Childhood Bereavement Trust if someone has been lost? Yes / No
Would your family do so if you thought these organisations understood Gypsies & Travellers/ Boaters/ Showmen/ Roma or these organisations had someone from your own community you could talk to? Yes / No Comments:
SECTION H: HEALTHY LIVING
What changes do you think you need to make to your life, or your family's lives, to be more healthy? <i>Please tick all that apply:</i>
Lose weight Comment:
Eat more healthily Comment:
Take more exercise Comment:
Cut down on drinking Comment:  Relax more Comment:
Cut down on / give up medication (such as anti-depressants) or non-medical drug(s)
Comment:
Other (please specify):
Would you/or your family members access the following services to help live a healthier lifestyle or
receive support with any of these things? Y / N  Please tick all that apply:
Information/advice Comment:
Class/support groupComment:
One-To-One Confidential Appointments
Health Literacy Comment
Other (please specify):
What health issues are most important to you and your family?
Would you like more information on any health issue? Yes / No If so, what?

Would you like to come to a special Gypsy/Traveller/Boater Health Event – run with and for

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Gypsies and Travellers - on the things you've said interest you? Yes / No

	do you get information about health issues?	
Please tick all that app	mmont:	
GP surgery Comment: Library Comment:  OVDs / CDs Comment:		
Library Comment:		
Children's Centre Cor		
Internet		
Special Traveller/Boater	/Roma/showmen websites or organisations (e.g. FFT/Showmen's Guild	
information Please spec	ify:	
Other (please specify):	,.	
(p		
family? Talking books/audio	alternative to receiving written information on health needs for you and your  Comment:	
Internet/Podcasts	Comment	
DVDs / CDs	Comment	
	Comment:	
	th advocates from your own community	
Comment:	ies/Travellers/Roma/Showmen/Boaters - available at certain times	
Comment:		
Other (please specify):		
Have likely are year to as	and and a dector if you have a modical problem?	
now likely are you to go	and see a doctor if you have a medical problem?	
$\otimes$ VERY UNLIKLY $1 - 2 - 3 -$	• <b>4 − 5 − 6 − 7</b> VERY LIKELY <sup>③</sup>	
	how likely men and women are to go and see a doctor? Yes / No	
- -		
SECTION J: OTHER	RISSUES	
you be in getting hand-h	re referred to a hospital specialist, physiotherapist etc., how interested would neld records of the letters and treatments? $\mathbf{6-4-5-6-7}$ VERY INTERESTED $\mathbf{\odot}$	
you are travelling/mobile	be interested in having an alternative to hand-held medical records for when $\frac{1}{2}$ ? $\frac{1}{2}$ $\frac{1}{2$	
Mobile phone S u Laptop S u	g alternatives to paper records:  SELESS 1 - 2 - 3 - 4 - 5 - 6 - 7 EXCELLENT ©  SELESS 1 - 2 - 3 - 4 - 5 - 6 - 7 EXCELLENT ©  I - 2 - 3 - 4 - 5 - 6 - 7 EXCELLENT ©	

Would you/your family feel 'hand-held' records for you ⊗ NOT GOOD 1 – 2 – 3 – 4 – 5	,
Are you interested in gettin Please tick all that apply: Information/advice Communition/training Other (please specify):	Comment:

Page left intentionally blank

FOR THOSE IN HOUSING	ONLY:	(for non-housed,	go to Q136)
		,	,

Do you feel it is better for you to be in housing in your current situation? Yes / No Please explain:

Do you feel that living in a house affects your physical health? Yes / No Please explain:

(e.g. easier to access doctors and health care)

Do you feel that living in a house affects your emotional wellbeing / mental health? Yes/No Please explain:

(e.g. safe from evictions/ can't keep a trailer/ racism/ loneliness etc.)

Other comments about living in a house:	
(if previously lived on a site/boat/Showman's yard	OR Roma migrant previously living in Europe)

FOR THOSE ON A SITE, BOAT OR	HOUSE: Please rate your environment on
Access to Sanitation	⊗ POOR 1 - 2 - 3 - 4 - 5 - 6 - 7 GOOD ©
Comment:	
Access to clean water (i.e. suitable for cooking/drinking)	⊗ POOR 1 - 2 - 3 - 4 - 5 - 6 - 7 GOOD ©
Comment:	
Whether you have Electricity	⊗ POOR 1 - 2 - 3 - 4 - 5 - 6 - 7 GOOD ☺
Comment:	
If on a site are you able to light a fire	on your site? Yes / No / Not applicable
Can you access wood/coal etc. easily	y? ⊗ NO <b>1 − 2 − 3 − 4 − 5 − 6 − 7</b> VERY EASILY ©
Comment:	
What sort of heating do you have? Wood stove Coal stove Calor gas heaters Multi-fuel stove (both wood & coal)	Please tick all that apply: Other (please specify):
How is your physical environment go	enerally? ⊗ POOR <b>1 - 2 - 3 - 4 - 5 - 6 - 7</b> GOOD ⊗

Please say if it depends, e.g., on where you are stopped or moored.

How are community relations (how you get on with your neighbours)?

 $\bigcirc$  POOR 1 - 2 - 3 - 4 - 5 - 6 - 7 GOOD  $\bigcirc$ 

Comment:

Please say if it depends, e.g., on where you are stopped or moored.

How safe do you feel (e.g. from hate crime/burglary/fear if walking alone in your area at night?)

Comment: \_\_\_\_\_

How do you feel that the people who live in your immediate neighbourhood feel about Gypsies/Travellers/Roma/Boaters/Showmen in general?

 $\odot$  NEGATIVE 1 - 2 - 3 - 4 - 5 - 6 - 7 Positive  $\odot$ 

Comment: \_\_\_\_\_

How well (in general) do you get on with people who live in your immediate neighbourhood who aren't members of your own community?

Comment:

Please say if it depends, e.g., on where you are stopped or moored.

Do you feel that your neighbourhood/estate/site/moorings/the towpath is a place where people look out for / support each other?

 $\odot$  NEVER 1 - 2 - 3 - 4 - 5 - 6 - 7 ALWAYS  $\odot$ 

Comment: \_\_\_

**Explain next section is about how well supported people feel living in their area** (probably more relevant to people in houses rather than on sites/boaters living on moorings with other people)

Not counting the people you live with in your household, how often do you speak to other family members?

Every day

5 or 6 times a week

3 or 4 times a week

Once / twice a month

Every few months

Once / twice a year

Not at all in the last year

Not counting the people you live with in your household how often do you speak to friends (not

counting neighbours)?

Every day

5 or 6 times a week

3 or 4 times a week

Once / twice a month

Every few months

Once / twice a year

Not at all in the last year

How often do you speak to neighbours (who aren't friends or family)?

Every day

5 or 6 times a week

3 or 4 times a week

Once / twice a month

Once / twice a year

Not at all in the last year

# Explain these next questions are about access to *practical support* and *community networks* amongst Travellers/ Boaters/ Roma/ Showmen

How many relatives/friends who you feel 'close to' live from you? (don't count your household members)	e within a 10 minute drive or 20 minute walk
None	3 - 4
1 - 2	5+
If you were ill in bed and needed help, is there anyon	ne you could ask for help? Yes / No
Who could/would you ask who you feel would look a	fter you?
Please explain:	
If you had a serious crisis how many people do you to (number)  Comment:	feel you could turn to for help?
Is there anything else you want to tell us about commarea?  Comment:	nunity relations and well-being in your

Ask if interviewee minds talking about 'difficult' subjects and explain this next section is about contraception / family planning /sexual health/family stress - skip questions if necessary/appropriate – PROBABLY MOST APPROPRIATE FOR NT/BOATERS nb: we can provide an interviewer of the same sex on request for this section if required.

If interviewee doesn't want to answer go straight to Q169

**SECTION K: (Family Planning/Sexual Health/Domestic Violence)** 

Do you have access to family planning services? Yes / No Comment

(ONLY if appropriate to probe or interviewee volunteers check if using contraception and what type... e.g. condoms/pill/contraceptive implants)

What do you feel are the most important elements in terms of encouraging your community to access family planning services if they need/want them? (*Please tick 3 priorities*):

Walk in services My community don't talk about/aren't aware of

Short waiting times the services

Discreet premises (won't be seen by anyone I Knowing you will see staff who are the same

know) sex as you (M-M or F-F)

Staff familiar with cultural issues for Non-judgmental

Travellers/Roma/Boaters Other for example leave this decision to my

Reassurance service is confidential partner

Where would you prefer to go to access family planning services?

Chemist Specialist nurse/community services for

Family Planning Clinic Travellers/Boaters
GP Other (please specify):

Hospital \_\_\_\_\_

How do you feel that family planning services can be made more accessible to Travellers/ Boaters/ Roma?

Comment

Would you know who to contact in your local area if you or someone in your family/ household/ circle needed advice on terminating a pregnancy? Yes / No Comment/Other

Do you have access to sexual health services if required? Yes / No

What do you feel are the most important elements in terms of encouraging your community to access sexual health services when they are needed? (*Please tick 3 priorities*):

Walk in services My community don't talk about/aren't aware of

Short waiting times the services

Discreet premises (won't be seen by anyone I Do you feel community members should be

know) willing to find out more?

Staff familiar with cultural issues for Knowing you will see staff who are the same

sex as you (M-M or F-F)

Non-judgmental

Reassurance service is confidential

Travellers/Roma/Boaters

Where would you prefer to go to access sexual health services?
Chemist
Family Planning Clinic
GP
Hospital GUM clinic (Genito- Urinary Medicine)
Specialist nurse/community services for
Travellers/Boaters
Other (please specify)

How do you feel that sexual health services can be made more accessible to Travellers/Boaters/Roma?

Comment

#### DOMESTIC VIOLENCE

Do you know where/how someone could access information and advice on domestic violence services if they were needed? Yes / No

If someone in your family/community was having problems as a result of domestic violence do you think they would...(please tick all that apply):

Talk to their GP

Talk to a specialist health worker with experience of Travellers/Roma/Boaters/Showmen Keep quiet about it

Reason(s):

Ask their family/community to deal with the problem for them

Call a specialist helpline

Go to a refuge

Yes / No

if No,

Why?

e.g. not culturally appropriate/facilities lacking/can't leave vehicle/boat

#### SUBSTANCE ISSUES

Do you know where/how someone could access information and advice on substance issues(drugs/alcohol) Yes / No

If someone in your family/community was having problems as a result of drugs/alcohol do you think they would... (please tick all that apply)

Talk to their GP

Talk to a specialist health worker with experience of Travellers/Roma/Boaters/Showmen Keep quiet about it

Reason(s):

Ask their family/community to deal with the problem for them

Call a specialist helpline

Other (please specify):

#### CONCLUSION

Is there anything else you want to tell us about the health needs of your community/your family or the services you receive in NS/B&NES?

# IF YES TO ANY OF THE FOLLOWING QUESTIONS (170 TO 173) PLEASE OBTAIN INTERVIEWEE'S CONTACT DETAILS:

Would you be interested in any on-going involvement in health and social care issues in your local area (for example advising the PCT or local authority staff on health needs which affect your community)? Yes / No <u>if Yes</u>,

Please provide contact details on the final page so that we can invite you any future meetings or consultations which might take place.

Would you like to know how to access information about the health report based on this survey in late Spring/early Summer 2013 or receive a copy of it?

Yes / No <u>if Yes</u>,

Would you like to receive a copy of the full report? Yes / No

#### THANK YOU FOR TAKING PART

# THANK YOU FOR TAKING PART – DETATCH FROM QUESTIONNAIRE

IF YOU WANT TO HEAR ABOUT THE RESULTS OF THE SURVEY, OR BE GIVEN A COPY OF THE REPORT, OR TOLD ABOUT ANY SPECIAL GYPSY/TRAVELLER HEALTH EVENTS WE MIGHT PLAN PLEASE GIVE US YOUR PHONE NUMBER OR AN EMAIL ADDRESS.

Name		_
Contact email:	or phone number:	
or address:		



# NHS Bath and North East Somerset

### **Gypsy Traveller Health Needs Assessment: Health Professionals Questionnaire**

This questionnaire is to inform a health needs assessment of Gypsy Roma Travellers in North Somerset Bath and North East Somerset.

1. W	hich is your main geographical area of work:		
	Bath and North East Somerset		
	North Somerset		
	Neither of the above (please specify)		
2. Pl	ease indicate your main professional area of v	vork b	y ticking one of the boxes below:
	Dentist		Nurse
	Emergency Care Consultant		Pharmacist
	Emergency Care Nurse		Practice Manager
	Emergency Care Receptionist		Receptionist
	GP		Unsure
	Health Visitor		Other places state
	Midwife		Other – please state
	you have any <b>current</b> contact with Gypsy, Rors? (tick one)	na or	Traveller patients in your daily
	Yes		
	No		
	Unsure		
4. If <b>y</b>	es – from which communities do these patient	s com	e: ( tick all that apply)
	Boat Dwellers		New Travellers
	Romany Gypsy		Roma/Sinti
	Irish Travellers		Scottish/Welsh Travellers

### Showman Other – please state 5. Do you currently (or have you recently) work/ed with housed Gypsies and Travellers? (tick one) Yes No Unsure 6. If so from which communities do these patients come: ( tick all that apply) **Boat dwellers** Romany Gypsy Irish Travellers Showman **New Travellers** Roma/Sinti Scottish/Welsh Travellers Other – please state\_\_\_\_\_ 7. If so, how many **housed** Gypsy and Traveller **families** are known to you in your local area. 8. Have you ever had any contact with Gypsies/Travellers in your professional role? Yes No Don't Know 9. If **yes** – please indicate if this was: (tick all that apply) Whilst working in my current job

	Whilst working in a different field of work (e.g. currently working in a community setting but previously a hospital midwife)
	In a different locality
	Other – please state
Gypsy R	e are particularly interested in finding out about your contacts with oma Traveller people in B&NES and North Somerset but you may ormation which we can draw on from your previous work experience
10. Gyps	If <b>yes</b> , how do/did you identify these patients as ies/Travellers? (tick all that apply)
	Address
	Attend with known Travellers/Gypsies/Boaters etc.
	Known to be Gypsy/Traveller/Boater etc. from previous contact
	Identify themselves as Gypsy /Traveller/Boater etc
	Other (please state
11.	Do you record ethnic status using READ codes (tick one)
	Yes
	No
	Unsure
	READ codes are not used in my area of work
12.	How many Gypsies / Travellers do you currently have registered with the service you provide:
Tem	porary
Peri	manent
	None
	Not applicable

<ul><li>☐ Ye</li><li>☐ No</li><li>☐ No</li><li>14.</li></ul>	es o ot applic	umber fluctua able do the numbe		uate?			
working with one)  \( \sum \text{Ye} \) \( \sum \text{No.}	Gypsie es	ic clinical or p s, Travellers	and othe	er commi	ınities liste	ed above	? ( tick
		ou specify the e tick all relev			al issues	by 'type (	of
Issue	Boat dwell er	Scottish/W elsh Traveller	Roma ny Gyps y	Irish Travel Ier	Showm	New Travel ler	Roma/S inti
Continuity of care							
Fixed health beliefs							
Illiteracy							
Understan ding Traveller culture							
Other (please state)							

17. How are the Gypsy/Traveller (and other communities listed above) that you serve contacted for routine health checks, vaccinations, appointments, etc.?

Other (please state)

	Drop in clinics
	Letters are sent
	Phone call
	Texts
	Visits to the site/towpath
	Not relevant to the service I provide
	Other (please state)
	you provide any 'reminder' services for routine health checks, ccinations, appointments, etc.?
	Yes
	No
	Not applicable
19. If	yes, how do you contact them (Tick all that apply)
	Drop in clinics
	Letters are sent
	Phone call
	Texts
	Visits to the site/towpath
	Not relevant to the service I provide
	Other (please state)

	G	ypsies/ Travellers and other communities listed above which you are vare of? (Tick one)
		Yes
		No
		Not applicable
occur:	21. If	yes, please provide details of the issues and why you believe this to
	(Tick	all that apply)
		Eviction
		Literacy issues
		Travelling for the Summer/Moved on if Boater without Mooring
		Other - please state

26. From your experience, please highlight which of these health conditions are most relevant to the Gypsies/Travellers and other communities (listed below) whom you have treated/treat. (tick all that apply)

Health Condition	Boat dwell er	Scottish/Wel sh Traveller	Roman y Gypsy	Irish Travell er	Showm an	New Travell er	Rom a
Alcohol							
misuse							
Anxiety							
Asthma							
Cancer							
Domestic							
violence							
Excessive							
cardio-							
vascular							
and heart							
conditions							
High rates							
of diabetes							
Injuries							
Lack of							
breast							
feeding							
Low							
screening							
uptake							
Mental							
health							
issues							
Obesity							
Poor							
immunisati							
on uptake							
rates							
Sexual							
health							
Smoking							

Health Condition	Boat dweller	Scottish/ Welsh Traveller	Romany Gypsy	Irish Traveller	Showman	New Traveller	Roma
Stress							
Substance							
misuse							
Others							
(please							
state)							

27. Does your healthcare practice/service have any special measures in place to increase the uptake rate of immunisations, health checks and screening by Gypsies and Travellers and related communities? (tick all that apply)

	Yes	No	Not relevant (e.g. not provided by my service)
Health checks			
Immunisations			
Screening			

28. If y	ves please provide details
20 [	No you have any non-health professionals who sign post or refer
G	Oo you have any non-health professionals who sign-post or refer ypsies and Travellers and related communities to you regarding ealth issues? ( tick one)
	Yes
	No
00.16	
30. If y	ves please provide further details e.g. local community group;

31. Are you aware of the specialist health visitor for Gypsies and Traveller in your area? (Tick one)
Yes
□ No
32. If yes what type of contact have you had with the specialist health visitor?
33. What, if any, concerns do you have about working with Gypsies/Travellers and related communities? (tick all that apply)
Cypolog, Travellere alla relation communities (not all matappiy)
Difficulties of working on sites/towpaths
Ensuring targets are met
Fear/poor communication
Problems retaining contact
☐ I have no concerns
Other please state
34. How do you think things could be improved for both the practice and
Gypsies / Travellers/related communities in your local area? (tick all that apply)
Access to Gypsy, Roma Traveller health advocates
Awareness raising training for staff
Culturally specific resources / information
Hand held health records for Gypsies, Travellers etc.
PCT contact for specific information
Specific Gypsy/Traveller etc. health drop-in sessions
Other please state

35. Would you be willing to be re-contacted to participate in a focus group
if one is held in your particular area? If so to retain anonymity of your
responses please send your email/phone or other contact details
separately to the contact address below -:
•

Or if you prefer insert your contact details here	

Many thanks for completing this questionnaire. Please return it **by 14**<sup>th</sup> **November 2012** either electronically to kay.sandy@nsomerset-pct.nhs.uk or post it to:

Kay Sandy
Public Health Directorate
NHS North Somerset
Public Health
PO Box 238
Castlewood
Tickenham Road
Clevedon
North Somerset
BS21 6FW

#### Appendix C: Information Leaflets distributed to potential/actual interviewee

B&NES and North Somerset Gypsy, Traveller, Roma, Showman and Boater Health Assessment

What's it all about?



In 2007 the West of England Accommodation Assessment for Gypsies and Travellers found that a lot of Gypsies, Travellers, and Showmen who took part in that survey reported having ill health and not always being able to get the care they needed. Some families felt that there was a real need for doctors, nurses and other health professionals to have a greater understanding of Traveller health needs and cultures.

As a result of that study and the fact that health professionals are beginning to understanding that **Gypsies, Travellers, Showmen, Roma and Boaters,** may have **special health needs** or problems in getting treatment, B&NES and North Somerset Health Authorities have asked us to carry out a survey on health needs and experiences of your community. The results will be used to help to improve health services for Gypsies, Travellers, Boaters, Roma and Showmen in your area as well as feeding into training for health care staff.



This health survey is a follow up to the 2007 West of England Accommodation Assessment; and the recent Site identification study in North Somerset (which you might have taken part in) and is also linked to the B&NES accommodation assessment – studies which were carried out to find out what were the accommodation needs of Gypsies, Travellers, Show People and other nomadic communities such as Boaters. We hope that the results of this survey will B&NES Health Survey 2012-13

also help local authorities who are planning for sites and considering needs of communities to have a better idea of how important it is for Gypsies, Travellers, Roma, Showmen and Boaters to be able to access good quality health care, and how being moved on, can affect family health and wellbeing.



We promise you that the information you give us about your health will be anonymised – your name won't be used in the report and the health authorities won't know who takes part in the study unless <u>you</u> ask us to pass on your name and contact details so that you can talk to a health worker about your health needs.

The questions we will ask about your family health cover a lot of information - from how living on your site/yard or in a house or being a continuous cruiser affects your health and access to care; to what help you might need if you are a Carer living in a trailer or a Boat; to whether you use alternative medicines and how easy it is to see a Doctor, visit an Optician or find a Dentist.

The health authorities don't want to just put in services which are of no interest to Travellers, Gypsies, Boaters, Showmen and Roma but they do need to know what help is needed, what works for you, and what you don't like about local health services. Knowing about health needs can also help local and waterway authority to think about site and mooring facilities and how to meet your needs as local people. So this is your chance to have your say about what you need, how you are treated by health staff, how your living conditions affect your health and anything else health related you want to tell us.

Because this survey has been put together with help from health professionals, Gypsies, Travellers, Roma, Showpeople, Boaters and gorgias/country people that have been working with your communities for many years, we hope the questions will help to provide you with the service you and your family want now and in the future.

In a nutshell, the survey has been designed to provide enough **FACTS** about the health needs of you, your

family and your community, so that North Somerset and B&NES health authorities can provide and plan for good quality care for you and your families in the future.



We can't speak to everyone in the areas but our interviewers (who are Gypsies, Travellers and Boaters themselves) want to speak to Boater, Showmen, Roma, Gypsy and Traveller families living on sites, boats (moorings and CC) and in houses in North Somerset and B&NES as well as some families passing through the area regularly who might need to use local health care or specialist services. By late Spring next year (2013) we will have produced a report on what you have told us which will then be used by the health authorities to work towards improving services and planning for the future in your area.

If you take part in the survey and want to find out what happens next we can make sure that you are given a summary of the report and told its findings as well as how you can take part in further consultations with the health authorities. If you have any questions about what we are doing, or how the information we ask for is going to be used, please get in touch with us. If you know of any other families who might like to speak to us, please let us know.







North Somerset North East Somerset

If you would like further information about this study please contact the research team who work for Buckinghamshire New University

Margaret Greenfields Tel: Removed

(before 6pm)

Sylvie Parkes Tel: Removed Jackie Tel: 01494 603 029

Administrator at Buckinghamshire New University



Our interviewers are Boaters and Travellers who will also be happy to try and help with any questions you may have or to give you the phone numbers of They are:

#### **Local Health Survey Contacts:**

Name and number removed.
Traveller – interviewing in B&NES
Name and number removed.
Traveller – interviewing in B&NES
Name and number removed.
Interviewing in B&NES
Name and number removed.
Gypsy – interviewing in North Somerset
Name and number removed.
Boat dweller– interviewing in B&NES
Name and number removed.
Boat dweller– interviewing in B&NES
Name and number removed.
Traveller – interviewing in B&NES



B&NES AND NORTH SOMERSET HEALTH AUTHORITIES'

Gypsy, Traveller, Boater, Showman and Roma Health Needs Study

### Thank you for taking Part



Thank you for taking part in this survey and for answering our questions. This leaflet has been produced to tell you why we've come to ask you questions about your life and what will be done with the answers.

It also provides the names and telephone numbers for people who may be able to provide you with help, whether that is local or national Gypsy, Traveller, Roma, Boater and Show People support groups or people within the local area who can provide information and advice.

In a nutshell, the survey has been designed for and by Gypsies, Travellers, Showmen, Boaters and, Roma to provide enough **FACTS** about you and your family/community health needs so that B&NES and North Somerset health authorities can start to provide you with the sort of health care that you want in the future. It's the first step in hopefully making sure you get the care you and your family need and in ensuring that people planning accommodation are also aware of how (and where) your community lives affects your health and wellbeing.

The survey is confidential. Your name will not be given to anyone else and the information you give can't be traced back to you.

We can let you know how to get hold of a summary copy of the report when it is finished and a full copy of the report will be available on with the health authorities if you want to be involved in future consultations.

request. We can also help you to get in contact

If you have any questions about what we are doing, or how the information that we ask for is going to be used, please get in touch with us. If you know of any other families who might like to speak to us, please let us know.

If you would like further information about this study please contact the research team who work for Buckinghamshire New University

Margaret Greenfields Tel: Removed

(before 6pm)

Sylvie Parkes Tel: Removed

Jackie Tel: 01494 603 029 Administrator at Buckinghamshire New University



#### **Useful Numbers and Contacts**

The following local Travellers and Boaters (who are members of the research team) are happy to be contacted if you need advice and support on accessing services – or just need to have a chat or get some information.

#### **Local Health Survey Contacts:**

Name and number removed.
Traveller – interviewing in B&NES
Name and number removed.
Traveller – interviewing in B&NES
Name and number removed.
Interviewing in B&NES
Name and number removed.
Gypsy – interviewing in North Somerset
Name and number removed.
Boat dweller – interviewing in B&NES
Name and number removed.
Boat dweller – interviewing in B&NES
Name and number removed.
Traveller – interviewing in B&NES

These LOCAL agencies/people can also be contacted for specialist advice and information:



NHS Health Central (Covers North Somerset and B&NES) Weston Super Mare 01934 627250

**Avon Traveller Education Service** 

West of England wide. Tel: 01454 862620

**Black Development Agency (Bristol)** – umbrella organisation and support for voluntary organisations. Tel: 0117 9396645

Citizens Advice Bureaux (North Somerset) Tel 01934 836201

**Children Society Travellers' Project** 

Tel: 01761 411771

**Gypsy & Traveller Co-ordination Team** 

(Bristol) Tel: 0117 9223371

**Kennet and Avon Boating Community** 

info@boatingcommunity.org.uk www.kandaboatingcommunity.org.uk

Tel: 07928 078208

Maggie Smith-Bendell (Member of the National Federation of Romany Gypsy Liaison Officers): 01458

North Somerset Council owned Sites and Advice

Tel: 01934 634959

North Somerset Hate Crime Officer: PC Marvin

Medley Tel: 01934 638225 B&NES Race Equality Council

Tel: 01225 787918

Race Forum (Bristol) 'the voice of Black and Other Minority Ethnic People in Bristol'

Tel: 0117 9222217

**Showmen Guild Western Office** 

Tel: 01454 228890

Somerset Race Equality Council (North Somerset)

Tel: 01934 414455

**Support Against Racist Incidents** (SARI) West of England wide. Tel: 0117 9420060

SWAN (South West Alliance of Nomads) Advice

Network - 0117 986 9732 or 01761 437176



Accommodation

Bath and North East Somerset Council Housing

Advice Tel: 01225 477000

North Somerset Housing Advice Team: Tel: 01934

426330

Home Choice Team (deals with the register and

waiting lists): Tel: 01934 426330

North Somerset Housing Advice and Homelessness team Tel: 01275 884080



**National Contacts:** 

**Calderdale Boaters** 

calderdaleboatclub@live.co.uk

**Cam Boaters** 

liveaboardboaterscam@gmail.com

**Derbyshire Gypsy Liaison Group** 

Tel: 01629 734805 or 01629 732744

**Facebook Group** 

www.facebook.com/groups/71446695351/

Friends, Families and Travellers Advice and

Information Unit Tel: 01273 234777

Gypsy Council for Education, Welfare and Civil

**Rights** Tel: 01708 868986

Gypsy and Traveller Drugs helpline (email only)

drugshelpline@uk49.fsnet.co.uk

**London Boaters** 

www.londonboaters.org

Low Impact Living On board

www.lilo.org.uk

National Bargee Travellers Association (NBTA) Tel:

07867 757095 Tel: 0118 321 4128 secretariat@bargee-traveller.org.uk

www.bargee-traveller.org.uk

**National Association of Boat Owners** 

south@nabo.org.uk www.nabo.org.uk

**National Romany Rights Association:** 

Tel: 01202 893228

**River Lee** 

**Residential Boat Owners Association** 

Richard Burchell Tel: 07810 671770

www.rboa.org.uk

**Roving Canal Traders** 

www.canaltraders.org.uk

Travellers Advice Team (legal advice)

Tel: 0845 120 2980 Tel: 0121 685 8595

Emergency Line 07768 316755

**The Gypsy Council** Tel: 07963 565952

The Irish Traveller Movement Britain (ITMB)

Tel: 0207 607 2002



#### Easy read information

### Gypsy, Traveller, Boater, Showman and Roma Health Study Winter 2012/2013 B&NES and North Somerset

Talk about your health experiences and needs to a trained interviewer from your own community. Help the local NHS get the information it needs to improve services.

Your name won't be given out to the health services and your name won't be in any report. Nobody will need to know you've spoken to us (It's confidential).

Find out more or call to be interviewed.

Name and number removed.

Traveller - interviewing in B&NES

Name and number removed.

Traveller - interviewing in B&NES

Name and number removed.

Interviewing in B&NES

Name and number removed.

Gypsy - interviewing in North Somerset

Name and number removed.

Boat dweller-interviewing in B&NES

Name and number removed.

Boat dweller-interviewing in B&NES

Name and number removed.

Traveller - interviewing in B&NES

### If you want to know more about this survey please call one of the research team who work for Buckinghamshire New University

Margaret Greenfields Tel: Number Removed

(before 6pm)

Sylvie Parkes Tel: Number Removed

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**Appendix D:** Topic Guides utilized in focus groups/one-to-one interviews (professional staff and service-users)

### FOCUS GROUP/INDIVIDUAL INTERVIEW TOPIC GUIDE SERVICE USERS

#### Name

Community Member e.g. GRT/Boater etc..

Thanks for taking part...

Explain that – this is a chance for community members to discuss how they access health care, any barriers which exist and how membership of their community (for example if they feel GRT people are more likely to have particular types of health condition) or their accommodation (for example on an unauthorized site or living in a house) impacts on their health. A chance too to let the NHS know what they can do to improve services for GRT people.

### We know that there are many more GRT people living in the area than health workers are in contact with

Do you think people are concerned about identifying themselves as being GRT people? Why?

Probe – differences/disguising identity if not living in a caravan/boat or on a site?

#### Access

Want to know how you and your family obtain health care - for example go to GP/clinic or hospital?

*Probe* – preferred service use or just what you can get? What makes a service good – e.g. GP who is familiar with Travellers? E.g. choose a surgery because other Travellers go there?

#### Service delivery/cultural outreach

Any particularly good health care you've experience in your local area e.g. outreach HV?

Or in other areas you'd like to see in your own locality?

What is a barrier to health care – e.g. highly mobile/eviction/refusal to attend on site?

Any particular services which are very good/culturally aware/accessible? E.g. midwives/HV/ambulance crew etc?

#### Worries/Bad Practice

Any areas of concern you are aware of? For example – children's health or how older people can access services/terminal care etc? Prejudice etc.

#### Recommendations/improved service delivery

What would improve your health care – for example if you are moving a lot? E.g. hand held records, text reminders etc?

Greenfields and Lowe – B&NES Traveller/Boater/Gypsy survey What (if any) health resources would you like to see made culturally specific – e.g. less writing/available on pod-casts/ pharmacist advice etc

What changes in attitudes or care are needed to reach out to GRT people?

#### **Health Promotion with GRT populations**

Any need for this?

Ideas?

What might help to ensure GRT people know more about particular conditions/ways of accessing care?

#### **Accommodation impacts**

Impact of living in a trailer/vehicle etc on health? – e.g. might have to move into housing if really ill? Or – if in a house and get ill – how does this impact – e.g. want to be on site with family etc?

#### Any need for specialist training of health staff?

If so what?

#### Anything else you want to tell us

Thanks – information on project background and how to ensure access to the report when completed.

#### D2 FOCUS GROUP/INDIVIDUAL INTERVIEW TOPIC GUIDE PROFESSIONALS

PROFESSIONALS

Name

Profession

Thanks...

Interested in exploring issues around how patients are identified in order to develop appropriate support:

#### Thoughts on the use of READ codes to identify GRT communities?

Probe: whether appropriate to use READ codes for this purpose (identification)?

If so or READ codes are used - are you able to identify this group within your practice - for example to assist us in analysis with themes such as immunisation uptake

# Do you think that there may be greater numbers of housed GRT populations in your area that you are in contact with?

If so do you have any idea of how it might be possible to contact/identify them for health promotion purposes?

#### Cultural variations in need amongst GRT populations

We are aware that some practitioners have identified that particular communities are more likely to have untreated conditions and/or substance/alcohol misuse issues.

Do you have any experience of such health variations across the different GRT populations?

Probe – why do you think that is?

# Any particular challenges that you have encountered consistently – for example 'fixed health beliefs' – how does this impact on appropriate treatment/patient access to services?

Do you feel that there is a need for culturally specific health resources?

If so - what sort of changes do we need to make to ensure these are appropriate/accessible?

Interested in exploring your thoughts on how health care services could be delivered differently - to meet the increased health needs in the areas of smoking, alcohol misuse, substance use, anxiety, domestic violence, injuries, screening, and immunisation uptake

Greenfields and Lowe – B&NES Traveller/Boater/Gypsy survey
If you are aware of special measures/services, what (in your experience) works well, what doesn't?

#### **Health Promotion with GRT populations**

Do you feel that that is any scope for use of texting/social media for reminders re check-ups; medication use, health messaging etc?

Any specific thoughts on ways of working with particular communities? (by ethnicity) or knowledge of good practice examples from other areas/translational research you might like to see in your locality?

#### **Service Delivery**

If specialist HVs exist in your area or were to be appointed - how best do you think this services could be promoted?

Any other thoughts on how to improve continuity of care for patients with high mobility? Probe: boaters?

*Probe:* any scope for cross-boundary working with other colleagues to ensure cost-effective and culturally appropriate service delivery or continuity of care??

#### Considering the scope for hand-held records:

How could hand held records work in practice - what level of detail to include/what format? – any concerns?

#### Awareness Training for Staff (and service users)

Do you feel there is a need for additional cultural awareness training?

In terms of awareness training - what would you like to see included in the training?

How could we improve attendance amongst staff?

Is there a need for training/specialist advice sessions for GRT populations? – if so – how to deliver and what might be needed?

#### Any other issues you wish to raise?

Thanks – information on project background and how to ensure access to the report when completed.