



Tell someone, don't keep it to yourself

**A study into the mental health needs of Gypsy and Traveller
Communities in Bolton using a Community Engagement Approach**

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Communities in Bolton using a Community Engagement Approach**

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The researchers would like to offer up the following narrative given by one of the respondents to illustrate some of the problems faced within the community.

I was going to kill myself loads of times – the devil was telling me to do it. But the Lord stopped me and thinking about who was going to look after my children. I couldn't sleep at night. Used to bang my head against wall and punch myself in the head and hear voices. So what helped me was family and friends and medication and fellowship in the Church and a scripture in the bible...Three year in my life I can't remember, but the Lord Jesus helped me. Tell someone, don't keep it to yourself. It is the worst pain you can ever have in your head.

Acknowledgments

This report has been written by Jez Buffin but it would not have been possible without the hard work of the community researchers, Hayley Kelbie, Tina Lee, Diane Price, Jacob (Fiver) Smith, Anita Wojcik, Jamie Young, Mariah Young, Victoria Young and Reggie Young; nor without the support of colleagues from Building A New Direction (BAND), specifically Petra Fehn, Karen Sharp, and Rita Liddell.

Thanks are also due to my colleague at the University of Central Lancashire, Alia Syed.

Finally, both I and everyone else involved in this project is grateful to those who took part in the study, both from the Gypsy and Traveller communities of Bolton and from local services. All must remain anonymous however.



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Executive Summary

Background

The project aimed to help improve access to psychological therapies for Gypsy and Traveller Communities in Bolton. Gypsies and Travellers have lived, worked and travelled throughout the UK for over 500 years. Official estimates suggest that there are between 90,000 and 350,000 Gypsies and Travellers in the UK.

Gypsy and Traveller children have the worst education outcomes of any group in the UK. The scale of health inequality between Gypsies and Travellers and the UK general population is large, with reported health problems between twice and five times more prevalent.

Health inequalities are often compounded by low take up of services. One of the main barriers to the take up of services is the stoicism and tolerance of chronic ill health within the community. Illness is often seen as inevitable and medical treatment as unlikely to make any difference. There is often more trust in family carers rather than in professional care.

Depression and anxiety are serious conditions that have a major impact on how well an individual is able to function. It is estimated that there are some six million people in the UK with these conditions, but that only a third of those with diagnosable depression and less than a quarter of those with anxiety disorders are in treatment. There have been suggestions that there are high levels of depression within Gypsy and Traveller communities with high use of anti-depressants (especially by women), high levels of fear about mental illness and services and low uptake of talking therapies.

The Gypsy and Traveller Community in Bolton is spread across 5 sites, with others living in houses usually located in the most deprived wards and areas of highest deprivation. There may be as many as 1,000 Gypsy and Traveller families living in Bolton.

Methods

Nine peer community researchers were recruited from across the 5 local Gypsy and Traveller sites. They underwent a two day bespoke training package developed and delivered by the University of Central Lancashire.

An audit tool for use with service providers was developed by the team. A questionnaire was developed for use with the community. A total of 51 people completed questionnaires.

Findings

The community researchers were impressed with what the IAPT services had to offer. However, they noted a discrepancy between what was actually on offer and what the local Gypsy and Traveller communities thought was on offer. There is a need to raise awareness of mental health and of what services do. Many travellers struggle to read and many traveller sites do not get regular deliveries of post. It should be possible to make initial appointments over the phone.

The fact that the service is available at various venues should be publicised more widely and people should be asked which venue they would prefer to be seen in when they are first offered an appointment. More should be done to publicise the system for reimbursing travel costs. The service should be able to offer some early morning and evening slots and also some slots at weekends. Services could be more proactive to ensure that good practice in relation to working with clients with poor literacy skills is properly embedded. Services need to check literacy levels and develop alternative ways of working and/or provide additional support where necessary. Existing methods of publicising the service were thought to be poor and inappropriate.

The service should include *Gypsy and Traveller* as a specific category in monitoring service uptake and outcomes.

Generally services have little contact with local Gypsy and Traveller communities. This has resulted in a lack of understanding about the specific needs of the community and a lack of consideration of the communities needs in the development of services. Staff had not received any specific training about Gypsy and Traveller communities.

One of the central findings of the project was the lack of awareness of mental health and mental health services amongst the Gypsy and Traveller community. Fear of services, often based on misconceptions, was major theme.

Low literacy levels amongst the community and a distrust of services, often based upon poor experience, mean that oral methods of awareness raising delivered by people who are trusted within the community are likely to be the most effective.

The Community Engagement approach proved effective at raising the awareness of the community researchers and shows some promise as a method for promoting awareness amongst the community as a whole

Recommendations

1. The value of the work undertaken by the community researchers should be formally acknowledged by local mental health service providers and

commissioners. Proper consideration should be given to the findings and recommendations of this report and formal feedback about next steps should be provided to the team.

2. A programme of targeted mental health awareness raising should be commissioned for the Gypsy and Traveller community. Consideration should be given as to whether this could best be delivered by the current team of community researchers who have the trust of the community and are well placed to deliver an oral programme which is likely to be most effective. Added value could be given to such a programme by training the team to deliver a broader programme of awareness around a range of public health issues. An existing model of partnership working has already been piloted elsewhere (Parry et al, *ibid*). Traveller women in Ireland were given training to develop their skills in providing community based health services to their own community in partnership with public health nurse co-ordinators.
3. IAPT services should review their current practices to ensure that poor literacy amongst the Gypsy and Traveller communities does not present a barrier to service use. This will include reviewing current methods of advertising and publicising the service, reviewing current referral and appointment systems and reviewing the appropriateness of intervention tools. Staff should be trained to support clients with low levels of literacy to get the best from services.
4. A training programme for staff working within mental health services (practitioners, managers and commissioners) should be commissioned. This should ensure that the findings of this report are fully disseminated but also that the culture and needs of Gypsy and Traveller communities are widely understood. Consideration should be given as to how such a training programme might be delivered in partnership with the Gypsy and Traveller community. GP's should receive similar training.
5. Service level monitoring tools for IAPT services should be amended to ensure that the access to, experience of, and outcomes from IAPT services for Gypsy and Traveller communities are appropriately recorded and can be analysed and used to drive service improvement.

1. Background

1.1 Aims and Objectives

The project aimed to help improve access to psychological therapies for Gypsy and Traveller Communities in Bolton. It aimed to do this by conducting an audit of existing service provision and gathering information from local Gypsy and Traveller populations about the enablers and barriers to seeking help.

The project used a community engagement approach (section 2 below) in order to simultaneously raise awareness about mental health within the community and build capacity.

1.2 Gypsy and Traveller Communities in the UK

Official estimates suggest that there are between 90,000 and 350,000 Gypsies and Travellers in the UK (Hagan et al, undated; Marr et al, 2008, Matthews, 2008). Gypsies and Travellers have lived, worked and travelled throughout the UK for over 500 years and come from a variety of rich and diverse backgrounds including Romany Gypsies; Roma; Scottish Travellers; Welsh Travellers (Kale); Irish Travellers; New Travellers; Bargees or Boat Dwellers; Showpeople; and Circus People (Matthews, *ibid*). With many Gypsies and Travellers choosing not to identify as such however – possibly in order to avoid racism - and with many services failing to include Gypsies and Travellers as an ethnic group in monitoring data it is extremely difficult to get an accurate picture of how many Gypsies and Travellers are living in or using services in any given area (Lau, 2010; Marr et al 2008).

The majority live in trailers on sites owned either privately or by local authorities. A minority live on unauthorised sites, often without basic services such as water, sanitation and rubbish collection which can have major health implications (Marr et al 2008).

Gypsy and Traveller children have the worst education outcomes of any group in the UK. Only a minority of Gypsy and Traveller children finish formal education which means that literacy problems are common place. Many Gypsies and Travellers say that they experience anti Gypsy Traveller racism in school and that this often leads to young people dropping out (Lau, *ibid*).

There have been a number of small scale localised studies that suggest that Gypsies and Travellers have poorer health status than non-Travellers, but reliable evidence is sparse (Perry et al 2004), often relying on anecdotal data from practitioners accounts.

Parry et al (*ibid*) suggest that the scale of health inequality between Gypsies and Travellers and the UK general population is large, with reported health problems between twice and five times more prevalent. The aspects of Gypsy Traveller health that show the most marked inequality are self-reported anxiety, respiratory

problems including asthma and bronchitis, and chest pain. They also observed excess prevalence of miscarriages, stillbirths and neonatal deaths and noted that premature death of older offspring was also conspicuous. While factors such as smoking, education and access to GP's is recognized as an important contributory factor to these inequalities, these do not give a full account (Perry et al *ibid*; Matthews *ibid*).

Mental health is under researched in Gypsy and Traveller Communities (Lau, *ibid*). There have been suggestions however that there are high levels of depression within the community with high use of anti-depressants (especially by women), high levels of fear about mental illness and services and low uptake of talking therapies (Friends, Families and Travellers, 2009). Marr et al (*ibid*) report that almost two thirds (n=90) of a sample of 147 Gypsies and Travellers stated that they had experienced multiple mental health problems.

Lau (*ibid*) reports a correlation between the shortage of traveller sites and acute mental illness, describing 'a cultural or psychological aversion to housing.' For most Gypsies and Travellers the ability to choose their lifestyle is of fundamental importance and crucial to their sense of independence and autonomy (Perry et al *ibid*). Living in a house is associated with long term illness and those who rarely travel have the poorest health.

A number of studies have shown poor uptake of services amongst Gypsy and Traveller Communities (Perry et al *ibid*; Matthews, *ibid*). Perry et al noted that one of the main barriers to the take up of services was the 'stoicism and tolerance of chronic ill health' within the community. Illness was often seen as inevitable and medical treatment as unlikely to make any difference. They also noted that 'there is more trust in family carers rather than in professional care.' This was also noted by Marr et al (*ibid*). Widespread communication difficulties between health workers and Gypsy Travellers, including a reluctance of GP's to register Travellers or visit sites, practical problems of access while travelling, mismatch of expectations between Travellers and health staff, and attitudinal barriers create further hurdles. Similar findings are reported by Cleemput et al (2007).

1.3 Improving Access to Psychological Therapies

Depression and anxiety are serious conditions that have a major impact on how well an individual is able to function. It is estimated that there are some six million people in the UK with these conditions, but that only a third of those with diagnosable depression and less than a quarter of those with anxiety disorders are in treatment (Department of Health, 2008). The cost is large: in human terms, to the individual, their family and friends; to the wider economy, in terms of lost employment and output; and to the NHS in terms of repeated visits to GP surgeries and avoidable referrals to specialist mental health services.

Based on evidence that psychological therapies such as Cognitive Behavioral Therapy (CBT) are as effective as anti-depressants in the treatment of conditions such as

depression and anxiety in the short-term and more effective at preventing relapse in the longer term NICE published guidelines recommending the use of psychological therapies for a range of conditions. Recognising that NHS psychological therapies were either unavailable or subject to significant delays in many parts of the country, the (then) Labour Government announced plans in to allocate £173m to the expansion of NICE compliant psychological services in 2007 between 2008 and 2011.

1.4 The Duty of Equality

The Race Relations (Amendment) Act 2000 places a duty on public authorities to carry out equality impact assessments on all of their policies and functions. Such assessments have highlighted the lack of health service provision to meet the needs of Gypsies and Travellers. Delivering Race Equality in Mental Health Care (Department of Health, 2005) specifically stressed the need to ensure equality of access, experience and outcomes for all Black and minority ethnic communities, including Gypsy and Traveller communities, from mental health services. In 2008, the NHS published the first of a specific set of commissioning guidance advising on commissioning IAPT services for the whole community and specific interest groups (Department of Health, 2008a).

1.5 The Traveller and Gypsy Community in Bolton

The Gypsy and Traveller Community in Bolton is spread across 5 sites, with others living in houses usually located in the most deprived wards and areas of highest deprivation. One of the sites is a local authority site and four are privately owned. The Gypsy and Traveller Liaison Service manage the local authorities registered caravan park. This is a registered site which can accommodate up to 26 families where Gypsies and Travellers can reside on a permanent basis on a license agreement.

By their very nature Gypsy and Traveller communities are transient, especially over the spring and summer months and it is therefore difficult to get an accurate picture of the number of Gypsies and Traveller living locally. However it has been estimated that at peak times there may be around 1,000 Gypsy and Traveller families living in Bolton.

In addition there are six sites for Showmen, all rented from the council via a sublet agreement. No data is available about the number of families living on these sites.

The Community Cohesion and Traveller Education Service is a multi-disciplinary team providing social, educational and access support. It offers advice to schools, agencies and families and works to support community cohesion, social inclusion and educational achievement.

Workers at BAND have reported high levels of mental health needs within the community, especially mild to moderate mental health problems, such as anxiety and depression.

Local Gypsies and Travellers report three recent (last two to three years) suicides within the community, all young men.

2. Methods

2.1 The Community Engagement Model

A community engagement approach was adopted. The model has been described in detail elsewhere (Winters and Patel, 2003; Fountain et al, 2007). Essentially it involved working in partnership with people from the local Gypsy and Traveller communities to develop the project tools, raise awareness, collect data, and ascribe meaning to the findings in order to develop recommendations.

2.2 Recruitment of Community Researchers

Nine peer community researchers were recruited from across the 5 local Gypsy and Traveller sites. Of crucial importance in the recruitment of the peer researchers was the relationship between the University of Central Lancashire and Bolton Association and Network of Drop-Ins (BAND). BAND employ a number of community development workers and one of these had an existing relationship with local Gypsy and Traveller populations. It was her contacts and relationships that enabled the recruitment process.

2.3 Training

The University developed a two day bespoke training package for the peer researchers. The training provided the team with some basic facts about mental health and the improving access to psychological programme, the objectives of the project, and a basic understanding of diversity, equality and improving service outcomes.

The programme was experiential and visual, relying on participants own experiences and visual prompts and cues to convey ideas and information. A number of the team had low levels of literacy.

2.4 Support

The community development worker from BAND played a critical role in providing day to day co-ordination of the peer researchers. As well as providing a conduit through which communication could be channeled she also arranged rooms for the team to meet in, organized transport where necessary and reimbursed expenses. She acted as a first point of contact for the team and worked hard to promote and maintain enthusiasm and motivation.

Two members of staff from the University worked alongside each other to support the development of the audit tool and a questionnaire.

Funding (£15,000) was provided by Bolton Primary Care Trust.

2.5 Development of audit tool

An audit tool (see appendix 1) was developed by the team as an outcome of the two days training. This was based on a series of questions that the team generated about the key 'touchpoints' that they thought were important to the Gypsy and Traveller community with regard to the provision of quality mental health services. The questions were agreed by consensus following discussion of a number of ideas generated throughout the training programme.

The team of community researchers visited the service at Brightmet Health Centre in Bolton in October 2010 in order to complete the audit. The team was supported by two community development workers from BAND. They met with the IAPT service manager and one of the practitioners. They took with them a list of questions about the service and the way that it was delivered.

Members of the community research team took it in turn to ask questions. The interview was taped.

2.6 Development of questionnaire

Once the team had completed the service audit they met to debrief from the session. They used this meeting to develop a questionnaire for use with the community. In developing the questionnaire the peer researchers also took advice from the IAPT service manager and the local mental health commissioning manager. They were supported by the research team from the University of Central Lancashire and the community development worker at BAND.

A copy of the pilot questionnaire can be found in appendix 2.

A considerable amount of time went in to the wording of the questions. While the support team from the university was keen to ask questions that were methodologically robust and free from bias, the peer researchers were keen to ask questions that made sense to the community and were in a language that they would understand. While on the whole this did not result in any major conflict there was some tension around the wording of question 6, which the University wanted to ask as, 'What might stop you from using a Psychological Therapy Service?', but which the peer researchers were keen to ask as 'What would frighten you from using Psychological Therapy Services?' After much debate, the team agreed to go with the latter version as being the question that the community would most understand and relate to.

The community research team was briefed on how to use the questionnaire and had the chance to rehearse practice interviews with each other. Each member of the community research team was then asked to try and complete 2 or 3 pilot interviews with Gypsies and Travellers in the local community using their existing contacts and relationships.

A total of 18 pilot interviews were completed and the team met again to go through these and discuss how the interviews had gone. On the whole the team felt that the questionnaire had worked well and they had had no major problems using it. It was felt that question 7 needed to be followed up with a prompt to illicit some qualitative data to support the simple yes/no answers given by people in response to the question as it stood.

A discussion was had about whether the age question should also be changed as some of the team experienced some reluctance amongst participants to discuss their age. After discussion it was agreed that the age question would be amended to ask respondents to give an age category, rather than an actual age.

2.6 Analysis

The tape from the audit visit was transcribed by researchers from the University of Central Lancashire.

The community researchers met to debrief from the session. This session was facilitated by researchers from the University of Central Lancashire. Notes from the transcript of the interview were shared and discussed. The peer researchers were asked to consider the answers that they had been given, review what they had learned, and make comments about the what they thought were the implications for the development of services for Gypsy and Traveller communities.

Questionnaires were passed on to the University of Central Lancashire to analyse. Quantitative data was analysed in excel. Quantitative data was reviewed by the University team and organised thematically. Again the community researchers met to review the data, ascribe meaning to it and develop recommendations.

3 Findings

3.1 Audit data

The full notes from the audit visit are presented in appendix 1. A summary of the key findings is set out below.

3.1.1 Range of services on offer

The community researchers were impressed with what the IAPT services had to offer. However, they noted a discrepancy between what was actually on offer and what the local Gypsy and Traveller communities thought was on offer. Prior to becoming involved in this project the peer researchers had had very little understanding of mental health and still less of mental health services. They had thought that mental health was about people in white coats and that services were there to take their children away and to lock them up. Through the training that they had received and through the visit to the service they had come to develop a much broader and more realistic understanding of mental health and mental health services. The community researchers felt that they would use services now, but that they wouldn't have done before becoming involved in this project.

Accordingly they felt that much more work needs to be done within the community to help others to gain a similar understanding to one that they had got. There is a need to raise awareness of mental health and of what services do.

3.1.2 Referral routes

Many travellers struggle to read and many traveller sites do not get regular deliveries of post. For this reason the community researchers think that the current appointment and referral system should be reviewed. It should be possible to make initial appointments over the phone.

3.1.3 Waiting times

The current waiting time of six weeks seems a long time to wait for a first appointment. That said, the community researchers accept that this is not an issue that is specific to Gypsy and Traveller communities – many potential service users might feel the same about this.

3.1.4 Service access

The fact that the service is available at various venues was seen as a good thing. However the community researchers felt that this fact should be publicised more widely and people should be asked which venue they would prefer to be seen in when they are first offered an appointment.

It was also felt that more should be done to publicise the system for reimbursing travel costs. It was felt that the staff who were interviewed were themselves unsure of the scheme. All staff should know about it and should talk to clients about it to promote its uptake.

It was felt that the current opening hours may not suit everyone. The community researchers accepted that this is a resource issue and that this is likely to affect everyone and not just people from the Gypsy and Traveller communities. However they felt that the service should be able to offer some early morning and evening slots and also some slots at weekends.

The community researchers felt that there should be some out of hours crisis service provision.

Again many of the concerns centered around the fact that the community lack awareness of mental health and mental health services. This needs to be tackled as suggested above.

3.1.5 Communication

While acknowledging that services were saying that they would take steps to work sensitively with clients with literacy problems the community researchers felt that services could be more proactive to ensure that good practice was properly embedded. Services need to check literacy levels and develop alternative ways of working and/or provide additional support where necessary.

3.1.6 Publicising the service

Existing methods of publicising the service were thought to be poor and inappropriate. There is a need to develop some specific resources for Gypsy and Traveller communities and the impact of these will be enhanced by use of specific traveller web-sites and magazines, and by the use of verbal communication, possibly including the use of health trainers recruited from the Gypsy and Traveller community.

3.1.7 Service monitoring

The service should include *Gypsy and Traveller* as a specific category in monitoring service uptake and outcomes.

3.1.8 Partnerships

Generally services have little contact with local Gypsy and Traveller communities. This has resulted in a lack of understanding about the specific needs of the community and a lack of consideration of the communities needs in the development of services.

3.1.9 Training

Staff had not received any specific training about Gypsy and Traveller communities. Staff working within IAPT and other mental health services could benefit from training to raise their understanding of the culture and lifestyle of Gypsy and Traveller communities. GP's and staff working within GP surgeries may also benefit.

3.2 Analysis of questionnaire data

3.2.1 Total number of respondents

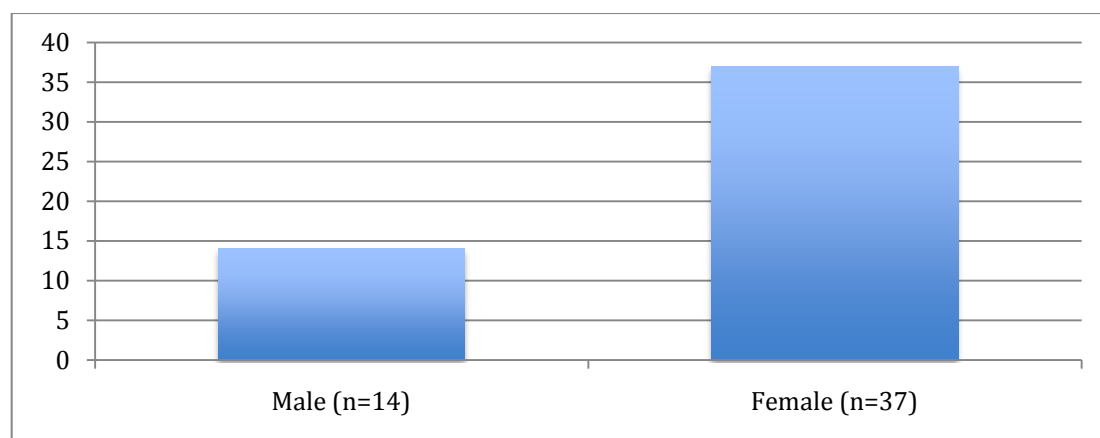
A total of 51 people completed questionnaires: 18 during the pilot phase and 33 during the second phase.

3.2.2 Gender

14 were men and 37 were women. During the pilot phase, the researchers managed to recruit equal numbers of men and women (n=9 each). The team had felt heartened by this as they had expected to find it difficult to engage men who they thought would be reluctant to take part.

Unfortunately the team found it harder to engage men during the second phase of the research, only managing to recruit a further 5. This is almost certainly due to the recruitment strategy that the team adopted – recruiting participants via a 'pamper day' event that was predominantly visited by women.

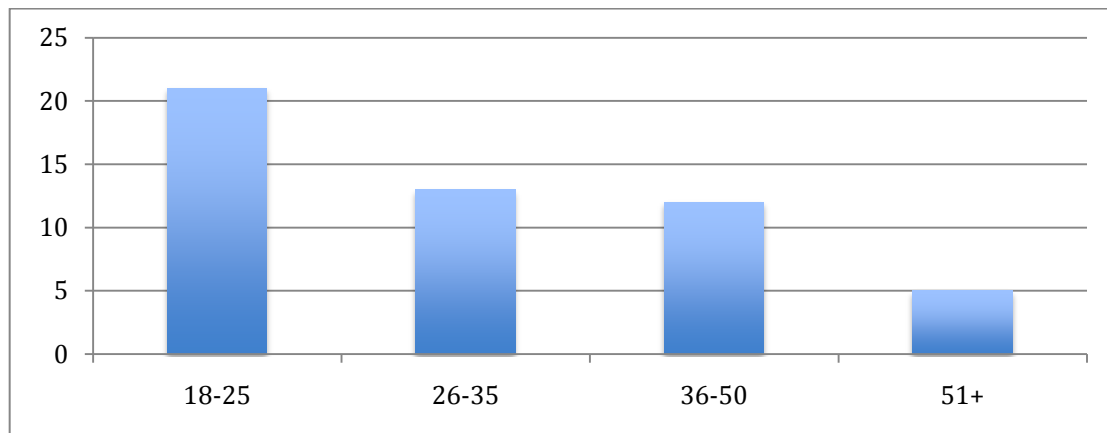
Table 1: Gender of respondents



3.2.3 Age

The ages of respondents ranged from 18 to 83. Most (n=21) were aged 18-25. N=13 were aged 26-35 and n=12 were aged 36-50.

Table 2: Age of respondents

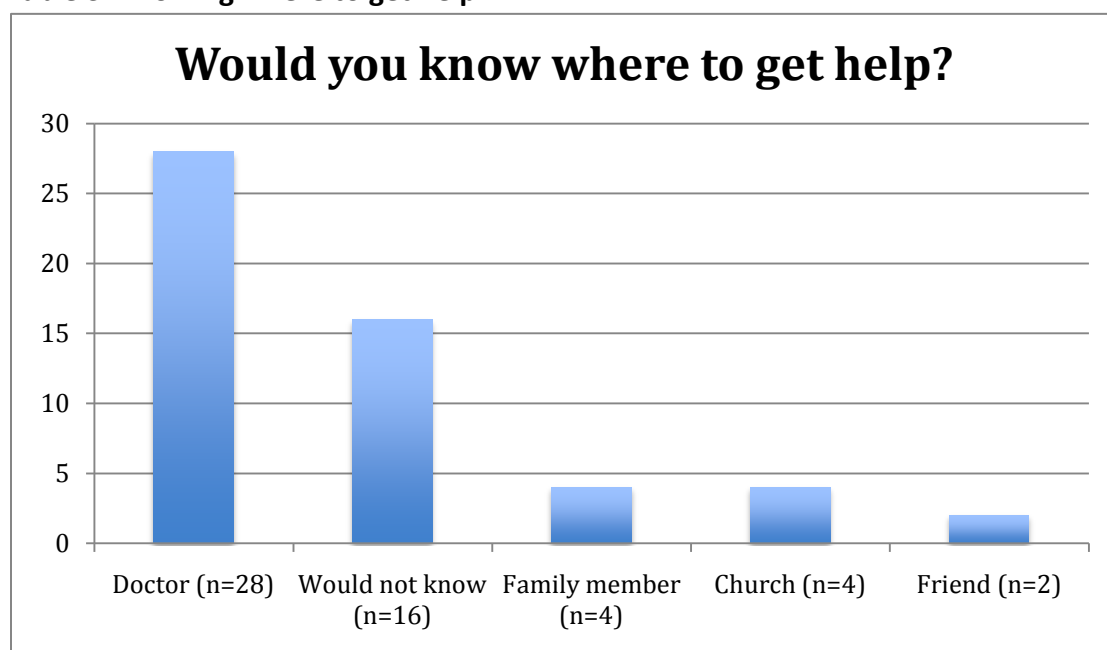


3.2.4 Knowing where to get help

Respondents were asked whether they would know where to go to get help if they were feeling unhappy, depressed or stressed out. 35 said that they would and 16 said that they wouldn't.

Of those who said that they would, the most common source of help known about was the doctor (n=28).

Table 3: Knowing where to get help



3.2.5 What kinds of things make you feel better when you are unhappy

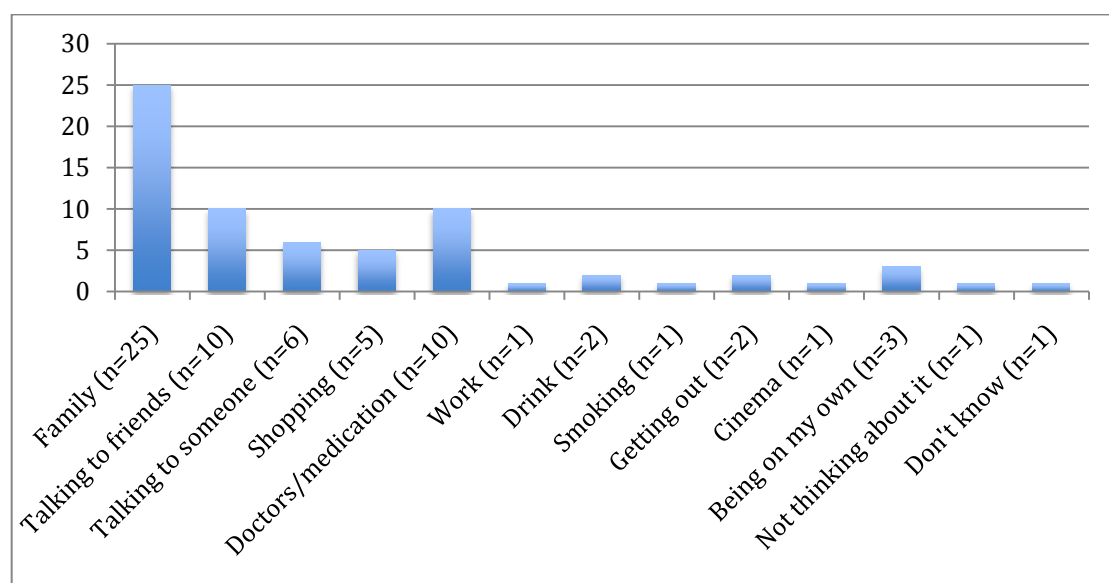
Respondents were also asked what kinds of things helped them to feel better when they were feeling down or unhappy.

Family was the most frequent response (n=25), although what this meant for respondents differed. For most it meant 'being with' or 'talking to' family, but for one it meant 'looking after my son' and for another it meant 'seeing my children'.

10 people said that talking to friends would help, while talking to 'someone' was important for 6 respondents.

5 respondents said that going shopping helped, although for 1 of these some form of social contact was also implicit in this ('going shopping with a friend'). 2 respondents mentioned the church, although again 1 respondent specifically talked about the 'fellowship of the church'.

Table 4: What made people feel better



10 respondents talked about visiting the doctor or taking medication.

Work was important for 1 respondent.

2 said that they would 'drink to blank it out' and 1 said that they would smoke.

2 said they would want to 'get out and about'; 1 said they would go to the cinema; and 1 said that they would 'do something to take my mind off it.'

3 said that they would just want to be on their own.

1 said that they would 'try not to think about anything bad' while 1 said that they did not know.

Although respondents have a variety of ways of coping, relationships with families and friends are clearly an important factor in maintaining well-being. Some form of social contact with either friends or family and the ability to talk to someone is implicit in many of the answers given above.

3.2.6 Best way to communicate information to the community about sources of help

Respondents were asked to identify what they thought were the best ways of telling people in the community about the help that was available. Several respondents gave more than one answer so the total number of responses was 77. Most respondents (69% n=53 out of 77) emphasised being told about sources of help via some form of oral communication. 21 people said word of mouth, with a further 6 saying either friends or family. 16 mentioned their doctor, 8 mentioned the church and 2 mentioned the radio.

Two things are significant here – first the emphasis on being told about it, but secondly (if 'word of mouth' can be taken to mean an informal method of communication) the importance of being told about it by someone within the community.

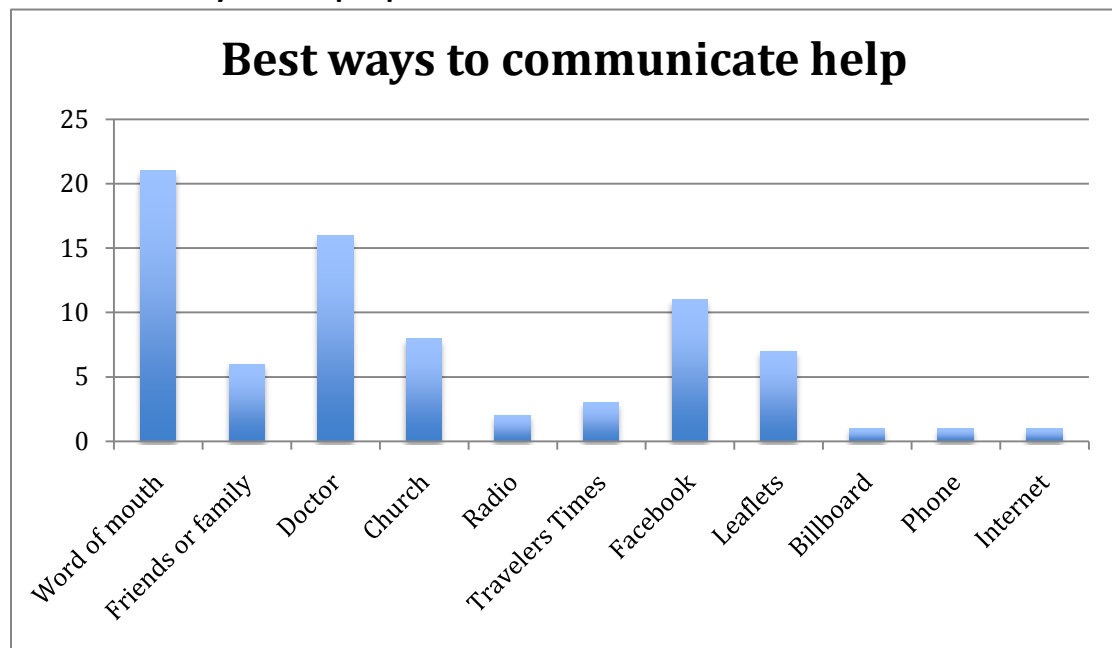
11 respondents talked about facebook and 3 mentioned the '*Travellers Times*'. What may be significant here is that a number of travellers appear to use specific traveller facebook sites, so both of these responses may point to the need to advertise using specific media sites used by Travellers.

7 respondents thought that leaflets were a good idea. 1 said a billboard, 1 said the internet and 1 said 'the phone', although it is difficult to get a sense of what lay behind this answer.

The importance of this question is emphasized by some of the qualitative data that respondents gave at the end of the interview when they were asked if there was anything further that they wanted to add or say. 5 of the 11 respondents who proffered further information talked about the need to advertise the service further.

They need to advertise these services more because if you don't know where to get help you won't

Table 5 Best ways to tell people about services



If they want to make a difference they should consider more advertising or leaflets in doctors or chemists

Advertising would be better

I think they should advertise it more and it should be talked about more openly

3.2.7 Knowledge of psychological therapies

Only 13 of the 51 respondents said that they knew what psychological therapies were.

Those who said that they knew were probed further to try and get a sense for what their understanding was.

Only 4 of the 13 were able to give an answer that suggested that they had a basic grasp of what psychological therapies might be however:

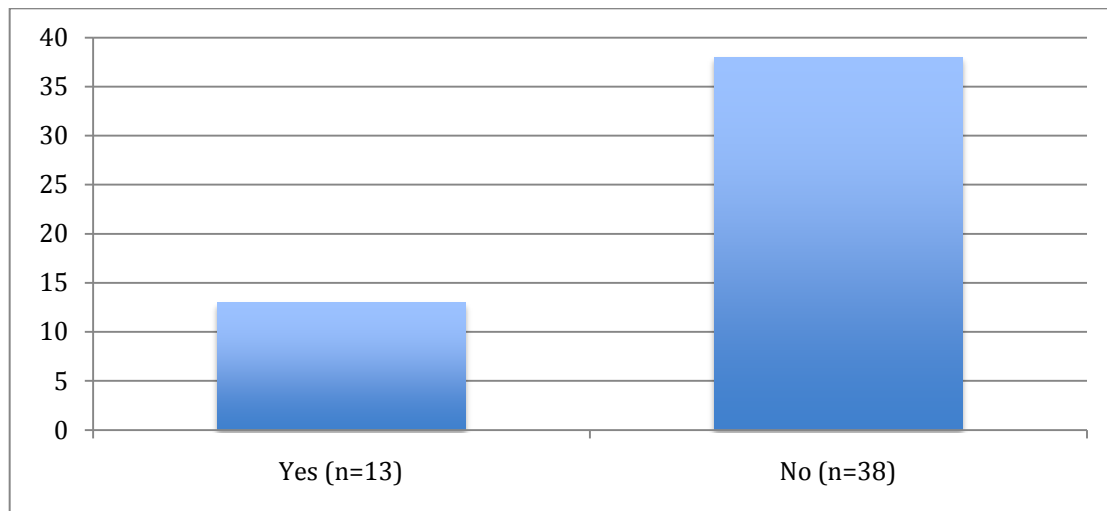
Like counselors

People who help you in a crisis

People who help with mental health

If you have problems like stress it's people who can help you

Table 6: Awareness of psychological therapies



The remainder were either unable to say anything further about what they thought psychological therapies were or gave answers that indicated little real understanding:

I know it isn't like hospital sign you away

I think it means you're mad

It means you are not altogether there, with it, if you know what I mean

The doctor

3.2.8 Fears about using Psychological Therapy Services

Prior to being asked this question, all respondents were given a basic outline of what psychological therapies are. This was to ensure that all respondents were in a position to give an answer to the question.

In response to the question about what fears people had about using psychological therapies, 22 respondents expressed fears about 'being locked away'.

Sending me away

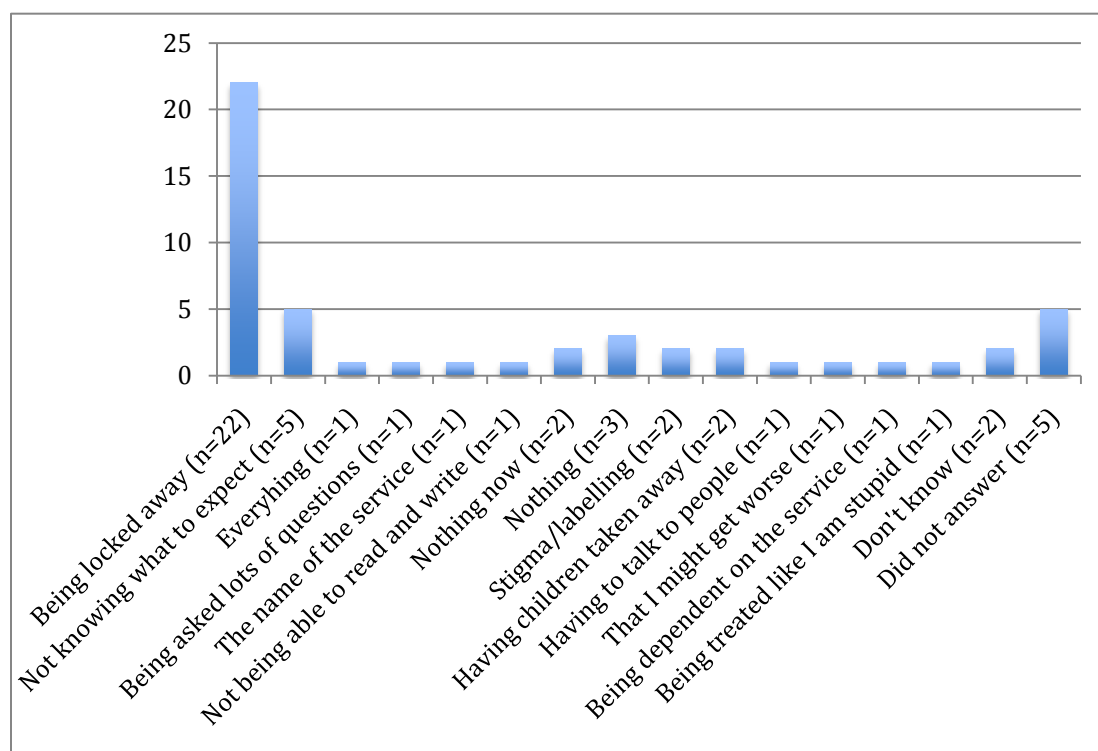
Get signed away

Getting put away and losing my children

Frightened of them being put away

Would be scared of getting section off

Table 7: Fears about using Psychological Therapy Services



It is interesting that 2 of the responses above came from 2 of the 4 people who appeared to have a basic understanding of what psychological therapies were.

Other fears included the name of the service (n=1), not knowing what to expect (n=1), fear of being asked lots of questions (n=1), not being able to read and write (n=1), stigma (n=2), having to talk to people (n=2), having children taken away (n=2), fearing that they might get worse (n=1), fear that they would become dependent on the service (n=1), being treated like they are stupid, and 'everything' (n=1).

5 respondents said that they were not frightened at all, with two of them specifically putting this down to fact that one of the researchers had explained to them what the service was about and so now they understood.

3.2.9 Should people who run Psychological Therapy Services know more about the Gypsy and Traveller Communities?

Nearly all (n=47) of the respondents said that they thought that the people who run psychological therapy services should know more about the traveller community and its needs. As discussed earlier however, further information about what it was that people should know about the community was only collected from the 33 respondents interviewed during the second phase of data collection after the initial pilot questionnaire had been amended. These respondents thought that the people

who ran Psychological Therapy services should *'know more about our way of life', 'our culture' and 'our traditions'*. Specifically they needed to understand *'how the lives of gypsy's are different to the lives of other people'*, and how people in the community would *'find it hard to say what they felt'* because gypsy's are *'a very private kind of people'*. Those who ran services needed to understand that many in the community would not *'understand long words'*, and also that many *'had trouble reading and writing'*. Concerns were expressed about the way that the community was often stereo-typed and labeled as anti-social or criminal and that often no recognition was given to the fact that *'we are all individual and we are all different'*. This included developing an understanding of the differences between gypsy and traveller communities. One respondent added that *'We (gypsy's) also need to know more about them (services)'*.

3.2.10 Other comments

11 respondents took this opportunity to say something. Many simply re-iterated points that they had already made. 5 re-emphasized points about the need for wider advertising and awareness raising.

One bemoaned the way that gipsy's were treated as a community of wrong-do-ers:

It is not for people to treat us like others what do wrong. We're not the same.

One talked about what she had learned as a result of being involved in the research and of how she had benefited from learning about services as a result.

One person said that they needed help and used the interview as an opportunity to ask for it. This person was referred to the community development worker at BAND for follow up.

Two respondents talked about their own experiences of mental health problems, one said that she had been in need of help after the birth of her daughter as she had 'baby blues'.

4. Discussion

The importance of talk and social contact as a means of promoting and maintaining mental well-being within the community bodes well in terms of its congruence with the notion of talking therapies. However one of the central findings of the project was the lack of awareness of mental health and mental health services amongst the Gypsy and Traveller community. Fear of services, often based on misconceptions, was major theme. This was paralleled by the lack of awareness and knowledge of the needs and norms of the Gypsy and Traveller community amongst service providers. Links between the community and service providers are almost non-existent and formal partnerships do not exist.

Low literacy levels amongst the community and a distrust of services, often based upon poor experience, mean that oral methods of awareness raising delivered by people who are trusted within the community are likely to be the most effective. Services will need to develop strategies for accommodating the low literacy levels within the community at all levels – from publicity and awareness raising, through referral and appointment systems and to treatment and intervention tools.

GP's were cited as one of the main sources of help by the community. Some respondents were critical of doctors however, saying that all they ever did was prescribe tablets.

Doctors never really helped – told me to take same tablet and that was it

They need to change it because I know from the past doctors are only happy to give you pills and that's it

This suggests that although doctors can be one of the main sources of help and support it is not automatic that they should be so. It is important that they take time to listen and explain things to patients and that they involve their patients in decisions about the most appropriate forms of treatment. GP's have the potential to provide a key point of access to mental health services for Gypsy and Traveller communities but in order to maximize the effectiveness of this it is essential that GP's fully understand the cultural needs and fears of the community.

The Community Engagement approach has proved effective at raising the awareness of the community researchers and shows some promise as a method for promoting awareness amongst the community as a whole. A number of respondents cited the information that they had received from the community researchers as part of the project as something that had reduced their own levels of fear about mental health and mental health services. There were also some additional benefits of this approach for the community researchers. One successfully gained a part time job directly as a result of the experience that he gained on the project and another has been involved in further strategic meetings with local public health officers, has

become chair of a residents association and has been successful in obtaining a post on the board of a local charity.

5. Recommendations

1. The value of the work undertaken by the community researchers should be formally acknowledged by local mental health service providers and commissioners. Proper consideration should be given to the findings and recommendations of this report and formal feedback about next steps should be provided to the team.
2. A programme of targeted mental health awareness raising should be commissioned for the Gypsy and Traveller community. Consideration should be given as to whether this could best be delivered by the current team of community researchers who have the trust of the community and are well placed to deliver an oral programme which is likely to be most effective. Added value could be given to such a programme by training the team to deliver a broader programme of awareness around a range of public health issues. An existing model of partnership working has already been piloted elsewhere (Parry et al, *ibid*). Traveller women in Ireland were given training to develop their skills in providing community based health services to their own community in partnership with public health nurse co-ordinators.
3. IAPT services should review their current practices to ensure that poor literacy amongst the Gypsy and Traveller communities does not present a barrier to service use. This will include reviewing current methods of advertising and publicising the service, reviewing current referral and appointment systems and reviewing the appropriateness of intervention tools. Staff should be trained to support clients with low levels of literacy to get the best from services.
4. A training programme for staff working within mental health services (practitioners, managers and commissioners) should be commissioned. This should ensure that the findings of this report are fully disseminated but also that the culture and needs of Gypsy and Traveller communities are widely understood. Consideration should be given as to how such a training programme might be delivered in partnership with the Gypsy and Traveller community. GP's should receive similar training.
5. Service level monitoring tools for IAPT services should be amended to ensure that the access to, experience of, and outcomes from IAPT services for Gypsy and Traveller communities are appropriately recorded and can be analysed and used to drive service improvement.

6. Appendix 1

Audit tool

Questions/themes explored	Service response	Community reflections and recommendations
<p>What do you do?</p> <p>What are you set up to do? What do you offer?</p> <p>What kinds of problems can you help with?</p>	<p>If you have got a mental health need and you are not already seeing someone and it is not an emergency then we have a central telephone number that you or a carer can ring.</p> <p>When we get that call we will decide whether you need something from us or a more specialised service (secondary care)</p> <p>Assuming you have a common mental health illness (stress, depression, anxiety, phobia, some kind of trauma [PTSD]) then we will pick you up.</p> <p>What we do not treat – serious disorders – loss of contact with reality – irrational beliefs about someone targeting them or that the TV is talking to them. They will need to see a psychiatrist – a doctor – we do not have a doctor.</p> <p>Key for us – can we help you by talking to you. If you are more complex than this and you need medicine etc that you will need a different service.</p> <p>Menu</p>	<p>We were impressed with what you do and what you have to offer.</p> <p>Our concerns are mainly around what the community may <i>think</i> you do and what the community may <i>think</i> that you have to offer.</p> <p>Before we were involved in this project we had very little understanding of mental health and still less of mental health services. We thought that mental health was about people in white coats and that services were there to take our children away from us and lock us up.</p> <p>Through the training that we have received and through visits such as this we have come to develop a much broader and more realistic understanding of mental health and mental health services. We would use your services now, but we wouldn't have done before becoming involved in this project.</p> <p>We feel that much more work needs to be done within the community to help others to gain a similar understanding to one that we have got. There is a need to raise awareness</p>

	<p>Different clinician and practitioners who offer therapy – psychological therapists, CBT therapists. CBT looks at the way you think about something. The way you think will impact on how you feel and how you behave. Eg panic – people may think they are going to have a heart attack and die – we can help them to panic less by teaching them that this is not the case. Can we dispel their beliefs by evidence. If they feel panicky in Asda, can we give them tasks to help them to overcome this.</p> <p>Therapy will depend on the problem – some problems respond better to certain therapies.</p> <p>Everyone will therefore get an assessment – what is the problem – how does it impact on your life – what is the best way that we can treat this.</p> <p>What kind of problems can we help with</p> <p>The therapies above will not treat everything. Feelings of sadness following a death or loss. Feel frightened if threatened. If you live in a horrible place, you will feel bad. We don't deal with normal feelings.</p>	<p>of mental health and of what services do. It could be that people such as us could be developed as 'community champions' along the lines of the health trainer model. The lack of awareness that the community has is not restricted to mental health and perhaps a team of people from the community could be trained up in a range of health related areas and could help act of community gatekeepers and sign-posters.</p>
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	<p>If you feel sad three months after someone dies, that is normal. If you are still feeling bad a year later, maybe you are stuck and have a disorder. Maybe you need help. Most people would be feeling a bit better. We don't treat everything for the way that people feel. Other services may do – CRUSE for bereavement. We would do bereavement counselling unless someone had got stuck.</p>	
<p>Referral</p> <p>How do you get in to the service – that is, do you have to be referred in by someone (if so who) or can you self refer?</p> <p>Do you have to be referred by your own doctor (GP)?</p>	<p>One phone call is all that is needed. The person who answers the call will make a decision about whether we can help you or not. We might refer you on.</p> <p>Most referral come through a GP however. This can be useful as the GP may be treating other things.</p>	<p>The fact that you can just ring up is good, although we are not sure how we would ever find out about the number or gain the confidence to use it without more awareness raising in the community as suggested above.</p> <p>Many travellers struggle to read and many traveller sites do not get regular deliveries of post. For this reason we think that you should look at your appointment system and offer initial appointments straight away over the phone. It is no good you writing out to us as many of us cannot read and many of us will not get the letter that you send for several weeks.</p> <p>Six weeks seems a long time to wait for a first appointment, although we accept that this is not an issue that is specific to us – we would</p>
<p>How long do you wait to be seen?</p>	<p>1st appointment normally within 6 weeks. We can offer more urgent assessment within 5 days.</p> <p>We would prioritise people with young children.</p>	

		guess that many potential service users might feel the same about this.
Where is the service based? Would I have to come in to see you or would you come out and see me?	<p>Where do we see people. Brightmet Health Centre . Also 33 Victoria Square. Some Health Centres. West Houghton College. We have a range of venues that we operate out of.</p> <p>We don't tend to see people at home. We can see more people here – no travel for staff. Also, it is a way of getting people more involved in their own treatment (homework – visit Asda). People have to engage and have to want to work with us. We need them to be keen and motivated to benefit.</p> <p>Also, home environment is often not a good place to talk. TV is on. Kids are around. Husband is in. We need a special place where people can concentrate.</p> <p>But having said all this – we would visit some people. Eg disabled. Agrophobia – here you can't go out because you get too panicky.</p>	<p>It is important that you make the fact that you operate out of various community venues this clearer to people generally. We don't think that most people would know this.</p> <p>Also, we think that you should ask people which venue they would prefer to be seen in when you offer them their first appointment. We think this is consistent with trends within health and social care around personalisation and choice.</p>
<p>If I have to come and see, is it easy to get there by public transport?</p> <p>Will you pay for my travel, or do I have to pay for it?</p>	<p>10 minute service in to town from here. Victoria Square is easy by bus.</p> <p>Generally people don't claim for travel, but there is a scheme that does allow people to</p>	<p>Again, our main concern centre around the fact that the community lack awareness of mental health and mental health services. This needs to be tackled as suggested above.</p>

Do you provide any travel services yourself?	claim for travel.	Also, you need to tell people about the scheme to reimburse travel costs. We didn't feel that you were particularly confident in talking about this. You knew that there was a scheme but you didn't appear to know the details of it. We think that all staff should know about it and should talk to clients about it to promote its uptake.
What are the opening times?	Mon – Fri 9-5	<p>This may not suit everyone. We accept that this is a resource issue and that this is likely to affect everyone and not just people from our community, however we feel that you should offer some early morning and evening slots and also some slots at weekends.</p> <p>We think you should provide an out of hours crisis service too.</p>
Is there a maximum number of sessions that I can have? Or can I see someone for as long as I feel I need to?	<p>Usually start with 6 and then review. How is the problem going. We do have guides for maximum number of sessions (e.g. 22) but this is not written in stone – we can extend if we feel we can help beyond this.</p> <p>Most people don't need the maximum number. We start off saying 'what would getting better look like' – and then we stop when we get there.</p>	We were happy with this, although as said above, this is only any good if we know about mental health and mental health services and have the confidence to use them – so it is linked to awareness raising.

<p>If you needed to contact me, how would you do this? How will you contact me?</p>	<p>Generally we would confirm the best way of contacting you at the initial assessment. We are used to contacting people confidentially – e.g. if someone else answers the phone, can we write to you.</p> <p>Some people ask not to receive letters to home address.</p> <p>What about initial referral? Normally we would try to explain how we would contact you at the outset. Normally we would write to someone, but you could say – don't send me a letter.</p> <p>If someone else referred you, you would need to make sure that they told us not to write to you.</p>	<p>It is great that you say that you will do this. This fits with what we were saying above about literacy and the difficulties many of us have getting post delivered.</p> <p>However, you need to make sure that your practice actually reflects what you say that you do. You need to make sure that you do actually ask us how we would prefer to be contacted and that you then stick to this.</p> <p>As stated above, we would prefer to be given our initial appointment over the phone when we first contact you rather than having to wait for a letter to come out.</p>
<p>Would I be given any written materials to read as part of my treatment? Will I have to complete any written materials as part of my treatment? If I had problems reading and writing, how would this be dealt with?</p>	<p>We do have forms that we use, but we will help people to fill them in if this is a problem (e.g. literacy or English). Some forms are used as part of the therapy, but we will try and work around this where people are going to struggle. The forms can help us to track whether people are getting better or worse.</p> <p>If you just turned up you would not be asked to</p>	<p>You need to take the lead here. Please can you make sure that you ask people if they need help with written materials or forms before you give them to them. Please do not simply think that people will tell you.</p>

	<p>fill in a form straight away. If we didn't know people had a problem with reading, we might send them written stuff. But if we knew we wouldn't send them. We can help people fill in forms here.</p> <p>If you did get written stuff, you could ring us and talk to us about it.</p>	
How do you publicise the services that you offer? What do you do to make people aware of them?	<p>The Primary Care Trust Web-site.</p> <p>In Victoria Square there is a notice board. NHS direct could point you to us. Professionals will know about us (GP's, social workers, mid-wives etc.) Some voluntary sector groups will know about us. Some job centres will know about us (if they have schemes to get people back to work).</p>	<p>We do not think that the service is well publicised to communities generally, and certainly not to ours.</p> <p>We think you need to develop some bespoke materials for our community – possibly making use of the 'health trainer' model suggested above.</p> <p>In order to promote the service to all sections of the community you could make use of television, radio, billboards, dvds, advertising screens in post offices etc.</p> <p>Travellers make use of some specific social networking sites, web-sites and magazines that you could also use. We could talk to you about this in more detail.</p>
What would happen in practice in a typical	We would try to understand the problem from	This all seems fine, but again is linked to our

<p>treatment session? What can I expect? How would you help me in practice?</p>	<p>your perspective. How do you see it? How does it impact on you? How is it a problem for you?</p> <p>Session will last for 45-60 minutes, with a beginning, middle and end.</p> <p>Beginning – review the last week Middle – therapy – suggesting strategies to help. End – review what we have learned – set plan for the week and tasks to try.</p> <p>Sessions are normally weekly.</p> <p>You do not lie on a couch and talk to a psychiatrist. You can look at the room – a normal room with a couple of chairs. We just talk. You tell how you see things and we suggest ways of coping better.</p>	<p>understanding and awareness of what you do. We had no idea that this is what you did before we became involved in this project.</p> <p>The community as whole will have no idea that this is what you do.</p>
<p>What kinds of options or choices might I have? Can I choose whether I see a man or a woman?</p>	<p>You can ask for a specific worker – and we will try to accommodate, but this may impact on waiting time. If you want to be seen in a certain place by a certain worker we will try to accommodate.</p>	<p>As mentioned earlier, we think that you should make the choices available and widely known about as part of the personalisation agenda</p>

	We have about 40 members of staff – but not all full-time.	
What kind of effect might treatment have on me? How will it effect me?	Hopefully it will make you feel better. But we do not have a magic cure. People may be asked to do quite a lot of things themselves and think about and talk about things that make them feel uncomfortable. It is not for everybody.	This is all linked to what we have said earlier about awareness. As a community we need to have a much greater understanding and awareness of this.
What would happen if I didn't feel that my treatment was working? What if I don't feel it is helping?	<p>The first thing would be to discuss this with the person you were seeing. Is the problem about who you were seeing (we could change them), or is it about the treatment itself. If what we offer does not help, there may be other treatments (e.g. anti-depressants). We can make suggestions about alternatives.</p> <p>Alcohol can be a difficult problem – e.g. they may be depressed because they are drinking. They may need help with an alcohol problem first. Can be a vicious circle.</p> <p>Complaints – procedure is outlined when you first come. There is a formal process. You can just ring up and complain and we will try to sort out straight away if we can.</p> <p>All complaints are investigated. The fact that</p>	

	you had complained would not go on your record.	
Can we (as a community) trust you (as a service provider)?	<p>When we first see you, we will tell you about confidentiality and about how we would deal with a situation if you told us about murder, terrorism or children who were at risk.</p> <p>Confidentiality is maintained within the service – we may talk to other people in the team.</p>	This is fine, but we may need to get someone to communicate and negotiate with you on our behalf. Not all of us are confident calling you up on the phone and negotiating what we want. We may want a friend or worker from another service to call you on our behalf.
Have any travellers and gypsy's ever used the service? How do you know?	<p>We wouldn't ask you directly in therapy if you were a traveller anymore than we would ask if you were Muslim or Hindu. It would be up to you to tell us if you felt that it was important. It may help us to understand you better if you do tell us certain things about you. These may come out as part of the discussions that we have. Certain data is collected as part of monitoring, but this wouldn't be used in treatment.</p> <p>Question – should we be identifying travellers as part of monitoring?</p>	<p>We think that you should monitor who uses your service, otherwise you will never know whether certain people are excluded.</p> <p>We think that traveller and gypsy's should be included as a specific ethnic group in monitoring and that we should not just be expected to tick 'white other'.</p>
When you set the service up, how did you take account of the particular needs that	We would assume that traveller community would experience similar issues as the wider	We think that we have a number of specific issues. We are aware of a number of suicides

<p>travellers and gypsy's might have?</p> <p>Are you aware of any particular mental health needs or issues that may affect the traveller and gypsy communities?</p>	<p>community. Not aware of any specific needs.</p> <p>We are reliant on other people to tell us about any specific needs.</p>	<p>within the community, mainly of young men and we think that this demonstrates the fact that we have unmet needs.</p> <p>There are a number of cultural issues that we think that you need to know about. For example, sometimes people from our community are settled in to houses and we find this difficult. We are used to having windows all around us and used to living our lives visibly in front of others and being seen. We are used to being able to hear the rain on the roof. We don't like houses – they are too quiet. And we don't like houses with stairs - you can't see downstairs and you don't feel safe.</p> <p>For you it is probably the other way around – you couldn't stand the caravan. That for you would cause stress and depression.</p> <p>Similarly we have experiences around how we are treated differently. People refuse to let us in their shops and refuse to service us.</p> <p>Parents at school are fine with us and our children until they find out that we are gypsy's, but then they change.</p>
<p>What do you know about the culture of gypsy's and travellers?</p> <p>Do you know how many gypsy's and travellers live in the Bolton area? Do you know where they are living?</p>	<p>No – we don't have any specific knowledge.</p> <p>We don't know how many live in the area or where they live.</p>	

		<p>If we complain about how we are treated to the police, they don't treat us the same as they would treat other people. We are not all thieves, but we get treated like we are.</p> <p>There are 8 different sites around Bolton where we live. There are dynamics between the sites.</p> <p>There are some norms about how men and women behave.</p> <p>We think that you need to understand more about our culture and our way of life.</p>
<p>Have your staff had any training about how to work effectively with gypsy and traveller communities? If yes, please can you describe what kind of training they have had?</p>	<p>Not specifically, no. A lot of what we do is about working with people, so staff won't need specific training. It is about working with people.</p> <p>You can get a good understanding by actually working with people. Example was given about a worker who had worked with the Orthodox Jewish Community in Salford.</p>	<p>We think that you could benefit from learning more about our culture and lifestyle. In the same way that we need to have our awareness raised about mental health and mental health services we think that you as a service provider need to learn more about us and our ways of doing things.</p> <p>We would like to be a part of this training and awareness raising. We would like to be supported to develop some training for you. In the same way that we could be used as</p>

		‘health trainers’ or champions within our own community, so we could be used to help raise your awareness too.
Do you employ anyone from a gypsy or travelling background?	<p>Not that we know of. But we could do. We wouldn’t know.</p> <p>We wouldn’t see the monitoring data re staff. It goes to HR. We would only know if someone told us. We don’t even know people’s names when we short-list.</p>	<p>We understand that you wouldn’t know what background people are from when you make decisions about short-listing people for jobs etc.</p> <p>However, we think that you ought to receive feedback from HR about the profile of the people that you do employ. What is the point of collecting data if that doesn’t get fed back to you and if you don’t use it reflect back on and make decisions about the kind of people that you employ.</p>
What kinds of links do you as a service have with the gypsy and travelling communities?	<p>This is the most formal link we have. We don’t record.</p> <p>In previous jobs I had patients who I know were showmen.</p>	<p>We think that you should build on the bridges that are being built as part of this project. We have already suggested a couple of ways that this could be done.</p> <p>We could be used as health trainers or project champions to raise awareness in our own community. We could be supported to put together some training for you and your staff and for local commissioners. Perhaps we could have a system whereby we met once a month or had some kind of contact whereby we could talk to each other and we could tell you about people in the community who we are worried about and we could try and refer</p>

		them to you or hand-hold them in to your service.
How would my family be involved in my treatment?	Would family be involved? Sometimes, if it is appropriate. Sometimes families are part of the problem. If you wanted your family involved we would talk to you about whether this would help or not. We start with you, but it may be appropriate to involve other people in the family too. We would only involve other family members with your agreement (e.g. if you are agrophobic and need help to leave the house). In some cultures, husbands always come in to the room, but we would want to check that this is OK.	
Does it cost anything?	Not to the people who use it	Good – but again we need to be made aware of this and to know about the service.
What would happen if I was late for my appointment?	Depends how late. If only 10 minutes, you could still be seen and some useful work done. But if you were 45minutes late, your worker will have someone else to see, so they wouldn't be able to see you.	

What would happen if I didn't turn up?	<p>If you let us know why you have missed then generally it is OK. If you don't contact us however, we may assume that you are not interested, and we may take you off our list. If you don't turn up you are taking up a slot that someone else could use.</p>	
What if it was my husband who was stopping me from coming?	<p>Hope that the person could discuss this with the therapist, then we could try and work around this.</p> <p>If someone's attendance was erratic, the therapist would ask them about this to explore what the issue was.</p> <p>If someone rang up on your behalf to tell us that someone was stopping you coming we may or not be able to talk to them. If you had given us permission to talk to them – no problem. But if you hadn't we would not want to breach your confidentiality by even letting on that we knew you.</p>	

Questionnaire

**Equality Impact of Improving Access to psychological Therapies project
Questionnaire**

Use the booklet to introduce yourself and the IAPT project

Core data:

Gender: (tick)

Male

Female

Age:

Note categories of 18-25, 26-35, 36-50 and 51 and over were introduced after the pilot

Q1a: If you were feeling unhappy, depressed or stressed out – do you know where to get help from? Tick:

YES []

NO []

Q1b: If YES: Can you tell me where you would go to get help from?

Q2: When you are feeling down or unhappy – what helps to make things better for you?

PROBE (talking to someone – friend, family; going to see the doctor – taking medication; anything else?)

Q3: In our community what do you think is the best way to find out what help is out there?

PROBE (from leaflets; billboard; the radio; doctor; facebook; conventions; word of mouth; the Church; Travellers Times)

Q4: Does the word Psychological Therapy Services mean anything to you? Tick:

Yes []

No []

Q5: Do you know what psychological therapies are?

(EXPLAIN about the IAPT project)

Q6: What would frighten you from using Psychological Therapy services?

Q7: Do you think that people running Psychological Therapy services should know more about our community and what our needs are?

Note: after the pilot Q7a was added

Q7a: If you answered YES, what do you think is very important to know about our community?

Q8: Is there anything else that you would like to say or tell me?

Thank you for your time.

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