SUBMISSION FROM EDINBURGH ACCESS PRACTICE

GYPSY & TRAVELLER NHS LOTHIAN SERVICE AND ‘UNMET NEEDS’

Executive summary

- Gypsy & Travellers (G&T) across NHS Lothian (NHSL) are a transient population of variable, unpredictable and perhaps inaccurate numbers. They are based on both local authority (LA) and roadside encampments and are highly mobile as local and national figures indicate.

- Evidence strongly indicates a high level of longer-term lifestyle risks, comparable to G&T populations in other areas, and incomplete concordance with follow-up for long-term conditions.

- There is a consistently stated tendency (as with outside NHSL) of G&T to use emergency care settings for routine healthcare needs.

- There appears sporadic self-initiated engagement with local services, but as a local population, they are usually <40yrs old (especially on roadsides).

- They report difficulty in accessing and maintaining follow-up with healthcare services and request a wide variety of health inputs when encountered on sites.

- Identification of both a local and geographically wider network of resources to follow-up and support identified healthcare needs for the range of ages may undoubtedly be hugely beneficial, perhaps through a nationally (rather than locally) governed service.

- From local findings, their main ‘unmet needs’ across NHSL appear to be: regular engagement at, and support for, ‘point of need’ requests from G&T of all ages at both types of site (particularly roadside), and supporting access and maintaining individuals’ engagement with local healthcare services.

- Acute and repeat prescription supply including those for long-term conditions appears lacking, and culturally appropriate mental health and substance misuse support, assessment and intensive follow-on support for lifestyle risks for those of all ages but especially <35yrs.

- There is no resourced Health Visitor capacity for engagement with G&T in Edinburgh City, East or Midlothian and that within West Lothian (which is perhaps not formally resourced) is used sporadically only.
• Establishing and maintaining trusting relationships with individuals and families is the most vital aspect of healthcare delivery for G&T, though requires consistent resources (people and time) and a flexible and responsive approach.

• Local evidence has highlighted the benefits of a dedicated service approach in both demonstrably improved clinical outcomes (and anticipated longer-term resource savings) and very positive qualitative service user feedback from what is a widely unengaged group. Ideally capacity would be identified in NHSL or nationally to continue and develop this work for G&T of all ages using this model, followed by detailed planning of the model and scope (and base) of the service.

• The G & T population’s health would remain at risk as summarized if they were expected to depend solely on mainstream services. There is a need to respond to, assess and triage the range of health problems identified by G&T of all ages on unauthorized encampments and on ‘their turf’. Without the support of a dedicated service which can provide a model of good practice we will fail to ensure the inequalities experienced by G & Ts whether on the roadsides or on dedicated sites are addressed.

• It should be emphasized that a G&T service locally could not operate without strong partnership working, with links to Lothian & Borders Police, the LA site managers, education and the voluntary sector (e.g. Shelter) being the most important to date. Using the model, as in Keep Well, of having a named individual with sufficient autonomy to respond appropriately and flexibly has demonstrated effective and productive working links.

• Anticipated annual cost of a dedicated service would be (for a part-time 0.6 WTE service comprising 0.6 WTE Band 6 Nurse and 0.5 WTE Band 3 Support Worker) estimated at £38,341 inclusive of travel expenses of estimated 100 miles/wk. The suggested base is the Edinburgh Access Practice with a Lothian-wide remit.

• The annual estimated caseload in terms of individuals is around 300 individuals, the majority of whom will require multiple encounters and interventions

• The service would proactively respond to all notifications of roadside encampments to triage and deal with all identified health issues and maintain links with those on both LA sites across Lothian. It would also engage and support the local Roma community in the same way but also support access to primary care services. At all settings the service would provide ‘point of need’ care, anticipatory care including tracking and follow-up as able locally, long-term conditions management and act as a
bridge to primary care as needed on an individual basis.

- Expanding this suggested simple model to work strategically across a number of health boards to create a ‘mapped network’ for the follow-up of individuals would require 1 WTE B6 Nurse instead of 0.6 and 0.6 WTE B3 instead of 0.5, with estimated total costs including travel expenses of £61,719. It would be suggested that the excess cost compared to the local simple model be sourced via national funds rather than local to reflect the wider geographical remit.

Introduction & purpose of paper

The purpose of this paper is to address a question posed by the NHSL Health Inequalities team, and the Lothian G&T Health Steering Group. Namely, to consider the future healthcare needs of the local G&T population as a whole, and, based on local and wider findings and evidence, to raise the question of how capacity in NHSL may accommodate the evolving clinical findings, and therefore needs, in this group.

In doing this, the paper will cover the following areas:

- Describing the local G&T populations
- Describing current and previous issues regarding access to healthcare provision for this community from the literature and available evidence
- Providing small-scale feedback from the local G&T community as to their preferences for healthcare input (i.e. what has worked? Why would it be an acceptable form of healthcare and what are their perceived needs?)
- Outlining perceptions from other local professionals working with G&T regarding features of an effective and appropriate service
- Describing features of a proposed appropriate local G&T service, which would provide a model of practice

The intention is to revisit and build upon the previous report of the Keep Well team (Lambie 2010) which presented the findings and insights gained by the team for those only in the (Keep Well) 35-64yr old age group of local G&T, and the rough suggestions made therein for consideration of a longer-term service for the wider G&T population. However, the aim is now to more fully describe the healthcare issues, points regarding access and how this might inform service provision.
History of NHSL input into G&T community

Lothian has a history of involvement in the G&T community evidenced back at least to the 1980s, with descriptions and reports of local service such as Save The Children (Michelle Lloyd) highlighting areas of health promotion and concerns over linking environment with ill-health and a concentration on female, child and baby health (Smart, Titterton & Clark 2003).

West Lothian has since 1992 had a named Health Visitor with allocated hours for G&T on LA sites and the roadside. This post still exists with reported full backing of local community nursing management, while the dedicated time commitment has varied over time but has approximated to around 7.5 hours weekly, both currently and historically. The worker was able to work flexibly to ensure provision of a responsive service, mainly to women and children, and was linked to one local GP Practice. There has been a strategic contribution element in this capacity, including involvement in the Scottish Parliament Participation Event and being part of the working group with the National Resource Centre for Ethnic Minority Health (NRCEMH) to develop The Patient Record of Personal Health. Following its completion, the worker was the main Health Visitor facilitator that delivered the G&T awareness Raising Seminars around Scotland with members of a team including Save the Children and members of the G&T community.

In mid 2000 NHSL further funded a full-time Health Visitor post to cover Edinburgh, East and Midlothian. Following the post-holder’s departure in 2004 the post became part-time and was based in Midlothian, though encompassing an additional Edinburgh and East Lothian remit. Because of competing demands on the post holders time this subsequently became limited to G&T in Midlothian, though from 2009 the hours for G&T were withdrawn altogether, hence this dedicated capacity dissolved.

In Edinburgh a lead Health Visitor for G&T was previously identified in each LHP but without resourced capacity. This model has received criticism around its effectiveness, on the grounds it has lacked co-ordination by a central person who is able to liaise with the other public sector partners and site managers to respond quickly to issues for people in roadside encampments. The model had been believed, however, to work more effectively in East and Midlothian where there was a named health visitor, though recent attempts to obtain advice for transient roadside G&T have emphatically not found this to be the case. Since 2009 a dedicated Keep Well service for G & T (based in the Access Practice, Edinburgh CHP) has also had capacity to engage with and provide assessment and support for adults >35yrs with a focus on reducing cardiovascular disease risks for individuals.

The NHSL G&T Health Steering group has provided strategic direction to this work and liaised with other key providers in Lothian to join up work with other public sector organizations and the voluntary sector. It continues to meet
quarterly, its members including the West Lothian Health Visitor, a GP from the Edinburgh Access Practice, representatives from Child Health, the Hospital Outreach Teaching Service, the voluntary sector (Shelter), education and the Health Protection Team, also currently Keep Well representation. Historically, through this forum, direct referral to maternity, women’s health service and dentistry were negotiated, for example, thus reducing the need to wait for temporary registration with a GP. Involvement of G&T on the Steering group has been welcomed and sporadic but has not been sustained on a regular basis. In terms of user involvement, the Keep Well team have involved G&T in their current service and in seeking their views for the future, for example a ‘Health promotion preferences’ questionnaire (2010, 25 responses).

The local G&T community in NHSL

Taken as a whole, Lothian (in the last available figures, Scottish Government 2009) has the fifth highest figures in Scotland of total numbers of G&T households (n=47) (box 1).

**Top 5 regions in Scotland for G&T populations (last available count 2008)**

1. South Lanarkshire (99 households)
2. Fife (95 )
3. Highland (70)
4. Perth & Kinross (55)
5. Lothian (47)

*Box 1. Breakdown of most densely populated G&T areas in Scotland (taken from Scottish Government 2009)*

The majority of these are resident on local authority (LA) sites, with each Lothian area having being also noticeably variable in the period 2005-2009 for unauthorized (‘roadside’) camps (Table 1). However, twice-yearly Scottish caravan counts, on which these figures are based, are limited to numbers of trailers on local authority and unauthorised sites on particular days, hence methods are flawed regards individuals (assumption one trailer = one household). Within the community, it is believed that the figure is 2-3 times higher than counts may suggest (Britain et al 2010 cited in Mitchel 2011). Further, it is usual for between 10-50% of LA site occupants to be absent from sites in the months leading to, and including, the count time periods ([http://www.scotland.gov.uk/Publications/2009/03/30145009/5](http://www.scotland.gov.uk/Publications/2009/03/30145009/5), section 3.2). Meanwhile, the North Cairntow site (below) records a higher than average percentage of tenants (>50%) off-site for ‘permitted periods’ (Scottish
Government 2009). Hence, there appears to be uncertainty regards numbers of individuals and a strong seasonal variation, creating a challenge for planning of health service delivery. Also, reasons for, and direction of, travelling may be unknown and could further inform health service planning. Attempts via Keep Well have recently been made to ascertain individuals’ patterns and travelling direction, but were ultimately fruitless as this information was not easily shared or known by G&T themselves.

Currently, two LA sites exist in Lothian: North Cairntow in Edinburgh (EH16) and Old Dalkeith Colliery in Midlothian (EH22), latest occupancy figures for which are summarized (Table 1). A third, outside Bathgate, closed in 2009 following a troubled period characterized by local unrest and bullying (personal communication from existing Lothian site managers). Prior to closure, its occupancy rates were <30%, supporting an occupancy variation across Lothian’s LA sites (compare occupancy figures in Table 1).

<table>
<thead>
<tr>
<th>Site</th>
<th>No. of pitches</th>
<th>Total let</th>
<th>Total let &amp; occupied</th>
<th>Let but with tenant absent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Edinburgh (North Cairntow)</td>
<td>20</td>
<td>85%</td>
<td>85%</td>
<td>0%</td>
</tr>
<tr>
<td>East/Midlothian site (ODC)</td>
<td>20</td>
<td>45%</td>
<td>30%</td>
<td>15%</td>
</tr>
</tbody>
</table>

Table 1. Occupancy rates for Lothian LA sites, July 2009

Age distribution for Lothian sites is roughly specified in Scottish Government (SG) figures (table 2), though crucially no breakdown of those aged 20-59yrs exists.

<table>
<thead>
<tr>
<th>Site</th>
<th>Total no.</th>
<th>Age &lt;5yrs</th>
<th>5-11yrs</th>
<th>12-15yrs</th>
<th>16-19yrs</th>
<th>20-59yrs</th>
<th>&gt;60yrs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Old Dalkeith Colliery</td>
<td>43</td>
<td>14%</td>
<td>14%</td>
<td>16%</td>
<td>9%</td>
<td>44%</td>
<td>2%</td>
</tr>
<tr>
<td>North Cairntow</td>
<td>44</td>
<td>7%</td>
<td>32%</td>
<td>16%</td>
<td>5%</td>
<td>36%</td>
<td>5%</td>
</tr>
<tr>
<td>West Lothian</td>
<td>30</td>
<td>23%</td>
<td>13%</td>
<td>10%</td>
<td>3%</td>
<td>50%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Table 2. Age distribution of those on LA Lothian sites, July 2009

Keep Well data (most adults on both LA sites from 2010) identified that amongst those in the remaining LA sites, many report registration with a local GP, with
Craigmillar, Dalkeith & Durham Road practices being the most prevalent. G&T attendance (and non-attendance) for these practice appointments has not been identified, and would doubtless provide clarity over individuals’ engagement with these practices. Many registered spoke highly, however, of their practice (particularly Craigmillar, whose staff also describe Cairntow residents with noticeable familiarity). Of those with a long-term condition however on these sites (n=10), only one was actively attending follow-up (at a hospital clinic, none at their GP practice), while all of the 5 interviewed for evaluation stated they wouldn’t have accepted a practice invitation to attend Keep Well (Mitchell 2011).

‘Unauthorised’ encampments in Lothian show a variable pattern (Table 3), with a higher concentration in West Lothian. However, potential inaccuracy should be considered given the count methods, particularly regarding duplication or omission. Otherwise, data on these is difficult to obtain and variable by authority. It is noted locally that despite many G&T on unauthorized sites possessing Irish accents, their geographic origins are unknown. From the Scottish Government updates (latest 2009), main features to consider related to Lothian would be:

- A general Scotland-wide trend for year-on-year increase in unauthorised encampments
- Tendency for increased frequency of these in summer
- Some sites are long-established ‘stopping places’, however, they may be remote and as such, not reported to local authorities or police
- Different occupancy periods on sites: usually more than one week but enforcement processes are variable
- Tracing travel patterns is challenging: unspecific reports of individuals’ origins and changeable intentions to move on noted by Keep Well team

<table>
<thead>
<tr>
<th>Area</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Edinburgh</td>
<td>10</td>
<td>0</td>
<td>21</td>
<td>4</td>
<td>14</td>
<td>49</td>
</tr>
<tr>
<td>East/Midlothian</td>
<td>10</td>
<td>6</td>
<td>21</td>
<td>5</td>
<td>0</td>
<td>42</td>
</tr>
<tr>
<td>West Lothian</td>
<td>5</td>
<td>79</td>
<td>21</td>
<td>14</td>
<td>20</td>
<td>139</td>
</tr>
</tbody>
</table>

Table 3. Trend 2005-2009 of ‘unauthorised’ encampments across Lothian

Additionally, since 2009 a concentration of Roma Gypsies has been particularly evident in Pilton and Portobello, though of unknown numbers and transitory to some extent. Many have registered, and attempted to register, at Muirhouse, Crewe and Portobello surgeries. Over half of The Big Issue’s 120 vendors in July 2011 were Roma Gypsy (personal communication, Edinburgh Big Issue co-
ordinator). Around 40-50 Roma individuals had difficulties registering at a Lothian GP practice (again personal communication, Edinburgh Big Issue co-ordinator) though good practice has clearly been evidenced by successful registrations, notably in Portobello and Crewe practices.

There appears currently to be only 10 G&T registered on Edinburgh's housing register - EdIndex. This represents 0.04% of the total number of applicants registered (currently standing at 25,616). Between 1/4/2010 to 31/3/2011 four of the 3207 tenancies across the City by all Social Register Landlords and the CEC allocated were allocated to G&T. As with all self selecting monitoring data there is uncertainty that these records accurately reflect the applicants identity - the G&T community appears particularly unwilling to identify themselves as such in case they face discrimination (Van Cleemput et al 2006, Papadopoulos & Lay 2007, Scottish Executive 2004). Therefore, incidence of housed G&T in Lothian is essentially unknown.

**Summary of background evidence of G&T and health issues**

There are evidently no Lothian or Scottish data around incidence or prevalence of health conditions or lifestyle factors relating to G&T, other than service data such as that from Keep Well (Lambie 2010). Similarly, there is no local research, only service reports and literature reviews (Smart, Titterton & Clark 2003) which in themselves had only highlighted the limitations and non-transferability of local literature. Most helpful data originates from Ireland, with further recent robust multi-methods English research on health beliefs (Van Cleemput et al 2007), mental health (Goward et al 2006) and health promotion (Papadopoulos and Lay 2007), amongst others. ‘Grey literature’ overwhelmingly suggests a predominant historical concern to tailor G&T health inputs to women and children only, despite a highlighted gap in the evidence around men’s and mental health (South West Public Health Organisation 2002, Papadopoulos and Lay 2007).

Parry et al (2007) tested the hypothesis that the health inequalities experienced by G&T were greater than those amongst non-G&T expected purely on the grounds of disadvantage or ethnicity. Matching a G&T cohort with those of a white deprived socio-economic group and ethnic (Muslim & Black African) groups of mixed socio-economic status, outcomes were worse (p= <0.005) for G&T including poorer overall and limiting ill-health, as well as disability, self-care problems and anxiety.

Meanwhile, the clearest evidence for providing long-term conditions care and cardiovascular risk screening and support (as in the Keep Well model) is Irish and English data. Heart disease and stroke report the most prevalent mortality rates in G&T via General Register Office and reported death figures (Department of Health Ireland 2010). Self-reported rates of prior MI, angina & diabetes are about quadruple those of background Irish populations (Galway Traveller Movement 2009), while elsewhere diagnosed myocardial infarction and angina
rates are roughly double that of background population, likewise risks of hypertension and high cholesterol (Department of Health Ireland 2010). The main challenge however in providing on-going care for acute problems and long-term conditions is partly illustrated by travelling patterns, (quotation locally from a 20yr old female G&T individual: ‘you know what Travellers are like, they change their minds like the wind’) although access to health services (frequently identified as a barrier by G&T) appears complex: G&T expectation of racism and prejudice underlie interaction with health-care staff (Parry et al 2007) and has been perceived as being behind refusal of registration at GP practices (Health Scotland 2004), although prevalence of denial of registration is unknown and arguably misunderstood to a point.

Evidence such as half of G&T individuals on regular medication having difficulties with concordance due to literacy difficulties (Galway Traveller Movement 2009) illustrates in action these complex issues of responsibility around health-care delivery. A perception that travelling conditions contribute to both positive health impacts (freedom, choice, ‘fresh air’) and negative (wet and damp directly causing arthritis and chest complaints) predominates (Van Cleemput et al 2007), but travelling itself dictates individuals’ outlook on all aspects of life. No practical concerns could potentially influence this urge, the only possible exception being the need to earn money, although there appears increasing G&T recognition that travelling, either chosen or enforced, compromises follow-up healthcare needs (Jesper et al 2008).

Other evidence findings around G&T and healthcare are:

- Fatalism but also fear of death, especially from ‘uncontrollable’ conditions (Van Cleemput et al 2007)
- Perception of personal health status: confirmed diagnoses not perceived as serious, symptoms tolerated as long as daily activities continue (Van Cleemput et al 2007)
- Genuine surprise from G&T that their health compares unfavourably to other ethnic and deprived groups (Van Cleemput et al 2007) yet a recognition that culturally a tendency to die young exists (Papadopoulos and Lay 2007)

Local findings and feedback

Local G&T feedback largely originates from two sources: Keep Well evaluation (Mitchell 2011) and Keep Well’s Health Promotion preferences questionnaire (Lambie 2010). The main findings from evaluation (5 G&T in-depth interviews in May-July 2011, triangulated with clinical data) were:

- Initial uncertainty about why a ‘dedicated’ service was approaching them, particularly in a climate of cuts, with initial mistrust until they met and spoke with the team. However, this is in context of general suspicion of health services. Some scepticism mentioned as remaining within the larger community (e.g. relatives) about the preventive approach. However,
an appreciation of a respectful approach that allowed them to maintain their cultural practices

- General appreciation of ‘relaxed, friendly service’ that came to them. A support service that through G&T perception could not be located in a GP surgery
- Gaining trust is of over-riding importance
- G&T were less open in discussion about lifestyle changes unless they were linked to a health condition e.g. high blood pressure. Changes made were then seen as having life-changing importance. However, they had to have the knowledge before they would contemplate a change
- Service viewed pragmatically as physical health-related: learning about healthy lifestyle and receiving diagnoses were both valuable for them. Benefits received related to specific health problems and tackling of diseases...support after this much more likely to come from within their community

Quotations to illustrate:

- ‘a life-line for Travellers…it’s reaching people who need health services who can’t get to them’ (41 yr old male G&T)
- ‘the nurse knows the whole family..that’s really important because we can trust them...not just a nurse, but a friend...they actually spoke to us like human beings’ (39 & 48yr old female G&T)
- ‘if we’ve not got addresses we can’t register with GPs. Sometimes we try to register as temporary residents but when they hear we’re Travellers they refuse, and we have to go to A&E instead’ (41 yr old male G&T)
- ‘us type of people, us Travelling people, we like to do things on our own, we like to be a wee bit privater’ (48yr old female G&T)
- ‘it’s a really good thing, yeah: some Travellers is ignorant of their health, they don’t bother and if they get any twinges it could be serious...so when x checks them out it helps them..I think you’re better knowing aren’t you? You can prevent anything happening to you and you can make a change to make it better’ (47yr old female G&T)
- ‘I think that for somebody to come in here into my home and take five minutes of our time to kind of save your life basically, do you know what I mean?’ (48yr old female G&T)

Clinical findings from NHSL Keep Well are based on adults >35yrs, though data from those <35yrs with a positive family link to premature cardiovascular disease (CVD) were previously included. These are updated from December 2010 and comprise data in an equal split from those on LA and unauthorized sites, with a 54% male, 46% female breakdown.

The latest update figures are from May 2011 (appendix 2) and detail distribution of ASSIGN cardiovascular risk scores among the G&T. Noted also are the reductions in absolute CVD risk for a number following lifestyle interventions: up
to 33%. The 14% at high risk (ASSIGN score > 20%) compares to 16% of whole Lothian population with ASSIGN > 20% (personal communication from Ciara Byrne, KW project manager, also McLean, Mackenzie & O'Donnell 2011), though caution is suggested with the comparison, given low G&T numbers (<100, compared with NHSL Keep Well data based on > 9,000) (McLean, Mackenzie & O'Donnell 2011) and the relatively young age of G&T, where ASSIGN risk increases substantially with age. Meanwhile, the contribution of Metabolic Syndrome towards cardiovascular risk (prevalence in local G&T, 45-51%, appendix 3) is almost equivalent to full diabetes (Scottish Intercollegiate Guidelines Network 2007), and local incidence is comparable to evidence elsewhere (Tan et al 2009, Slattery et al 2010). Without intervention, this progresses to Type 2 diabetes within 2-5 years, though evidence shows reduction in terms of risk if targeted (Grundy et al 2005). Given the high likelihood that G&T with Metabolic Syndrome may miss subsequent interventions either by chosen or enforced travelling (Jesper et al 2008) and locally, those affected have required intensive support to address these risks, furthermore that 52% of those with Type 2 diabetes will die of CVD (Diabetes UK 2010), the potential risk for CVD via these states alone appears noteworthy independent of ASSIGN score. The success locally in reducing absolute risk via interventions may suggest potential for further risk reduction if such interventions can continue.

In the absence of local practice data regarding trends of attendance versus missed appointments, Keep Well data from Edinburgh Access Practice indicates in four case studies (Appendix 3) general patterns and interventions undertaken to encourage attendance at planned appointments (e.g. for review). This illustrates that positive attendance outcomes require interventions of chasing-up, phoning and prompting, suggesting caseload management requires dedicated time. The widely-discussed hand-held records were initially intended for widespread use, but have yet had no evaluation and they are not noted recently to have been used locally with any consistency.

**Current NHSL service provision**

Apart from fixed-term funded Keep Well (currently 3.75- 7.5 hours weekly divided in to one to two half-days) and dedicated Health Visitor hours in West Lothian (approximating 7.5 hours weekly) there is currently no dedicated funding or capacity for work with G&T in Lothian, including clinical and development work such as cultural awareness training of staff.

Currently, Keep Well G&T capacity is funded until March 2012 as above deploying two staff (to accommodate local lone working guidelines) with a Lothian-wide remit. Presence of new unauthorized sites and new individuals on LA sites are communicated to a nominated individual in the Keep Well team via strong links with police, site managers and voluntary sector. The aim is to ensure no potential >35yrs individuals would arrive in Lothian and not be seen. The priority is engaging new G&T adults aged >35yrs for CVD risk screening, and the
plans post-March 2012 for G&T as a vulnerable population remain to be defined. Personal strong belief is that a dedicated G&T service needs to be established pre-March 2012 who could coincidentally deliver Keep Well rather than perpetuate the existing model of fitting unmet needs round the anticipatory care requirements, with staff currently struggling to raise capacity to accommodate the unmet needs, which are clearly out-with the Keep Well remit, and variable time-wise.

Service level agreement with the Edinburgh Access Practice (till March 2012) stipulates that G&T in the Keep Well criteria (>35yrs) with follow-up needs (including prescribing) but without a GP may be accommodated there providing individuals have eligibility. Engagement of new G&T in the age range is variable as most ‘new incoming’ G&T are <35yrs, hence, in the available capacity, follow-up processes also occur in line with general Keep Well planning to review and support those already having had an assessment, depending on their level of CVD risk. These are currently up to date as capacity has been used. Similar to the detail of interventions made out-with the Keep well remit within the previous report, support for miscellaneous problems continues, mainly at unauthorized sites. A summary of recent requests made to the Keep Well team for support out-with the age range is below (Table 3).

<table>
<thead>
<tr>
<th>More frequent requests (&gt; half of visits to sites)</th>
<th>Less frequent requests (&lt; half of visits to sites)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Weight management advice (mostly &lt;30yrs)</td>
<td>• Advice re injury</td>
</tr>
<tr>
<td>• Contraception/family planning advice</td>
<td>• Advice re children’s routine immunizations</td>
</tr>
<tr>
<td>• Blood Pressure check and advice (&lt;30yrs)</td>
<td>• Alcohol support</td>
</tr>
<tr>
<td>• Access to midwifery support</td>
<td>• Support to access secondary care services</td>
</tr>
<tr>
<td>• Support in accessing GP (repeat script or acute problem)</td>
<td>• Advice re musculoskeletal problems</td>
</tr>
<tr>
<td>• Support in accessing dentist</td>
<td>• Advice re potential testing for blood borne viruses and risks re substance misuse</td>
</tr>
<tr>
<td>• Support for ‘nerves’ (= mental health and wellbeing)</td>
<td>• Smoking cessation advice</td>
</tr>
</tbody>
</table>

Table 3. Requests for interventions and support ‘out-with Keep Well’ remit (<35yrs) since January 2010

It should be emphasized that a G&T service locally could not operate without strong partnership working, with links to Lothian & Borders Police, the LA site managers, education and the voluntary sector (e.g. Shelter) being the most
important to date. Using the model, as in Keep Well, of having a named individual with sufficient autonomy and capacity to respond appropriately and flexibly has demonstrated effective and productive working links.

**Perception of ‘unmet needs’ summary (from colleagues within Lothian working with G&T)**

A questionnaire (appendix 4) was sent to three non-NHSL colleagues using purposely open questions regarding their perceptions of G&T health needs, barriers to access and interventions which they felt would improve longer-term G&T individuals’ health. Those chosen were a Shelter support worker who has dedicated weekly time for G&T work in Edinburgh and East Lothian, a manager of an LA site and a teacher with dedicated G&T time in Midlothian. These were chosen partly by convenience and in the absence of clear feedback from healthcare workers within NHSL who had previously undertaken G&T work. The emphasis was placed on the degree of involvement these people had with G&T both by time and intensity and their perception of health needs, with no bias on how they should be met, as they had no healthcare backgrounds.

The results (appendix 5) appear to recommend an ‘outreach’ service that visits sites, as well as establishing and maintaining trust, as mentioned above. The voluntary worker (respondent b)’s comment regarding mental health support is interesting, as also are the taboo subjects. The perception of adverse lifestyle risks and need to meet this appropriately appears to tally both with the G&T feedback about health promotion (Lambie 2010) and the clinical findings, especially regarding weight and smoking.

**The wider picture: summary of G&T services out-with NHSL**

A number of dedicated G&T services, both fixed-term and permanent, have existed in the UK, but more prominently in Ireland. Discussion of these is out-with this paper’s scope, however the model of visiting sites appears common (‘Pavee Point’, Galway Traveller Movement, both Ireland) and a balance between clinical delivery on-site and supporting access to primary care. Fixed-term projects with a CVD focus similar to Keep Well have occurred, notably in Wales (Welsh Assembly Government 2008) with ‘Redressing the Balance’, whose findings regarding weight and cholesterol in particular resonate with Keep Well’s.

**Suggested model of delivery for a dedicated local service**

The estimated caseload numbers annually for clinical interventions are based on extrapolation of figures but could potentially be higher or lower, as they are based on historical data in the absence of prospective numbers. They are based on annually 100-150 individuals across both LA sites, 100-150 individuals on roadside encampments and 50 Roma individuals, giving a total of around 300
individuals of all ages. Based on local Keep Well and health visiting experience, variable but numerous encounters will be required for most individuals.

Local community nursing lone working policies and inter-professional best practice suggest use of two individuals for most G&T work, especially with roadside encampments, hence the service is costlier than a single worker model. However, the model of developing a Band 3 Clinical Support Worker is clearly more cost-effective than using a second registered nurse. There are also numerous precedents for this role (with existing job descriptions and KSF post outlines) clinically both locally and elsewhere. Use would be made of existing services, for example GP practices, central midwifery booking and the Access Practice to signpost into as individually required.

The Band 6 Nursing role is based upon the EAP Practice Nurse, local generic Community Nurse Band 6 and Nurse Case Manager (Keep Well) job descriptions and KSF post outlines which are at this level.

Costs as stated in the executive summary are based upon the top of Bands 6 and 3, inclusive of on-costs of 22.5%, annual miscellaneous £4,000 (stationary, equipment maintenance etc) and separate travel expenses based upon an (over) estimation of 100 miles/week (over-estimated from average Keep Well mileage pan-Lothian).

As a minimum it is suggested that a 0.6 WTE service is developed, given the trend numbers-wise. However, the option of developing and formalizing a geographically wider network to ensure tracking and follow-up for those who have these specific needs is strongly suggested as a necessary strategic piece of work, but the excess cost being sought out-with NHSL, perhaps from national funds given the cross health-boards boundaries of this work.

**Conclusion and implications for future service delivery**

The transient nature of G&T and the varied nature of their healthcare needs perhaps raises the question as to who has responsibility for assessing and meeting identified needs, and at what point (and where) resource savings may be made by improving longer-term G&T health meantime. Regarding CVD, for example, it is difficult to quantify for individuals the cost savings by measured risk reduction, as recent attempts have focused on relative rather than absolute risk, and on whole populations rather than individuals. However, local evidence has indicated both measurable success via clinical outcomes and approach. Feedback from G&T and other professionals who deliver a service to G&T also appears concordant with evidence from elsewhere and available research. The main recommendations in terms of the approach and what should be included in an effective G&T local service are:
Ability to respond to, assess and triage range of health problems identified by G&T of all ages on unauthorized encampments, on ‘their turf’

In doing so, assist temporary registration at a local GP practice or other identified ‘hub’, with signposting onto interim support services for sexual health, mental health or other (NHS24 for example)

Continue to have a dedicated link person for both LA sites within NHSL for all ages to maintain and develop the trusting relationships built up by Health Visitors and Keep Well with the community and family, but with skills to support a range of longer-term interventions, however to act also as a liaison back towards primary care services. Ensure there is a dedicated liaison HV in each CHP with two in Edinburgh.

Identify as able for individuals with acute or monitoring needs their direction of onward travel and refer on appropriately to a responsive service in that area who can support the ongoing needs, which will require wider and co-ordinated development work, perhaps across a defined geographical area and involving other health boards.

James Lambie
Practice Nurse
Edinburgh Access Practice
23 May 2012
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Papadopoulos I, Lay M (2007) The health promotion needs and preferences of Gypsy Travellers in Wales Diversity in Health & Social Care (4) 167-76
Smart H, Titterton M, Clark C (2003) A literature review of the health of Gypsy/Traveller families in Scotland: the challenges for health promotion, Health Education, 103(3) 156 - 165A
Stanley W (1997) The road less travelled Nursing Times 93(43)16
## Appendix 1

**Age distribution of residents on remaining Lothian sites, July 2008 figures**

<table>
<thead>
<tr>
<th>Site</th>
<th>Total number</th>
<th>&lt;5yrs</th>
<th>5-11yrs</th>
<th>12-15 yrs</th>
<th>16-19yrs</th>
<th>20-59yrs</th>
<th>60yrs+</th>
</tr>
</thead>
<tbody>
<tr>
<td>North Cairntow</td>
<td>54</td>
<td>4%</td>
<td>22%</td>
<td>20%</td>
<td>6%</td>
<td>44%</td>
<td>4%</td>
</tr>
<tr>
<td>Old Dalkeith Colliery</td>
<td>25</td>
<td>24%</td>
<td>16%</td>
<td>8%</td>
<td>4%</td>
<td>44%</td>
<td>4%</td>
</tr>
</tbody>
</table>

*(adapted from Scottish Government 2009)*
Keep Well G&T clinical update, May 2011 (NB: more activity has occurred since this)

1. Total seen to date:
   - 128 adults for Keep Well assessments
   - 48 individuals seen out-with the age range for non-Keep Well interventions
   - 7 Keep Well checks done for those <35yrs but with a 1st degree relative having had premature CVD onset <55yrs

2. New diagnoses in total:
   - 58yr old man with new Type 2 Diabetes
   - 13 adults managed locally for initiation of cardiovascular disease (CVD) Primary Prevention therapy as ASSIGN score >20% (statin, many also referred on for BP medication also)

3. 96 adults out of 128 have complete data allowing either calculation for ASSIGN CVD risk score or assessment of possible Metabolic Syndrome (excludes those with prior known diagnosis of DM or CVD, or new diagnosis via Keep Well input, hence numbers lower than total of those seen).

<table>
<thead>
<tr>
<th>ASSIGN score band</th>
<th>G&amp;T seen by KW team</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;10% ('Low risk')</td>
<td>41/96 (43%)</td>
</tr>
<tr>
<td>10-20% ('Intermediate risk’)</td>
<td>35/96 (36%)</td>
</tr>
<tr>
<td>&gt; 20% ('High risk’)</td>
<td>13/96 (14%)</td>
</tr>
</tbody>
</table>

- Metabolic Syndrome is defined (consensus opinion, SIGN 97) as three or more of the following: increased waist circumference (‘in the red’), elevated Triglycerides, low HDL Cholesterol, elevated BP or on treatment for BP and elevated fasting glucose (e.g. IGT/IFG). The guidance does not specify that Triglycerides must be fasted. The CVD risk of those who meet criteria for Metabolic Syndrome is almost identical to those with Diabetes, and it will develop into Type 2 Diabetes unless the risk factors are addressed. Best practice states those with Metabolic Syndrome should be identified and followed up to prevent risks escalating.
- G&T Females seen: 14/31 with all available data to help diagnose Met Syn (45%) met the criteria for Metabolic Syndrome.

- G&T Males seen: 22/43 with all available data to help diagnose Met Syn (51%) met the criteria for Metabolic Syndrome (over half!)

- Many more than this also met two out of three criteria (e.g. elevated BP & waist circumference only) so these individual risks are also important

4. Re-assessments undertaken so far of those on sites at North Cairntow & Whitecraig. These were repeated after agreeing with individuals to repeat after a period of time and after a range of lifestyle interventions. No other re-assessments other than these have been undertaken to date.

<table>
<thead>
<tr>
<th>Description</th>
<th>1st assessment</th>
<th>2nd review assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>38yr old female</td>
<td>ASSIGN score 11% Feb 2010</td>
<td>ASSIGN score 7% November 2010</td>
</tr>
<tr>
<td>42yr old male</td>
<td>ASSIGN score 18% Feb 2010</td>
<td>ASSIGN score 17% November 2010</td>
</tr>
<tr>
<td>49yr old male (several encounters)</td>
<td>Established CHD (previous MI 10yrs before) BP 153/96 weight 98kgs Total Cholesterol 4.9 LDL Cholesterol 3.3 BP 144/94 weight 97kgs Total Cholesterol 4.6 LDL Cholesterol 2.9 Improved concordance with medication</td>
<td></td>
</tr>
<tr>
<td>47yr old female</td>
<td>ASSIGN score 11% Jan 2010 Weight 60.7kgs Triglycerides 1.8 ASSIGN score 8% Jan 2011 Weight 59kgs Triglycerides 1.4</td>
<td></td>
</tr>
<tr>
<td>48yr old female (several encounters)</td>
<td>ASSIGN score 15% Feb 2010 Poor concordance with BP medication BP 153/96 ASSIGN score 15% Jan 2011 Better concordance with BP medication BP 145/86 (at best during encounters with good concordance 123/83)</td>
<td></td>
</tr>
<tr>
<td>47yr old female (several encounters)</td>
<td>ASSIGN score 15% Feb 2010 Weight 120kgs Triglycerides 2.4 BP 140/90 ASSIGN score 14% Feb 2011 Weight 113.5kgs Triglycerides 1.4 BP 135/91</td>
<td></td>
</tr>
<tr>
<td>42yr old male</td>
<td>ASSIGN score 15% Feb 2010 Triglycerides 6.0 ASSIGN score 14% Feb 2010 Triglycerides 1.6</td>
<td></td>
</tr>
</tbody>
</table>
| (positive FH of CVD) | Weight 81kgs  
Triglycerides 2.7 | Weight 75kgs  
Triglycerides 1.1 |
|---------------------|-----------------|-----------------|
| 28yr old male      | June 2010: BP 143/89  
Weight 78.2kgs | Feb 2011: BP 141/87  
Weight 78kgs |
## Pattern of attendances versus non-attendances at planned appointments and interventions

<table>
<thead>
<tr>
<th>G&amp;T description</th>
<th>Possible attendances</th>
<th>Number of attendances</th>
<th>Interventions</th>
</tr>
</thead>
</table>
| 58yr old man, new T2 diabetes                | 10                   | 3                     | • Attended when prompted or agreed to meet at convenient spot outside practice (e.g. to hand over prescription when unable to take time off work)  
• 8 unsuccessful attempts to contact via phone  
• Expressed wish to remain under KW care  
• Prescriptions now up to date                  |
| 35yr old man, new high single CVD risk factors | 9                    | 4                     | • 1 follow-up encounter opportunistically 'on the road'  
• 3 follow-up encounters via phone re medication  
• 6 unsuccessful attempts to contact via phone  
• Follow-up x 4 arranged in Ayrshire and Glasgow: one attendance only  
• Family bereavement reason given for one non-attendance  
• Reports prescriptions up to date currently |
| 33yr old female, new high single risk factors | 5                    | 3                     | • Follow-up on roadside and via phone  
• 8 unsuccessful attempts to contact via phone  
• Follow-up arranged elsewhere as above, same attendance rates  
• Reports prescriptions up to date currently  |
| 40 yr old man, end-stage renal failure        | 3                    | 1                     | • Had missed 3 appointments at renal clinic in Newcastle: discharged from their care  
• Follow-up on site and via phone x 5  
• Follow-up arranged, received renal transplant July 2011 and concordant now with follow-up |
Questionnaire given to non-health colleagues in Lothian

QUESTIONNAIRE GYPSY & TRAVELLERS HEALTH NEEDS

Please answer the following questions by filling in free text electronically underneath the individual questions, based upon your ongoing dealings with Gypsy & Traveller (G&T) individuals of all ages. Please consider G&T both on local authority & roadside encampments. All information provided with remain confidential.

1. In your experience, what are the main health problems or issues faced by G&T?

2. What have been the main barriers for G&T in their dealings with health care providers?

3. What, in your experience, has been successful in providing health care for G&T? Why would you think this is?

4. What do you think would help to improve the health both short and longer-term for G&T?
Verbatim responses by Lothian colleagues (n=3) to the questionnaire in Appendix 5

Q: In your experience, what are the main health problems or issues faced by G&T?

Respondent a (LA site manager): Compared with the settled community smoking and consumption of alcohol is more common and to a more excessive degree, therefore higher related illnesses.

Men tend to be more physical in their employment resulting in more ware and tare on the body contributing to a shorter life span.

Health issues can be a taboo subject within the family and visiting the doctors in the early stages of an illness is not common.

Respondent b (voluntary sector worker): In my experience the main health issue is mental health problems. Most of the G&T I work with suffer from depression or stress. In addition to this, weight and related problems are an issue.

Alcohol abuse and the consequent health issues is a problem particularly in the male G&T community.

Respondent c (Teacher with remit for G&T children): In the area in which I work, there can often be personal hygiene difficulties observed by others working in close contact with young Gypsy/Travellers which can impact quite badly on their relationship building

Q: What have been the main barriers for G&T in their dealings with health care providers?

Respondent a: There is the taboo angle within the families, most say it doesn’t exist but it can be clearly identified. Families don’t like discussing health issues with people they don’t know and trust.

The men in particular tend not to visit the doctors.

Sitting in a waiting room with a group of strangers can be embarrassing to some of the families.

When families are on the road it is difficult/impossible to get an appointment with a doctor and A&E departments are always crowded with long waits for attention.
We have had one recent case of a Traveller being taken to the A&E by ambulance and walking out after an hour or two because they haven’t been attended to.

Gypsy/Travellers are very much now or today people, it’s not in their nature to be kept hanging around.

Respondent b: The main barriers are literacy issues and lack of trust in statutory organisations due to experiences of discrimination. Also keeping appointments would be an issue as Travellers tend to live on a ‘day to day’ basis and frequently forget about appointments. Lack of understanding of the consequences of poor health is also an issue.

Respondent c: Not really in a position to say but on site I suspect the lack of a private place to talk can be problematic

Q: What, in your experience, has been successful in providing health care for G&T? Why would you think this is?

Respondent a: During the 20 odd years I have worked with Gypsy/Travellers a number of ideas have been tried, but only one has ever been fully successful, and works well. That is the present Keep Well project.

The trained staff had the confidence and backing of site managers and the Gypsy Church, which helped the team gain access to the families on a friendlier footing, and the way that they approached the families was very un-intimidating.

Respondent b: Going out to the sites and visiting Travellers in their own homes is a big step forward as it encourages them to face their health issues and discuss them in a familiar environment. Also having a male health worker has made a big impact on the male Travelling Community, and has encouraged them to engage with health care where they would not have done previously.

Having a known and trusted contact is also a big step forward as Travellers have a mistrust of strangers and they are more likely to engage and discuss personal issue with someone they feel comfortable with.

Respondent c: Groups who visit the site regularly are most beneficial. Gypsy/Travellers in my opinion take a long time to be happy to talk openly to people so continuity of personnel is essential. Also often Travellers have a different set of priorities to the settled community and don’t actively seek medical help; the provision of this on site is undoubtedly the most successful way to provide health care
Q: What do you think would help to improve the health both short and longer-term for G&T?

Respondent a: The Keep Well format used in our area has proved the way forward, the team are accepted by the community, and an open offer is there for them to repeat their success in other areas of the country by introduction from Site Managers and the Life & Light church.

Razing awareness is difficult to achieve when working with Gypsy/Travellers.

Leaflets look nice but in reality achieve very little, regular face to face contact with the community is the answer, visit sites regularly and have a presence at any Life & Light events in Scotland, you would be most welcome.

Respondent b: Continued input from a service which goes out to the Travellers in their own environment.

Structured health education including healthy eating, and promotion of early intervention – particularly related to heart and weight related health issues.

Awareness raising on issues of alcohol and substance misuse.

Respondent c: I’m not a health professional so difficult for me to be sure but I would definitely think that private facilities, on site for regular clinics dealing with a range of issues, would I suspect provide the best preventative and early diagnosis service.