Surveying Hard to Reach Groups – Final Report

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1. Executive Summary

1.1 In this project, a team from the University of East Anglia and Norfolk and Waveney Mental Health Foundation Trust (NWMHFT) address the issue of contacting Hard to Reach groups of people on behalf of NHS Great Yarmouth and Waveney (NHS GYW). Within this work, the project team sought to establish some demographic information for the NHS GYW region to determine the size and localities of each of the Hard to Reach groups and the health services that provide to these people; review the potential for collaboration with Local Government or County Councils on data survey based collection; develop a sampling strategy and a set of methods for collecting Hard to Reach patient feedback from key contacts, and conduct a data gathering exercise.

1.2 From the literature we understand that broadly speaking, there are two different groups within the Hard to Reach category: On the one hand, there are people who are not 'heard', and on the other hand, there are groups of people who do not want to be 'reached'. The first group feels that they are consulted and over-researched, but that nothing is done for them, whereas the second groups feels that research on them is an intrusion into their lifestyles. This project challenges some of these presumptions.

1.3 This report addresses each of the project objectives and – as a separate document – has established a data base of key contacts (including suggested methods of contact).

1.4 Demographic data is discussed in this report with further commentary regarding each of the Hard to Reach groups. NHS GYW has a clear understanding of the demographic data and the issues concerning this.

1.5 The potential for collaboration with councils and local government on survey data is presented in this report with the recommendation that existing association with the Norfolk Joint Strategic Needs Assessment program offers the best option.

1.6 A model for a sampling strategy for Hard to Reach groups has been developed and then each of the Hard to Reach groups are discussed individually. In this discussion we address the following questions;

In what capacity did key informants have contact with the group?

Is there any existing information about this group?

What strategies might be helpful to access the views of this group?

What are the views of key informants about this group in response to the key questions?

1.7 Recommendations from this project are that;

A the NHS GYW use the Hard to Reach contact database (provided as a separate document from this project) and continue to develop and maintain it;

B suggestions within this report regarding models of engagement with Hard to Reach communities be piloted (Section 9.3.1, 10.2.5, 10.3.13, 10.4.4, 10.5.8, 10.6.3, 10.7.3, 10.8.4, 10.9.4);

C decisions be made regarding other Hard to Reach categories (i.e. men of working age, single parents, elderly) and methods of engagement with these groups be sought out;

D an easily accessed community engagement fund be established to sponsor activities that engage with the Hard to Reach communities;

E changes to healthcare provision for Hard to Reach groups be developed through the recommended consultation approaches (as per B above);

F examples of best practice for GPs to engage with Hard to Reach communities be communicated;

G NHS GYW consider the engagement of members of Hard to Reach communities in the evaluation of these changes (i.e. expert patient or advocacy exercises)

H NHS GYW develop methods for communication with Hard to Reach groups within the trust communication strategy;

I consistent, predictable and person centered care models are the most successful for Hard to Reach communities and NHS GYW should consider these as key qualities in healthcare provision for these groups

A Survey of the Health Needs of Black and Minority Ethnic Groups in Norfolk

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2. Background

2.1   The National Health Service in Great Yarmouth and Waveney (NHS GYW) commissioned the University of East Anglia to report on how to access the views of those people described as 'Hard to Reach' regarding the health services in the region. This followed previous attempts to access patient views via a survey, which had limited success amongst these groups. 'Hard to Reach' groups are also referred to as 'Seldom Heard', 'Socially Excluded' and 'Easy to Ignore'.

2.2   These people include:
- Travellers (including those who prefer to known as Gypsies)
- Migrant Workers
- Looked After Children
- Individuals within the criminal justice system
- Asylum seekers and refugees
- Black and Minority Ethnic (BME) Groups
- People with Learning Disabilities
- People with long-term mental health problems.

In addition to the above groups specified by the NHS GYW in the original commission, the following groups were added on the suggestion of the Project team.
- Lesbian, Gay, Bisexual and Transgender people
- Homeless and insecurely housed people

2.3   The health service would like to know;
1. How people in the above groups use health services?
2. What barriers to accessing health services do they report?
3. What sources of health information and advice are used by people in these groups?
4. Where do they source this information and advice?
5. What health checks, tests and illness prevention services do people in the above groups use?
6. What health checks, tests and illness prevention services do people in the above groups say they need?
7. What improvements to health services would people in the above groups like to see (to help people in their position)?
8. What services are needed to help women from the above groups who are having a baby or who have young children?

2.4   These questions originally emerged from a report 'TOWARDS THE BEST, TOGETHER' CONSULTATION REPORT (Vision Twentyone 2008) and were further developed in consultation with NHS GYW and the project team.

2.5   While health care for all members of the above groups is important, there is particular interest in healthcare for men, as there is concern that men are even harder to reach and less likely to access services (email correspondence with EoE NHS – 9th June 2009).

2.6   The strategy to engage with 'Seldom Heard Groups' is also emphasized in the NHS GYW Strategic Plan 2008 – 2013;

We are preparing for an improved and more formalised way in which to engage with the population, ensuring we listen to all groups of the population, especially the 'seldom heard' which have previously been less influential. (pp28)

2.7   The recently published Annual Public Health Report 2009 (Dr Winters et al 2009) also addresses (section 9) some of the issues addressed through this project. In particular descriptions of populations, barriers to accessing healthcare and recommendations for the Black and minority ethnic community, Migrant workers, Prisoners and Travellers are discussed in this report. This project seeks to compliment and not to duplicate this work.

2.8   A Plain Language Statement for this project was developed and is at Appendix A.

3. Project Team

3.1 To conduct this project a team was formed of the following;
Dr Steven Wilkinson (Project Manager) - Senior Research Associate, School of Education and Lifelong Learning University of East Anglia

Dr. Andrea Stöckl, Lecturer in Medical Sociology, School of Medicine, Health Policy and Practice, Faculty of Health, University of East Anglia

Dr Danny Taggart, Clinical Psychologist, Norfolk and Waveney Mental Health NHS Foundation Trust

Dr Wendy Franks, Clinical Psychologist, Norfolk and Waveney Mental Health NHS Foundation Trust & PhD Student, Faculty of Health, University of East Anglia

3.2 The project team also acknowledges Dr Michael Pfeil, Senior Lecturer, Nursing and Midwifery Research Unit, University of East Anglia, who contributed to this project through providing key publications and consulting with the team.

3.3 The project team also acknowledges the contribution of Sandy Griffiths, Public Involvement Manager, NHS Great Yarmouth and Waveney, who contributed significant amounts of information and was the liaison between the NHS GYW and the project team.

3.4 The project team would also like to thank Dr Tim Winters, Senior Information Analyst NHS GYW and his team for providing demographic information and information within the Annual Public Health Report 2009 (Dr Winters et al) which was complementary to this project.

3.5 Finally, the project team would like to thank all those people from, and working with, the Hard to Reach communities, who helpfully contributed to this project.

4. Objectives

The objectives of this project were to;

4.1 Establish some demographic information for the NHS GYW region to determine the size and localities of each of the Hard to Reach groups and the health services that provide to these people.

4.2 Review the potential for collaboration with Local Government (Citizen's Panels) or the County Council 'Place Survey' in order to avoid duplication.

4.3 Develop a sampling strategy and a set of methods for collecting Hard to Reach patient feedback. This may involve NHS GYW healthcare workers and/or patient representative groups collecting information from Hard to Reach groups.

4.4 Conduct a data gathering exercise through NHS GYW healthcare workers and/or patient representative groups.

4.5 Undertake an analysis of the consultation findings.

4.6 Provide a report.

5. Ethics

5.1 This project was conducted through the University of East Anglia (UEA) and governed by the University's Research Ethics Policy. The approximately 5 month timescale of this project did not allow for a formal research process (including ethics application), given the time necessary to take a research project through University or NHS Research Ethics processes. This has informed the team's decisions about the conduct and scope of the project. As a result, a broad consultation was undertaken with key informants and representatives of local professionals and Hard to Reach communities. Although the university ethics committees did not review the project formally, the conduct of the project was nonetheless subject to UEA ethical guidance. The University Research Ethics Committee (U-REC) Chair is Professor Nigel Norris, (Head of the School of Education and Lifelong Learning),

Contact email n.norris@uea.ac.uk

6. Literature Review

6.1 A literature review was carried out to inform this project. This review can be found at Appendix B. The findings from this review are as follows;
- Broadly speaking, there are two different groups within the Hard to Reach category: On the one hand, there are people who are not 'heard', and on the other hand, there are groups of people who do not want to be 'reached'. The first groups feel that they are consulted and over-researched, but that nothing is done for them, whereas the second groups feels that research on them is an intrusion into their lifestyles.
- Focus groups are sometimes quoted as the best way of reaching and surveying members of Hard to Reach groups, and so are online consultations via email or blogs. However, Nottingham county council contests this approach. They argue that members of Hard to Reach groups very often need the personal contact.

- Time and timing has to be taken into consideration: Members of Hard to Reach groups need time to get used to people who want to listen to their opinions. They also suggest that a multi-agency approach seems the best way of contacting members of 'hard-to-reach' groups.
- The 'doctor-patient' relationship is of utmost importance when it comes to establishing a working contract with members of Hard to Reach groups. That means that respecting their choices and giving them autonomy is a necessary underlying principle that should influence all aspects of the relationship.
- Those with learning disabilities have particular problems including staff attitudes, waiting times, fear of clinical settings and communication/literacy problems.
- It is the responsibility of all individuals and organisations to make the environment, systems and activities inclusive and accessible for everyone. It is not the responsibility of individuals to 'fit in' to a system or environment that excludes them and not their fault if they cannot participate because an event, information, building or environment is not accessible.
- An ongoing involvement of people is necessary, such as regular listening events and an ongoing annual evaluation of the independent complaint and advocacy services as well as from voluntary and statutory organisations and from organisations that represent Hard to Reach or vulnerable groups.

While in many cases, these findings correspond with those of the project, in other cases our findings differ. In particular, we did not find many cases of Hard to Reach groups who did not want to be reached.

7. Objective 1: Demographic Information

7.1 In 2008 NHS GYW produced a Health Atlas (www.phi.gywpct.nhs.uk/.../Health%20Atlas%20 2008%20v4.ppt)

While data of this type is often reliant on census type information, it is possibly the most accurate impression that can be gained of the size and localities of the Hard to Reach in the NHS GYW boundaries. Anecdotally, we were able to gain an impression of the accuracy of this data through speaking with key stakeholders. Generally the view was that due to the nature of the Hard to Reach groups, the health atlas information may vary in accuracy (according to group) – this is information that was addressed in the literature and is known to NHS GYW.

7.2 Difficulty in establishing accurate demographic data

7.2.1 The numbers of people included in some Hard to Reach populations may be difficult to estimate for a range of different reasons. For example, there are likely to be large numbers of people with long-term mental health problems and learning disabilities who are not currently in contact with services. Some groups may be in contact with services but not identified as members of a particular Hard to Reach group, such as people from Lesbian, Gay, Bisexual and Transgender (LGBT) communities and homeless/insecurely housed people. Some groups are by their nature more transient, such as migrant workers and Travellers. Other groups, such as Looked After Children and prisoners are more straightforward to count when they are currently in care or in prison, but may continue to have particular healthcare needs after they have moved out of contact with services/prisons and become less visible in the population.

7.2.2 Gathering accurate data on all of these populations is complex. In the case of Migrant Workers, previous local studies have attempted to generate data for this population by calculating numbers of working age adults applying for National Insurance and for the Worker Registration Scheme (for Nationals of the recently acceded Eastern

European countries). However, this data may not fully represent the local population, due to the rapidly changing populations, and the extent to which it only measures numbers of people who are registered with the relevant agencies. Confirmed data does not correspond with estimates provided anecdotally by key informants working with some of the communities.

7.3 Migrant workers and BME groups

7.3.1 This group is one of the more researched of the Hard to Reach groups in the Great Yarmouth and Waveney area. This was reported to us during the process of the project. Many of the key informants that we spoke to worked with Migrant Workers, BME groups, Asylum Seekers and Travellers. They considered these four groups to be under an umbrella terms of 'BME' and as a consequence, some of the information provided was general, rather than specifically related to any one group.

7.3.2 A key finding of the migrant worker survey was that there are over 40 different nationalities represented amongst the population in Great Yarmouth. The four largest migrant populations are, in order of size; Portuguese, Polish, Lithuanian and Latvian. Demographic calculations were attempted to estimate the size of the different migrant communities in Great Yarmouth, however in conversation with the authors of this report and an analysis of the sampling strategy it appears that these represent a significant underestimation of the actual populations. It is also likely that the numbers reported have changed significantly since this time.

7.3.3 To briefly summarise, the data was compiled using National Insurance (NiNos) applications and registrations with the Worker registration Scheme. This provided an estimate of the number of European Nationals of working age who registered to work in the GY area between 2004-2007. The National Insurance applications were approximately: Portuguese- 700, Polish- 300, Lithuanian- 275 and Latvian- 150. The registrations with the Workers Registration Scheme was broken down into numbers for eight recently acceded Eastern European countries. The total number registering in the Great Yarmouth area number 445 between May 2004- March 2007. However, as outlined above, this only reflects the number of people registered on

the schemes, and not the whole population.

Also see Annual Public Health Report 2009 Dr Winters et al 2009 section 9.

7.4   Looked After Children

7.4.1   Numbers of Looked After Children are recorded. At the time of the report, in the Great Yarmouth area there were 184 Looked After Children however the number in Waveney was not know to the project team.

7.5   Individuals within the Criminal Justice System

7.5.1   This is a group with fluctuating numbers, which are difficult to estimate at any given time. This group includes prisoners currently in custody, young offenders, people on probation and released from custody on license, people recently arrested, and people bailed and on remand. Many people within the criminal justice system who reside in the Great Yarmouth and Waveney area may be detained in women's prisons or Young Offenders Institutions outside of the area. There are is no secure accommodation for young offenders in the area, and when given a detention/training order, young people are often transferred many miles from home, sometimes as far away as Milton Keynes, Kent, Bristol, Southampton or Rugby. The only prison in the Great Yarmouth and Waveney area is HMP Blundeston, a prison for adult males. According to the HR Inspectorate of Prisons, the capacity of Blundeston Prison was 526 at February 2009.

Also see Annual Public Health Report 2009 Dr Winters et al 2009 section 9.

7.6   Homeless and Insecurely Housed

7.6.1   It is difficult to estimate the number of individuals in the Great Yarmouth and Waveney area who are homeless and insecurely housed. There are a number of hostels for people who are homeless, however there may be some individuals who are sleeping rough and not identified in any given hostel. In addition, there are unmeasured numbers of people who are insecurely housed, who may be living in a range of circumstances, such as staying temporarily with friends and family, living in accommodation that is overcrowded and attached

to employment, or under informal arrangements without letting contracts or awareness of their rights.

7.7   Gypsies & Travellers

7.7.1   The Great Yarmouth and Waveney Housing Market Assessment (Project 4 – Accommodation Needs of Travellers – September 2007) attempted to predict the housing needs for travellers up to 2011. While this was problematic in several ways, an assessment was made of the current and predicted housing needs across both Norfolk and Suffolk. This is indicated in the table below.

	Est pitches on authorised sites	Est pitches on unauthorised sites	Need for additional pitches
Norfolk	165	26	94
Suffolk	159	25	100

It should be noted that these figures are for the whole of Norfolk and Suffolk, and not isolated to Great Yarmouth and Waveney. What is known is that across the sub region of Great Yarmouth and Waveney, it is estimated that an additional 15 pitches will be needed by the year 2011.

7.7.2   It is calculated that each pitch houses an average family size of 2.9 people. Additionally, interviews indicated that nearly one third of all pitches/households was effected by poor health and disability.

7.7.3   From the NHS GYW Annual Public Health Report we know the following;

	July 08	Jan 08	July 07	Jan 07	July 06
East of England	4322	4389	4229	4163	3891
Great Yarmouth	25	4	25	4	9
Waveney	80	38	43	43	38

Table 6: Count of Traveler caravans in the East of England

7.7.4 A pitch is defined as area on which one or more caravan may reside. There is one private pitch in Waveney in Kessingland and one council owned and managed pitch in Great Yarmouth (Table 7)

7.7.5 At the Gapton Hall Travellers site, there are 6 families who are regularly seen on site. These families have 18 children between them, 6 of which are under five years. Overall these numbers tend to increase in the summer.

Local Authority	Council Owned/ managed sites (No. of pitches)	Private Sites
Waveney	0	1site (20)
Great Yarmouth (Gapton Hall Travellers site)	1(19)	0

Table 7: Current authorised Gypsy and Travellers site provision (Public and Private) by local authority area (Norfolk CC & Suffolk CC)

http://www.gywpct.nhs.uk/searchresultsNew.asp - September 2009

Also see Annual Public Health Report 2009 Dr Winters et al 2009 section 9.

7.8 Others

7.8.1 It has not been possible to accurately estimate the numbers of people from Lesbian, Gay, Bisexual and Transgender, Learning Disability, and Long-term Mental Health groups within the scope of this report, for the reasons outlined above.

8. Objective 2: Review the potential for collaboration

8.1 The potential for collaboration and data sharing with Local Government (Citizen's Panels) or the County Council 'Place Survey' was investigated.

8.2 While some information may have been available via the Norfolk County Council 'Access4Life' project it was not in a publishable format at the time of asking and specific data was then only offered to this project at a cost. (email correspondence with Access4Life Project Officer 28th May 2009). This offer was declined.

8.3 Collaboration with County Councils in initiatives such as 'Access to Services' projects remains a possibility and could be further investigated by NHS GYW. http://www.norfolkrcc.org.uk/wiki/index.php/ Access_to_Services

8.4 The Norfolk Joint Strategic Needs Assessment is a partnership program of work between the Norfolk County Council, NHS Suffolk and NHS Great Yarmouth and Waveney. Access to data generated by this group can be located at http://www. norfolkinsight.org.uk/

8.5 Further participation with this group appears to be the best option for collaboration as access to information should be a matter for internal data sharing.

9. Objective 3: Develop a sampling strategy

9.1 The project team developed a sampling strategy and a set of methods for collecting Hard to Reach patient feedback.

9.1.1 Initial contacts with representatives of most of the Hard to Reach groups indicated that directly accessing the views of members of these communities would be a complex and time-consuming undertaking that was beyond the scope of this project.

9.1.2 Without being circular, the very fact that these groups are identified as Hard to Reach indicates the complexity of the task. Some of the issues that contribute to the difficulty in reaching these groups in this project are:

- These groups are by their nature diverse, both within groups and between groups. Memberships of the different groups are based upon various characteristics, experiences and beliefs, and consequently a single way of approaching the different groups may not be appropriate for them all.
- Many of the groups may have developed a mistrust of representatives of services, or may not consider these services to be of relevance or benefit to them.
- Contributing to information gathering exercises has been previously experienced by members of some groups as an extractive process whereby data is taken away by outsiders, feedback has been offered inconsistently and there has been limited visible impact on services. This is particularly relevant for some groups such as those under the BME umbrella, who key informants have described as over-researched locally.

9.1.3 Although it has not been within the scope of this project to access the range of Hard to Reach groups directly, it has been possible to develop a database of key informants, made up of professionals and community representatives (see separate database). These key informants are by the nature of their proximity to and level of contact with these groups, able to provide an informed perspective on the health care needs of members of the groups. They are also well positioned to provide guidance on appropriate ways of accessing the perspectives of Hard to Reach groups more directly. Within the roles of the key informants, there are some people who work professionally with members of Hard to Reach groups, and people who are both members of these groups themselves, and also working in a professional, community leadership or advocacy role with other members of the communities.

9.1.4 Clearly, people are only able to represent their own perspectives, when asked about the health care needs of others. Some of these perspectives will be informed by close working relationships and direct experience, however, the authors do not claim that the data gathered in this project is able to broadly and accurately reflect the actual health care needs all members of each population. However, level of proximity to (and inclusion in) Hard to Reach groups provides a more informed perspective than we would otherwise be able to access.

9.2 Sampling strategies

9.2.1 Based on our experience, we would suggest a range of complementary strategies for accessing the views of the Hard to Reach groups.

9.2.2 There are a few key contacts that can provide an up-to-date map of the local organisations who are well placed to provide information about Hard to Reach groups.
- Waveney Community Forum
- Voluntary Norfolk

  NHS Great Yarmouth and Waveney have existing relationships with both of these organisations, and it is through these that current information can be accessed.

9.2.3 From these initial points of contact, which are relatively stable over time, it will be possible to access a range of other sources of information. Some of the current local resources and organisations are listed in the database (separate to this report), however it is important to note that some of these services, individuals and resources do change over time. It is therefore necessary to maintain and build upon existing relationships between the NHS GYW and the local agencies.

The feedback that we have received is that there are existing positive relationships between different departments within NHS GYW and a wide range of community organisations that could helpfully inform future attempts to access information from Hard to Reach groups.

9.2.4   Lessons learned from the current project:
- There will be different strategies needed to access information for different groups.
- In general, written surveys are unlikely to be accessible for people who have literacy problems, are not fluent in English, do not have a fixed abode or do not share assumptions about the importance of representing their perspectives to the NHS.
- Some groups may be harder to reach than others in relation to accessing their views, for example, the project team have had difficulties accessing views of key informants representing Travellers. However this was a time limited project, and it may be that professionals with more established local networks with those groups may find this more straightforward.
- Project team members were advised that there is a risk of discouraging some groups from offering their perspectives as a result of repeatedly seeking their views without any apparent subsequent action, change or development of services. Some key informants expressed cynicism about the benefits of repeated consultation, and suggested the alternative of taking action on the basis of initial consultation and then evaluating outcomes.
- Members of the project team with existing relationships and regular contact with local groups were better positioned to access information. There are multiple local agencies working closely with people from Hard to Reach groups (see Appendix B), who have existing relationships with NHS GYW, whose services are fully or partially commissioned by NHS GYW, and who have expressed a willingness to help to develop strategies for accessing the views of the communities with whom they work.
- Going out to places where people are was generally a more productive strategy than making other forms of remote contact such as email and telephone calls.

9.3   Sampling Strategy Recommendations

9.3.1   A written survey or other one-size-fits all method of information gathering is unlikely to enable the NHS GYW to gather information about the health care needs of all Hard to Reach groups in the area. The NHS GYW will need different ways of accessing different groups and this is best undertaken on an ongoing basis by working with key informants who have current knowledge about ways of accessing community views. Specific information relating to the different groups is given in the relevant sections below.

9.3.2   A range of recommended approaches are shown in the diagram overleaf:
- To develop capacity to within the NHS GYW to support local key informants and voluntary sector organisations to access the necessary information from members of Hard to Reach groups – for example, to offer funding and support for key informants to run focus groups or use other appropriate forms of data gathering directly with members of Hard to Reach communities (blue arrows)
- To develop and expand existing roles within the NHS GYW for community liaison directly with Hard to Reach communities (green arrows)
- To develop structures within the NHS GYW to involve members of Hard to Reach groups at a strategic level within the NHS GYW to represent and inform strategy for accessing views and developing services (red arrow)
- Black arrows show means for NHS GYW to identify key informants, voluntary sector and community organisations and Hard to Reach communities.

Key informants /
voluntary sector
organisations

Members of
Hard to Reach
Communities
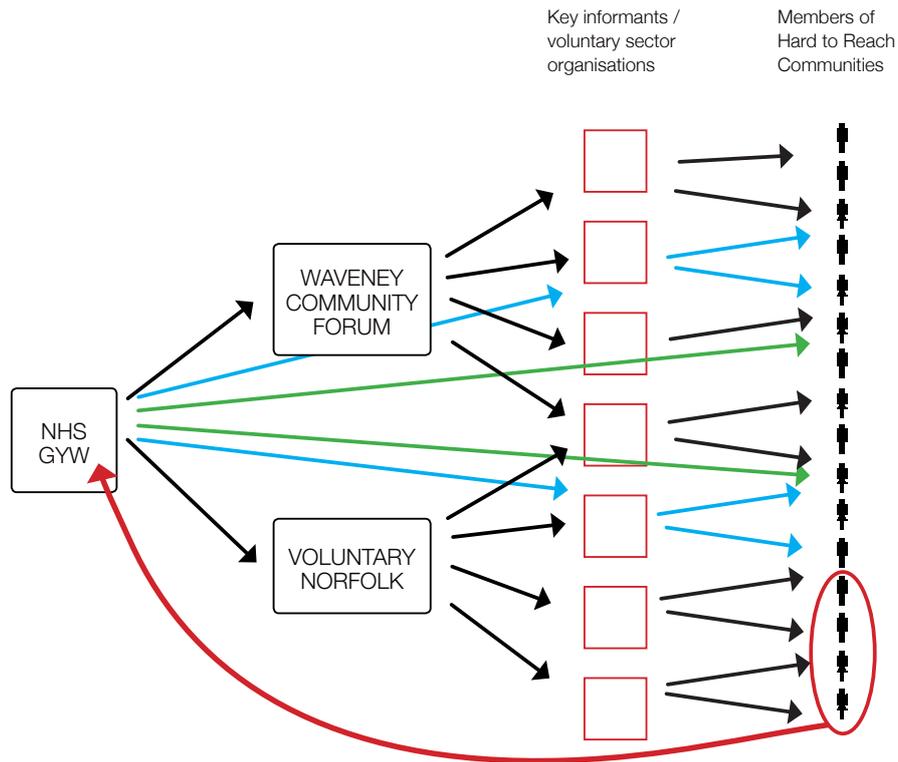
10. Objective 4: Conduct an information gathering exercise

10.1   The approach used by this project has been to recognise that accessing the views of the Hard to Reach groups directly is not possible given the allocated time frame and set parameters of the project. One of the key findings of conversations with representatives of some of the Hard to Reach groups has been an appraisal of how challenging it would be to directly access the views of those groups.

10.1.1 There are a number of complex and interrelated reasons for this:

- These are disparate and diverse groups, which are often thought of as a homogenous whole. For example, several of the representatives who participated in this project were trying to work with people from a wide range of geographical, cultural and ethnic backgrounds with the only unifying feature being that they were not indigenous to Great Yarmouth. Within individual communities there were also reported differences along generational, ethnic, socioeconomic, gender, length of time in GY and other social lines. What was presented was therefore not the views of a coherent set of 'communities' but rather a complex network of small groups and individuals bound together along tenuous lines of language and background with some more coherent groups organising visibly at the centre of these groups. Therefore from the very outset the representatives who contributed were at pains to present the limitations of their own insights in terms of generalisability to a wider population.

- A second challenge in accessing the perspectives of Hard to Reach groups in GY is the reported desire for many people who are of these groups to remain 'below the radar of services' as one representative described it. For a range of reasons many members of Hard to Reach groups locally are reported to not want to actively engage with health services.

- Representatives who contributed to this project also spoke about the challenges for them in trying to access the views of some Hard to Reach groups. They had each been working extensively with some groups for, in some cases, a number of years. They reported that engaging with these communities was a slow process that required creative thinking, a network of local contacts and the development of local understandings. They each presented innovative strategies that they have employed to reach these groups that will be synthesised in the action/recommendations section.

- Several of the representatives referred to the 'research and survey fatigue' of some of the Hard to Reach communities. They presented a paradox of the views groups being underrepresented at a local service level and yet being closely scrutinised by agencies keen to access their views and remove barriers to engagement. One respondent said that a difficulty for them when trying to access the views of members of Hard to Reach was a low expectation among some that any action will come from findings. Emergent solutions to this potential problem will be discussed in the action/recommendation section.
- A particular critique offered by key informants was that surveys carried out by large organisations are often done so in an unreflective, reactive fashion and that the findings are not visibly acted upon. There was a connected point made that some surveys done primarily serve the interests and needs of the organisation and can have little resemblance to the concerns of the groups they are trying to access. One solution to this presented by key informants was that surveys and other information gathering exercises could be done collaboratively with members or representatives of these groups and that this would provide health services that was not only more substantive but that also more accurately reflected local need

10.1.2 While these issues were found by members of the project team, it should also be stressed that there were examples of willing collaboration and enthusiasm to engage with NHS GYW in a dialogue around health needs. In particular, the prison service, looked after children and one sheltered housing contact offered to host focus groups.

10.1.3 Information gained regarding each of the identified Hard to Reach groups is reported below. It is important to be clear about the limitations of what we are able to present in this report. This report contains summaries of conversations and information given to the report authors about the views of people who work with, or are in some other way connected to the Hard to Reach groups. These summaries are inevitably shaped by the way the questions have been formulated and asked, and the way that the report authors have understood, recorded and summarised the answers. This

represents information that is therefore at least two parts removed from the actual experiences of these groups and needs to be considered as such.

10.2   Gypsies & Travellers

10.2.1 In what capacity did key informants have contact with the group?

Key informants who provided information about gypsies and travellers did not describe themselves as being close to the community. They were professionals working locally who were connected with the communities.

One key informant came from Eastern Europe and was working with some Eastern European Gypsies living in Great Yarmouth.

10.2.2 Is there any existing information about this group?

A key report 'Health care for members of the Travelling community' has been produced by Sandy Griffiths, Public Involvement Manager, NHS Great Yarmouth and Waveney. In this report Key Health Issues for Travellers at Kessingland were identified as:
- Unwillingness to access health care at GP surgeries but will discuss issues with GP when visiting site
- Unwillingness to attend hospital appointments or clinics – fear of discrimination by health professionals and other members of the public
- Unwillingness to being admitted to hospital particularly if other family member etc has died in that hospital. Conversely, there is also a widespread belief amongst those who work with Travellers that community members often prefer to give birth or die in a hospital, as these are contaminating activities.
- High instances of alcohol use and abuse in some families
- Instances of domestic violence against women are also high in some families. Many remain unreported due to the existing culture of fear and acceptance and also a fear of discrimination by 'authority'.
- Poor diet may be apparent in some families where there is evidence of low income and lack of education about good nutrition.
- Higher percentage of community smoking

leading to associated long term health conditions

- Sexual Health – discussing sexual health issues, particularly contraception, has culturally been unacceptable and remains problematic even with the younger generation. Encouraging women to have smear tests is a major problem as they will be unlikely to respond to a request to attend the surgery and carrying out the test on site is not feasible unless facilities are made available. Only 25% of travelling women have smear tests whereas the practice average is 90%. Other sexual health issues are not discussed and subsequently remain unchecked within the community.
- Child Health – major health issues for children i.e. immunisation etc are addressed but conditions such as asthma and eczema may not be identified.
- Should health care be provided on site wherever possible to maximise take-up of services? A contentious issue as perhaps Outreach work should both target meeting the community's immediate needs effectively whilst also educating and building confidence so that uptake of mainstream services is improved.

10.2.3 In a further study of Travellers, The following key issues were identified;

Family and Health Issues

1.	There is evidence that the instances of 1st cousin marriages are approx double the national average which research suggests may contribute towards some genetic health conditions.
2.	Many families do have experience of learning difficulties and environmental conditions may also be a contributory factor.
3.	The language used in many families is rudimentary, conversation is carried out at a basic communication level which does not evolve into debate or discussion.
4.	The Travellers lifestyle which could be described as a pre-industrial sense of time, possibly precludes our time driven lifestyle. Many travelling people are not aware of times, dates or days of the week and this presents problems for health services when arranging appointments etc.
5.	Appointments are still being sent by letter even though the health Trusts, GP Practices, opticians and dentists are aware that patients are unable to read. Travellers would prefer to arrange appointments and receive reminders by phone not text (still a literacy problem)
6.	Problems are still apparent with dental care. As travellers are moving around possibly part of the year and also for the reasons previously identified they miss check-ups and subsequently find they have difficulties in accessing treatment.
7.	The Travellers are extremely sensitive to people's perception of them. Occasionally they perceive, maybe incorrectly, they are being discriminated against when perhaps GP Practice staff's communication skills are less than acceptable to all patients and this experience may prevent Travellers attending essential clinical appointments in the future.

The full text of these reports can be accessed by contacting Sandy Griffiths – NHS GYW.

10.2.4 How to access the views of this group
The best way to get responses to the questions from Travellers would be to talk to the site managers themselves and perhaps one or two representatives, and the GP surgery with experience in delivering services to the traveller community. We have to bear in mind that this is a highly researched group and access may be problematic. However there are two potential sources of information: traveller liaison group and Site managers. There is a small but distinct group of Eastern European Gypsies living in Great Yarmouth and Lowestoft. Most are currently in permanent residences and share common languages with other Polish, Slovakian and Czech Republic nationals living locally. However they describe themselves as a distinct group.

10.2.5 What are the views of key informants about this group in response to the key questions?

The findings presented here are based upon conversations with professionals who work with Eastern European Gypsies.

10.2.6 How do people from Gypsy and Traveller groups use health services locally?
- Key informants reported low levels of GP registration
- There was a reported perception that access to GP surgeries is more difficult for foreign nationals, including Gypsies.

- Generally very low levels of knowledge regarding the local health system and how to access services were reported.

10.2.7 What prevents people from these groups from accessing health services?
- Perception from some that they are discriminated against.
- It was reported that many Eastern European Gypsies have radically different expectations of services based upon their experiences in their countries of origin. For example, waiting in a queue for important surgery. This systemic process then can become translated into a belief that they are being discriminated against.
- Only painkillers prescribed.
- Specialist treatment perceived to be inaccessible. Reported perception that this is about cost saving.
- Difficulty describing symptoms in general because of language barriers. Brevity of GP consultation times do not reflect this additional need.
- There was a reported feeling that many of these barriers face all people but that other groups may be more adept at circumventing problems, while people less familiar with the system may be more vulnerable to it's failings.
- Mutual lack of understanding between GP surgery staff and patients. Leads to increased alienation and estrangement.
- There was a reported lack of understanding of the nursing role in modern British health care.

10.2.8 What sources of health information and advice are used by people in the above groups, and where do they find it?
- Many were described as getting most of their health information and advice from within their own communities.

10.2.9 What health checks, tests and illness prevention services do people in the above groups use?
- Prevention literature was reported to be very visible but that this contradicted with waiting times for urgent procedures.
- It was reported that people sometimes returned to their country of origin to receive treatments that they do not believe they will be able to access locally.

10.2.10 What health checks, tests and illness prevention services do people in the above groups need?
- Cancer care was identified as the top priority for the Gypsy group
- Gynaecological assessment and treatment was also reported as important.

10.2.11 What improvements to health services are needed for these groups?
- People from these groups were described as being attached to feelings of discrimination. Therefore part of what needs to improve is how these groups perceive GYW NHS. Therefore changes need to not only address barriers to access but do so visibly and in a way that is convincing to these groups.

10.2.12 What services are needed to help women from the above groups who are having a baby or who have young children?
- The screening and immunisation of children was reported to be treated with suspicion by some parents from Gypsy communities. This mistrust was said to be exacerbated by the absence of an examination prior to immunisation, as would be the norm in their countries of origin.
- Parents from Gypsy communities were described as a highly anxious group in need of information and reassurance from health care professionals.
- Again there were reported differing expectations about accessing specialist paediatric care based upon countries of origin.

10.3 Black and Minority Ethnic groups

10.3.1 In what capacity did key informants have contact with the group?

Many of the contacts can be considered to be both of this group and also working directly with other members of this group. They each said that they felt able to participate in the project both as representatives of this group and as professionals providing a service to other members of this group.

10.3.2 The respondents presented perspectives on the views of several Hard to Reach groups identified by this project. This reflects their work roles but also the interconnectedness and overlap of the groups themselves. Each of the respondents spoke about their work with BME groups and these included

migrant workers, asylum seekers and refugees, and travellers. The respondents also commented that the BME groups they worked with also included people who could also be considered to be part of other Hard to Reach groups such as people with long term mental health problems; Lesbian, Gay and Bisexuals; and people with Learning Disabilities.

10.3.3 The information provided by respondents often pertained to all groups under the BME umbrella but often there were areas of commonality and difference both within and between groups. The groups are presented here as even though respondents were reporting on the views of several groups. Clearly issues such as language are more likely to be problematic for people who have recently arrived from non-English speaking countries than for Black British people, for example.

10.3.4 Is there any existing information about this group? There is a wide range of health related policy documents available locally and nationally on migrant workers who have moved to the UK. Some reports have been commissioned locally.

10.3.5 Two reports conducted by Community Connections relate to the demographic make up of migrant workers in Great Yarmouth, as well as an analysis of their needs. These both include information about health related issues:

10.3.6 Community Connections (2008)- Survey on perceived issues and needs of the black and minority ethnic (BME) communities in Great Yarmouth (available on request)

Carlos Antunes, Community Connections (2008)- Building a picture of migrant communities in Great Yarmouth (available on request)

10.3.7 A third report focused on the mental health needs of these groups and used data from qualitative interviews with key informants and members of the communities:

Franks W, Gawn N & Bowden G (2006). 'Understanding the mental health needs of refugees, asylum seekers and migrant workers in Great Yarmouth' This research was funded by the Neighbourhood Renewal Fund and is available to the NHS GYW on request from the first

author. Many of these reports disseminate similar findings and recommendations in relation to the communities in question.

10.3.8 A key finding of the BME survey was; "It is clear that BME communities would like a directory of services translated in different languages." In addition two thirds of respondents said that they; "Would like some support to help to be able to live independently in their own homes."

10.3.9 In Waveney the Lowestoft International Support Group (LISG) published a report in 2007 entitled; The New Communities in Waveney (Bukanska & Holland).

10.3.10 Similarly to the Community Connections report for Great Yarmouth, the authors discuss the difficulties of compiling accurate data on numbers of migrant workers living in the area. Between 2002-2006 a total of 1,150 EU migrant workers applied for National Insurance Numbers in the whole of the Waveney area, the majority of these thought to be living in Lowestoft. However local voluntary agencies placed to actual number of EU nationals at around four times this number. The largest of these groups came from Portugal, with large numbers also coming from Poland. Other EU nationalities also moving to Lowestoft included Romanians and Bulgarians.

10.3.11 In addition to EU old state and new state nationals the report also listed a range of other migrant workers living in Lowestoft. These included a significant number of students from India, Pakistan and Bangladesh who attend the local Marine Studies Department at Lowestoft College.

10.3.12 What strategies might be helpful to access the views of this group?

The reports cited above attempted to develop methodologies that could access the perspectives of the migrant worker and BME communities in Great Yarmouth directly. The first two used questionnaire methods and the sampling strategy was to actively seek out people from these communities in the local area. Community Connections staff using insider and local knowledge to take an outreach approach to accessing members of these communities at sites where

they congregated; shops, cafes etc. Focus group methods were also employed when people came to access support services at Community Connections. Qualitative and quantitative data was collected. The third report used similar strategies to the first two, to gather qualitative data from key informants, community members and representatives in individual interviews and small groups.

10.3.13 What are the views of key informants about this group in response to the key questions?

The findings presented here are designed to present a synthesis of the responses of the various representatives to these questions.

10.3.14 How do people from Migrant Worker/ BME/Asylum Seeker and Refugee groups use health services locally?
- Key informants reported low levels of GP registration
- People in these groups may wait until health care needs become urgent and then presenting to A & E (reflects working hours, perceived poor access to primary care services and means of accessing health care in countries of origin)
- Generally very low levels of knowledge regarding the local health system and how to access services were reported.

10.3.15 What prevents people from these groups from accessing health services?
- Language differences and communication problems
  - With front line and admin/clerical staff in booking appointment and accessing services
  - When using the phone to book appointments
  - Lack of language support available at time of booking on-the-day appointment due to early booking times (around 8 am) and later availability of interpreters (after 9 am)
  - Problems with written information including complex information and information that carries a range assumptions about shared knowledge (for example - knowledge of cervical screening procedures, rationale, etc)
  - Inconsistent availability and quality of interpreting and translation services
- Cultural differences such as taboos around talking about issues such as mental

health and drug/alcohol problems may lead to suspicions about professionals who raise these issues directly
- Different expectations of health care services arising from experiences in the person's country of origin
- Reliance on other community members' expertise and use of traditional medicine from other cultures
- Negative previous experiences of accessing health care services
- Perceptions of racism or lack of cultural understanding by staff in services

10.3.16 What sources of health information and advice are used by people in the above groups, and where do they find it?
- Many migrant workers received most of their information from key informants and others within their own communities. Although this was perceived to be readily accessible, it may perpetuate inaccurate information being shared.
- Local voluntary sector organisations such as Community Connections, GYROS and the Lowestoft International Support Group provide information and are able to signpost, act as mediators with local services, and gather information about community health needs.
- Information filters through to families from children who access information at school.
- GP surgeries were mentioned, but were described as less commonly used than other sources.
- Face to face contact with people was reported as being a more acceptable way of providing health related information and advice than via leaflets and other forms of media.

10.3.17 What health checks, tests and illness prevention services do people in the above groups use?
- It was reported by some representatives that people in this group needed easier access to medical assessments and specialist medical treatments. There was a reported perception among some migrant workers that they were not able to get access to specialist services and that they were prevented from doing so by their local surgeries.
- Sexual health checks were reported as being important for migrant workers as with the rest of the population but there was recognition

that communicating these services to people from other cultures could be problematic.

- Health checks and tests that are available may not be fully taken up by some groups because of cultural differences and misunderstandings between migrant workers and services. Cervical smear tests and immunisation for children were given as examples of services not taken up.

10.3.18 What health checks, tests and illness prevention services do people in the above groups need?

- health promotion services around nutrition and help dealing with problems such as vitamin deficiencies
- This was particularly the case for migrant workers who may have changed their diets and lifestyles significantly since moving to the local area.

10.3.19 What improvements to health services are needed for these groups?

- Access to information in accessible places and through agencies with whom these communities have existing relationships
- Access to sexual health information and contraception
- Distribution of culturally appropriate, well-translated road maps of how to navigate health services
- Extending existing diversity awareness training (GYROS) for staff at GP surgeries that attempted to address the underlying problems of perceived discrimination toward migrant community members
- There were specific issues around the use of mental health services. One representative said that the psychiatric system in the UK is based upon a Westernised model of illness that is at odds with other cultural conceptualisations. They said that mental health services in the UK were perceived by some BME groups as dealing mainly with the person's illness and to largely ignore the importance of mental and spiritual wellbeing. In this way it was reported that some services may be inappropriate for Afro-Caribbean and other ethnic groups.

10.3.20 What services are needed to help women from the above groups who are having a baby or who have young children?

- Antenatal and postnatal services for women and babies were seen as examples of good

practice in health care. It appears that good communication from midwives and health visitors ensured a high level of predictability regarding what to expect from services

- A clear set of procedures for who women were due to see and when, as well as detailed advice about what to do in an emergency may reduce anxieties and encourage engagement with these services by migrant workers.

For further detail on the consultation regarding these groups, see Appendix C.

10.4   Looked After Children

10.4.1 In what capacity did key informants have contact with the group?

Key informants included people working with Looked After Children within health and social services roles.

10.4.2 Is there any existing information about this group?

There are existing reports into the mental health needs of Looked After Children at national and local levels. In particular 'The mental health of young people looked after by local authorities 2003) (Internet www.statistics.gov.uk/releases - September 2009) Available free on the National Statistics website:
www.statistics.gov.uk/statbase/Product.asp?vlnk=10432

Other key findings include:
Prevalence of mental disorders
Among 5- to 10-year-olds, the rates of disorders for children looked after by local authorities compared with those obtained from the 1999 ONS survey of the mental health of a representative sample of 10,500 children living in private households were:

- *Emotional disorders: 11 per cent compared with 3 per cent.*
- *Conduct disorders: 36 per cent compared with 5 per cent.*
- *Hyperkinetic disorders: 11 per cent compared with 2 per cent.*
- *Any childhood mental disorder: 42 per cent compared with 8 per cent.*

Among 11- to 15-year-olds, the prevalence of mental disorders for children looked after by local authorities compared with children from the private household survey were:

- *Emotional disorders: 12 per cent compared with 6 per cent.*
- *Conduct disorders: 40 per cent compared with 6 per cent.*
- *Hyperkinetic disorders: 7 per cent compared with 1 per cent.*
- *Any childhood mental disorder: 49 per cent compared with 11 per cent. (ibid)*

10.4.3 A 'Google' search on this issue will locate many reports on this subject.

10.4.4 What strategies might be helpful to access the views of this group?

Looked After Children are routinely asked to express their 'wishes and feelings' at regular reviews of their care needs within Children's Services. Health services could negotiate for the children to be asked questions about their views on health care and their health care needs at these times. However, it has been noted that some children see this as a paper exercise to meet the needs of adults and services, although some children find it useful to express their views. There are multiple sources within the systems that care for Looked After Children, which could also be approached for access to information about children's views. Within Child & Adolescent Mental Health Services, a number of multi-systemic groups are being set up, which include groups of foster carers and Looked After Children themselves. It may be possible to negotiate access to children's views through these groups and through foster carers directly. There is a group of Looked After Children called the Children in Care Council, which represents Looked After Children to professionals. It may be possible to request information from this group directly, via Children's Services. A website is run by Children in Care called Kids in Care Together (www.kict.norfolk.gov.uk) and this was suggested as another means of contact. It was suggested that young people who may otherwise have problems with literacy may be better reached through electronic forms of contact such as social networking internet sites (e.g. facebook) and mobile phones, using SMS or text-based spellings and language, although this may need to be translated

for many adults to understand.

10.4.5 How people in the above groups use health services?
- All Looked After Children have a named Social Worker, and regular Looked After Children reviews, regardless of whether they are placed in foster care, parental placements, adoption, residential care or are supported to live independently. The reviews involve a review of their health care needs.
- When young Looked After Children are in stable placements, their healthcare needs are normally taken care of by the adults responsible for them.
- Older Looked After Children may take responsibility for accessing healthcare themselves, but there are potential difficulties which will be outlined below.

10.4.6 What may prevent Looked After Children from using services?
- Many Looked After Children are reliant on adults to identify their health care needs and access services for them. There may be a general under-reporting of health concerns due to the nature of the relationships between Looked After Children and the adults who care for them, including placement instability and breakdown.
- Although the health care needs of all Looked After Children is monitored routinely as part of the statutory Looked After Children review, there may not be one adult in day to day contact with the Looked After Child over the long term. As a consequence, the responsibility for their health care needs may be shared and may not be fully understood or handed over from one responsible adult to the next.
- Mental health problems may be under-reported by foster-carers due to stigma, uncertainty and the focus on immediate management of behaviour and safety of the child.
- Mental health problems may be largely unrecognised and untreated. Looked After Children may not be referred for psychological or psychotherapeutic services and problems may be compounded by care systems around the child.
- Due to placement instability, peer relationships, friendships and education are often disrupted, and the normal routes for access to health care services are less often available to Looked After Children.

- Looked After Children may be registered only temporarily with GPs due to frequent moves, and may find it difficult to get registered at the practice used by foster parents if it is over subscribed. Many are likely not to have a consistent GP who knows them and understands their health care needs.
- Older Looked After Children may find it difficult to be motivated to go to GPs for many reasons, including – previous negative experiences with GPs; fear of judgement or stereotyping; a lack of trust in adults; lacking a culture of looking after their health in previous family experiences; lacking motivation for the effort required to get an appointment.

10.4.7 What sources of health information and advice are used by Looked After Children, and where do they find it?
- Where Looked After Children have more stable placements, they are likely to access health information and advice through normal routes, including parents (including adoptive and foster parents), peers and health education in schools.
- Where there is frequent change, placement breakdown and disrupted relationships, these sources of information and advice may be less available to Looked After Children, compared with other children.
- For older Looked After Children there are several community-based services such as MAP who provide health information to young people.

10.4.8 What health checks, tests and illness prevention services do people in the above groups use.
- Looked After Children in stable placements have access to routine health checks and illness prevention, including childhood immunisation, dental and optical examinations.
- This is often triggered by social workers at regular reviews and assessment carried out through questionnaires to foster carers, and is dependent on foster carers reporting and returning the forms. This is potentially less likely to happen for children in unstable placements.
- Older Looked After Children use sexual health services and there is a relatively open culture within services in relation to talking about sexual health and family planning services.

10.4.9 What health checks, tests and illness prevention services do Looked After Children need?
- Many Looked After Children were described as having more risky and chaotic lifestyles compared with other children. This includes higher levels of unprotected sex at younger ages. Due to the experience of family discord and breakdown, these children may lack protection and seek love and care outside of the home. The home environment may be unpleasant, and they may be vulnerable due to spending time away from home.
- Looked After Children are therefore likely to need appropriate information and health promotion services in relation to sexual activity.

10.4.10 What improvements to health services are needed for Looked After Children?
- Primary health care professionals including GPs need to be well trained and take a sensitive approach to the needs of Looked After Children. Looked After Children should be able to have a choice regarding the gender of their health care practitioner.
- There needs to be better outreach and accessibility of services for some Looked After Children who may have had negative experiences in health care and in relation to trusting adults. It is often difficult to get through to GP surgeries to book an appointment on the day, and there should be more accessible walk-in style clinics with extended hours.
- Many Looked After Children are also considered to have Learning Disabilities and services need to be joined up to provide adequate care.
- Looked After Children have higher than average experiences of emotional and mental health problems. They need access to flexible and responsive services that are appropriate to their needs. This may not necessarily involve traditional settings for therapeutic services, but will need to be developed according to their needs.
- Enuresis is often a problem throughout childhood for children who have been sexually and physically abused. The services for helping with enuresis should be improved and accessible across the age range for Looked After Children.
- Services are needed to work directly with Looked After Children, as well as to support the systems around them, to promote placement stability and work through relevant others to

enable responsive support for the child.

- It is important to note that gender affects the way that Looked After Children will express their distress and mental health needs. Service development needs to consider the effects of gender.

10.4.11 What services are needed to help women from the above groups who are having a baby or who have young children?

- There is a small number of young women in the local area who are Looked After Children, and who are mothers themselves.
- The health care needs of this group include the sensitive support as outlined above in addition to support in helping them to make sense of the transition to parenthood.
- Health Visitors and Midwives have a narrow window for engagement, and therefore need to be well trained in the needs of Looked After Children and bring a sensitive approach to engagement.
- It is not clear how many young men are Looked After Children and have become fathers, however there are anecdotal reports of some young men having frequent unprotected sex and fathering several children with a number of young women. This is an important area for prevention and health promotion, however this needs to be undertaken with an appreciation of the broad range of issues affecting Looked After Children, rather than an approach to prevention that just focuses on the provision of information.
- The extent of emotional vulnerability and lack of secure and supportive parenting experienced during their own childhood is likely to increase the need for specialist support for Looked After Children to develop their own abilities to parent their own children sensitively and responsively.

10.5 Individuals within the Criminal Justice System

10.5.1 In what capacity did key informants have contact with the group?

Key informants included a healthcare manager based at HMP Blundeston, a psychiatric nurse who works with offenders and members of a Youth Offending Team.

10.5.2 Is there any existing information about this group?

Measuring the Quality of Prisoner Life (MQPL) survey. This survey contains information that closely relates to that which this project seeks to discover. The healthcare section of this survey is reported here (with permission);

10.5.3 Current dimension scores were made more meaningful by comparing them to average scores obtained from surveys of other establishments of all types (Figure 3.2.3) and of training prisons alone (Figure 3.2.4). None of Blundeston's scores fell notably below the mean or middle of the 'typical' range of scores for the estate… Most positive was the score for Drug Culture which fell close to the top of the 'typical' range, bordering on unusually high in both comparisons; as did the scores for Healthcare and Rehabilitation when compared to training prisons alone. (pp6)

10.5.4 Healthcare

Sample	Mean	SD	SEM			
Blundeston				Strongly Agreed/ Agreed	Neither Agreed nor Disagreed	Strongly Disagreed/ Disagreed
Whole Estate	3.00		0.35			
Training	2.93		0.35			
I feel cared for by staff on the healthcare unit *				49.4%	21.2%	29.4%
Healthcare staff are interested in helping me with my physical health concerns *				49.4%	27.6%	23.0%
I am happy with the treatment I have received in this prison for my health problems *				48.3%	18.4%	33.3%
Healthcare staff show understanding for my mental health and emotional concerns *				44.2%	32.6%	23.3%
The doctors here take the time to listen to my physical health concerns *				55.8%	15.1%	29.1%
The doctors in here believe me when I tell them about my health problems *				49.4%	14.9%	35.6%
Healthcare staff explain things (treatment and diagnosis) clearly to me*				57.5%	23.0%	19.5%

* Responses to all 7 statements were recorded for only those 88 prisoners who said they had experienced Healthcare services at Blundeston.

10.5.5 What strategies might be helpful to access the views of this group?

There is not a specific health care focus group. Although there is a desire to develop one, time limitations are a major problem. There are regular prisoner forums. Healthcare services engage with these forums.

10.5.6 The Trust is also going to use a 'viewpoint touchscreen' as a way of making contact with service users at Blundeston. The Prison's Security lead has agreed for one terminal to be placed n the healthcare dept. and another in the Resettlement area so those not seeking healthcare can be accessed. The terminals will use the main 'other' languages in current use at Blundeston in addition to English. Blundeston Prison healthcare will be just one of the locations for this roll out across Community Services; the provider arm of the NHS GYW.

10.5.7 It was suggested that people would be willing to give their views if they felt there was some return for doing so. For people in custody, it was suggested that time out of the cell and alleviation of boredom may be a sufficient reward.

10.5.8 A further strand for patient engagement being explored is the use of a named Community Development Worker to assist us in surveying prisoners with a BME background and their access to prison healthcare services. This particular project is in it's infancy - no dates as yet. (email correspondence 4th August 2009)

10.5.9 A health needs assessment has been carried out by the Youth Offending Team in Great Yarmouth, and this is due to be reported back in the Autumn of 2009. Initial attempts at assessing health needs via questionnaire were not successful, but the most recent questionnaire had better response rates due to redesign. This reflects the importance of carrying out pilot versions of questionnaires, if these are to be used to access the views of any group.

10.5.10 How do people from these groups use health services locally?
- Many people within the criminal justice system were described as using health services opportunistically. There are multiple factors that may make it difficult for people in these groups to use health services (see below), and opportunities to access health care whilst in custody were described by some key informants. People within this group were described as not planning ahead for their health care, and not typically seeking health services except in emergency.
- Physical health care services were described by key informants as very responsive and rapid to access for people in custody of the criminal justice system, or under the care of the Youth Offending Team. In this respect, it was suggested that people may have significantly better access to health care whilst in custody than at other times, and than other people around them (for example siblings of young offenders)
- When under the care of services, or when in custody, professionals are responsible for ensuring that health needs are assessed and treatment offered and this makes it more likely for health needs to be met.
- At the point of assessment, prescriptions can also be made available free of charge to offenders.

10.5.11 What prevents people from these groups from accessing health services?
- Lack of available resources was considered to be a significant barrier for young offenders who have mental health problems. Many young people who are distressed were described as not meeting criteria for existing services.
- Lack of identification of problems as related to mental health was also a barrier. Some young people were described as having problems of depression and misuse of alcohol or drugs which led to crime, but which would be more appropriately treated if recognised as a mental health problem.
- Offenders were sometimes currently or previously Looked After Children, and had complex mental health needs that went unrecognised.
- Many people in the criminal justice system were considered to be reluctant to seek help from a GP regarding physical and mental health problems, and some are not registered with a GP.
- At the point of access to mental health services, some people may experience barriers to care due to the type of services offered (eg services that require regular, organised appointments

that are difficult to maintain an otherwise chaotic lifestyle) and extensive waiting times.

- A minority of people have been excluded from health services due to their previous behaviour, and some were described as using the criminal justice system in desperation to access health services.
- Services were seen as being difficult to access by people who may want to remain 'under the radar' of authorities for a range of reasons.

10.5.12 What sources of health information and advice are used by people in the above groups, and where do they find it?

- Information is provided to people in the criminal justice system by professionals at the point of assessment, and this may be the only point of contact for these groups to access health information and advice.

10.5.13 What health checks, tests and illness prevention services do people in the above groups use?

- A wide range of health checks, tests and illness prevention services were described, from identification of chronic illnesses like diabetes and arthritis, to pregnancy testing.
- Some people were described as entering the criminal justice system as a result of mental health problems such as psychosis, bipolar affective disorder, or complex needs arising from a history of abuse in childhood. In such cases, initial screening was a point of assessment and redirection to psychiatric services.

10.5.14 What health checks, tests and illness prevention services do people in the above groups need?

- Key informants suggested that the need for health checks, tests and illness prevention is extensive in sections of this group, particularly in relation to basic healthcare for those who live chaotic and risky lives.
- Mental health was frequently cited as a significant problem in these groups, although it was often seen as being obscured by drug and alcohol use.
- Lack of safety in using drugs and alcohol was an issue that contributes to the physical health needs of people in this group, however, it is unlikely to be a straightforward matter of raising awareness of health promotion in groups where there are complex emotional needs that contribute to health behaviours.

- Smoking cessation was reported as a health promotion service that some young offenders requested.

10.5.15 What improvements to health services are needed for these groups?

- In general, the greatest concern raised by key informants was of the mental health of people in the criminal justice system.
- More accessible mental health services, and services that were flexible in relation to criteria and means of access were suggested.
- There were complex issues relating to this group because of the potential for misuse of the systems in place to provide health care, and this issue merits further exploration than was possible in the scope of this project.

10.5.16 What services are needed to help women from the above groups who are having a baby or who have young children?

- If women say they are pregnant in custody, they are routinely offered pregnancy testing and subsequent advice and access to midwifery services if tested positive.
- In common with women in other groups, such as Looked After Children and people with long term mental health problems, women in the criminal justice system may be vulnerable, experience poor mental health and have a history of abuse in childhood. There are therefore further complex issues relating to parenting that were beyond the scope of this project to explore.

10.6   People with Learning Disabilities

10.6.1 In what capacity did key informants have contact with the group?

The key informant was an Advisor for the Great Yarmouth branch of People First of Norfolk, advocacy organisation for people with learning difficulties.

10.6.2 Is there any existing information about this group?

None was identified.

10.6.3 What strategies might be helpful to access the views of this group?

Advisors and advocacy workers who work with this group have been able to ask the views of group members directly as part of this project This was done in a group and was a productive way of finding out people's views. It should not be assumed that people with learning disabilities are able to read and respond to questionnaires without support, but it would be important to seek advice from the group regarding the best way to find out their views in future.

10.6.4 How do people with learning difficulties use the health services?
- In a crisis, when something goes wrong, like an accident or they feel ill.
- Support workers or carers take them for repeat of medication.
- They would go to see the nurse at the surgery.
- Three people said they never go to the doctors.

10.6.5 What prevents them from accessing health care?
- Lack of support to go to the doctors.
- Staff not recognising when they are ill.
- Fear of going.
- Not understanding what is going on.
- People don't listen to them.
- Made to feel silly about things.
- Unable to read written information (may receive an appointment but cannot read)
- Don't know where the doctors are.

10.6.6 What sources of health information and advice are used by this group?
- Information given by support workers.
- Information from Day Service.
- Staff at college.
- Advocacy Group (People First) give information and do workshops and training.
- 2 people said that they got information from the doctor's surgery.
- Sue Smithurst has produced some accessible books as part of her PHD, these are on health topics and many of the group have been asked to look at them and give feed back.
- 5 people said they had no information and didn't know where to get it from.
- People give them talks e.g. Karl Jackson Food Fitness Fun project.

10.6.7 Where do they find this information?
- As above much of the information is told to them; unless information especially written information is given in an accessible way it has little or no meaning.
- Some people said that talking to the Practice Nurse was helpful.

10.6.8 What health checks, tests and illness prevention services does this group use?
- 1 lady with cerebral palsy said that she couldn't have a cervical smear because her body shape made it too difficult to do.
- A parent carer said that her daughter was refused a smear because she was not sexually active.
- Out of a group of 10 ladies only one of them had ever had a cervical smear; her mum took her to the doctors.
- A lady with Down's Syndrome said she went to a clinic with a 'water infection' (cystitis) and was made to feel very ashamed, the nurse told her she shouldn't be sexually active. She isn't!
- There were ladies in the group over the age of 50yrs and none of them had received appointments that they knew about or had been screened.
- The 6 men said they had not had any health screening to do with men's health but 2 have had their B/P taken by the nurse.
- Accessing opticians seemed to be a universal problem in the group; This may relate to accessing buildings for the disabled.
- There was also a problem accessing NHS dental care and 1 lady said that she now found it difficult to see her dentist because of problems with getting up the stairs.
- Over all this question produced a fairly negative response. People were either not aware of the routine health screening they should be able to access or had not been able to access it for some reason.

10.6.9 What health checks, tests and illness prevention would people from this group say they needed?
- Help with loosing weight and finding out about healthy food.
- Regular dental check ups.
- 2 People have diabetes and would like to know more about it.
- 7 People said they would like to find out if they had diabetes or high blood pressure.

- 2 people said they would like to know who can help them when somebody dies, such as a family member or a friend. Support for grief and bereavement counselling doesn't seem to be available.
- All the women agreed that they would like to be able to have cervical smears because they were worried about cancer.

10.6.10 What improvements to health services would people in this group like to see?

- Information that is more accessible so they can understand it, with pictures and no long words or jargon.
- Being listened to by the doctor or nurse and being treated with respect. Staff being trained to work with people with learning difficulties.
- 2 ladies complained that they had to give information about themselves which they felt was private in crowded waiting rooms where everybody was listening. They would like to have been offered somewhere private to do this. They need support to fill in forms.
- Forms should also be more accessible, the writing is always too small.
- Having the same access to treatment as everybody else and not being treated as special cases.
- Better counselling services when they need somebody to talk to, they don't always want to share information with carers or support workers.
- Being able to find out more about healthy things like food and exercise and how to lose weight.
- Better access to buildings for people in wheelchairs or who can't walk very well.
- Having routine check ups once a year at the doctors to find out if you are healthy.
- More information about getting cancer.

10.6.11 What services are needed to help women from the above groups who are having a baby or who have young children?

- This question could not be answered by this group as none of them have ever been pregnant so were not sure about how to answer the question.

- The key informant identified the need for good communication skills for the staff important so that people understood what was happening, and a high level of support through the pregnancy and afterwards to ensure that the person was coping.

10.7   People with long-term Mental Health Problems

10.7.1 In what capacity did key informants have contact with the group?

The focus group consisted of a number of mental health service users who come together as a service users group to support one another in recovery. They meet weekly and have contact with a wide range of mental health service users in Great Yarmouth and Waveney. The group was speaking as an advocacy organisation on behalf of people with long-term mental health problems and also as a group of mental health service users.

10.7.2 Is there any existing information about this group?

No existing local reports were identified.

10.7.3 What strategies might be helpful to access the views of this group?

This group and others like it locally are clearly visible and easily accessible to interested health care professionals. Indeed the majority of them are at least partly funded by NHS GYW. The group reported that they would be happy to participate in this project and to be approached to act as a focus group in future. However, as can be read below, members of this focus group expressed high levels of dissatisfaction with the perceived inaccessibility of mental health services locally. If this continues to be the case in the future then asking repeatedly about access to health services will be unproductive and potentially harmful to focus group members.

10.7.4 How do people in this group use health services?

- GP surgeries and the attached Link Worker services were described as the main point of contact.
- Representatives described many mental health service users as relying on their GPs to provide a wide variety of health care services that stretch their role. For example, it was reported that in the

absence of any secondary mental health services being involved GP's may take on a counselling and supportive role around mental health.
- Link workers were cited as providing an important interface between primary and secondary care and were often seen as the only form of specialist mental health service available.

10.7.5 What prevents people from these groups from accessing health services?
- Barriers to accessing mental health services were the principal focus of the group.
- Secondary mental health services were seen as inaccessible. Some representatives expressed that their lives were being affected in an ongoing way by what they perceived as 'rationing of services'.
- There was a perception among some representatives that GPs were charged with managing low-level mental health problems and that the use of medication as a first point of treatment was not always helpful.
- Secondary mental health services, specifically in the form of psychologists and psychiatrists, were perceived by some representatives to be almost completely inaccessible for all but the most serious of problems. Examples of inaccessibility were provided, including people having to pay for their own assessment and diagnosis, and people not being able to get through to secondary services when they had major mental health diagnoses, e.g. PTSD and Bipolar Affective Disorder.
- Certain types of specialist mental health treatment were not available on the NHS. One example of this was Neuro Linguistic Programming (NLP) not being available on the NHS. This lack of availability was reported to result in many mental health service users accessing treatment privately.
- Some representatives interpreted this lack of availability as evidence of not being taken seriously by health services. This was described as adding to their sense of alienation and exacerbating existing mental health problems.
- While some GP surgeries were described as being very supportive others were seen as taking a dismissive attitude towards 'revolving door patients.' This was reported to result in important physical health problems being missed.

- The group described feeling that health services were increasingly motivated by financial concerns, going as far as to say that they their service level involvement with for profit employment agencies means that they are less committed to helping people who are unlikely to return to work.

10.7.6 What sources of health information and advice are used by people in the above groups?
- The group described themselves and other mental health service user groups as important sources of information and advice for other service users. They said that they provided both a useful signposting service to other agencies and a source of support when services were either inadequate or ineffective for people.
- The Link workers service was held up as an exemplar of good practice. They were seen as a highly accessible service that provided good low-level support and had excellent knowledge of what was available locally.

10.7.7 What health checks, tests and illness prevention services do people in the above groups use?
- Representatives described not being able to access the health tests they needed to. These included assessment by a psychiatrist or psychologist.
- There was a perception among some representatives that they were not 'mad' enough to warrant specialist tests or assessments. This was informed by a belief that their mental health would have to deteriorate before they could get access to any specialist services.
- Mental health service user groups were presented as a form of illness prevention that was readily available to this group. The peer support available was described as being more flexible than anything that health services could offer and was seen by the group as having an important health promoting function.

10.7.8 What health checks, tests and illness prevention services do people in the above groups need?
- There was a suggestion from the group that mental health services could operate a triage system for mental health. This would differ from the existing Link worker service in that there would also be a psychiatrist and psychologist available for consultation.

- In relation to illness prevention, representatives cited the example of day care facilities as a way that mental health service users can stay well and prevent deterioration in their mental health.

10.7.9 What improvements to health services are needed for these groups?
- The group presented specific suggestions regarding how mental health services could be improved locally:
  ° Panic and anxiety workshops were held up as examples of good practice that were relatively easy to implement and had been helpful for people in the past.
  ° Groups of different varieties for mental health service users were described as being good at building confidence and allowing for the development of supportive relationships that could transcend the need for health service intervention.
- Some Link workers were again cited as examples of good practice with regards to how to engage with people with mental health problems. Ideal qualities included treating people as a 'whole person' and not just a diagnosis, an ability to concentrate on positives and mobilise the person's resources and not having a strict sense of time limits like GPs.

10.7.10 What services are needed to help women from the above groups who are having a baby or who have young children
- Representatives said that mental health service users would benefit from having a designated health visitor who was trained in mental health who could pay particular attention to 'bonding issues' in the early weeks of the baby's life.
- It was also suggested that there could be space for mothers to access Acute services with their babies if they become acutely unwell, e.g. post-partum psychosis.

10.8   Lesbian, Gay, Bisexual and Transgendered

10.8.1 In what capacity did key informants have contact with the group?

Key informants from the community included a worker from the Sexual Health Promotion Unit (Specialists in HIV, STI prevention, chlamydia screening, sex and relationships training, and harm reduction) and volunteers from BLAH, an organisation offering support to Gay, Lesbian and Bisexual young people across the area.

10.8.2 Is there any existing information about this group?

Yes. Presentation notes and slides were provided by the Sexual Health Promotion Unit. These have been placed (with permission) into the project data base. While they do not address the key questions directly, they do inform discussion about the problems. Further suggested data included that which could be located at;

SIGMA- http://www.sigmaresearch.org.uk/go.php/about/contact/
Norfolk DAAT - http://www.nordat.org.uk/
Terrance Higgins Trust - http://www.tht.org.uk/
Stonewall - http://www.stonewall.org.uk/

10.8.3 Reducing health inequalities for Lesbian Gay and Bisexual people: Evidence of health care needs (Ruth Hunt and Adam Minsky 2007) is a national report which was suggested by one of the key informants, who considered that the issues it addresses are relevant to the local community. (For more detail, see Appendix D)

10.8.4 What strategies might be helpful to access the views of this group?

Key informants suggested that a questionnaire based survey of these groups would be an appropriate method of accessing their views. They suggested that people within these groups are rarely asked about their health care needs, and that many would value the opportunity to represent their views. Clearly this group is internally diverse, and may incorporate members from any of the other Hard to Reach groups. People with learning disabilities, mental health problems, BME groups, Travellers, Looked After Children, people in the criminal justice system and homeless people may also be lesbian, gay, bisexual or transgendered. Therefore, these additional issues would need to be taken into consideration for some members of the Lesbian, Gay, Bisexual and Transgender communities.

10.8.5 What prevents people from these groups from accessing health services?

- Key informants suggested that national research on this topic is reflected in the local communities. They thought that gay men and women may avoid disclosing their sexuality to health care workers because of fears of discrimination, or an excessive focus on sexual health by care providers.
- Many young people who are gay face social assumptions that they are heterosexual, and may not feel able to be open about their sexuality with health care providers.
- Where the health care issues pertain to sexuality and sexual activity, many young people may be afraid to seek advice and services, and may not have anybody they feel they can talk to for advice or support.

10.8.6 What sources of health information and advice are used by people in the above groups, and where do they find it?

- Information and services regarding sexual health are likely to be accessed through the local G.U.M clinic by gay men
- There are some new initiatives by BLAH to take sexuality and sexual health information into schools, however, some school staff have expressed doubts that there are children in their schools who are gay or questioning their sexuality.

10.8.7 What health checks, tests and illness prevention services do people in the above groups use or need?

- Key informants thought that health care issues may have areas of overlap between lesbians, bisexuals and gay men.
- There are a range of health care needs that are common to these groups and the whole population. Although there are health promotion needs associated with sexuality, this is the case for the heterosexual communities as much as for the gay communities.
- Many young people in these groups want advice on healthy eating, lifestyles and fitness.
- Lesbian and bisexual women's health needs were thought to be overlooked, particularly in relation to information about safer sex and sexually transmitted infections, as many young lesbians may mistakenly think that they are not at risk

of a range of sexually transmitted infections.
- Mental health was thought to be a significant issue for young lesbians, bisexuals and gay men in Great Yarmouth and Waveney. In particular, self-harm and eating disorders were considered to be more common in these groups.
- Issues raised were associated with poverty and deprivation, experiences of bullying and feelings of stigma, shame and isolation.
- Being 'out' in Great Yarmouth and Waveney was considered to be more difficult than other places (like Norwich) due to the lack of a gay scene, and fears of sexuality-based hate crime.

10.8.8 What improvements to health services are needed for these groups?

- Local volunteers thought that people who are transgendered have different health care and support needs than people who are lesbian, gay or bisexual, and that within these groups there are a range of differing health needs.
- The issue of mental health was raised as particularly significant for young people in these groups, and access to mental health services was raised as an important improvement needed. Staff training to understand issues of sexuality is important.

10.8.9 What services are needed to help women from the above groups who are having a baby or who have young children?

- Key informants were not aware of what services may be needed, however, national research suggests that lesbian women's fertility and reproductive health needs are complex, and this may be an area where further research is needed. It was suggested that lesbian women may feel isolated as mothers due to their sexuality.

10.9 Homeless and Insecurely Housed People

10.9.1 In what capacity did key informants have contact with the group?

Key informants included a director of services for an organisation that operates 6 supported accommodation schemes for homeless plus a drop in service for rough sleepers in Great Yarmouth, the manager of the Aspire supported housing scheme for young people in Great Yarmouth and a support worker who works for the St Matthew's Housing

Project in both Great Yarmouth and Waveney.

10.9.2 Some of the Key informants have worked in the 'Hard to Reach' area for a number of years, within NHS primary care service for homeless people in Norfolk. As with other Hard to Reach groups there is a high level of cross over between groups by people and so these Key Informants also have extensive experience of working with people from multiple Hard to Reach Groups. These include people with long term mental health problems, people with learning disabilities, migrant workers and people involved in the criminal justice system.

10.9.3 Is there any existing information about this group?

The Queen's Nursing Institute, Homeless Health Initiative, Service User Consultation Report, February 2008 , Groundswell UK

www.qni.org.uk/userfiles/file/HHI/Groundswell-HHI-Report3.pdf

See Appendix E for brief recommendations from this report.

10.9.4 What strategies might be helpful to access the views of this group?

Key informants suggested that certain sub-groups within this population would be easier to access than others. For example, they said that people who had recently entered any of the hostel or supported housing sites locally could be accessed through support staff. They said that it is more difficult, but potentially more important, to access the perspectives of the two types of homeless described- those who are street homeless or sofa surfers. By their very nature these sub-groups are in different ways less accessible. One reported way to access the views of street homeless people who also use mental health services would be through the Assertive Outreach Team who work with people in this category.

10.9.5 Once people have entered a hostel or supported housing scheme Key Informants suggested using their Residents Meetings, which typically occur monthly, to hold focus groups. Another suggestion was accessing the views of service user representatives who live in supported

accommodation and advocate on behalf of their fellow residents. It was also recommended that payment of some form to participants would encourage participation and place value on people's views.

10.9.6 How do people in these groups use health services?
- People most regularly access specialist services such as Drug and Alcohol Services and Mental Health Services.
- Many will already have a mental health care coordinator when they enter into the hostel or supported housing accommodation. These professionals are then seen to be responsible for all aspects of the person's health care.
- It was reported that some hostels in Norfolk had an NHS in-reach nursing service but it was reported that this was not available in Great Yarmouth or Waveney.
- Entry into a supported housing scheme was described as crucial before people can effectively access health services. Most medium term supported housing schemes will help residents to get registered with a GP and dentist when they begin their tenancy. This often involves support workers accompanying them to their local surgeries.
- It was reported that voluntary agencies such as the Mancroft Advice Project will screen new residents living in supported housing for mental health problems and then refer on to relevant agencies.

10.9.7 What prevents people from these groups from accessing health services?
- Several informants said that finding a service provider can be difficult for homeless people, when an address is often needed to register for services.
- Providing services to homeless people is expensive.
- Many homeless people have poor literacy, and this may present a barrier in relation to appointment letters, and so on.
- People who are temporarily housed in Bed and Breakfast accommodation by the Council while awaiting accommodation were described as isolated and therefore less likely to get access to health services.
- People with substance misuse problems may be excluded from a range of health services

due to attending appointments intoxicated.
- Accessing services may not be a priority for people who are street homeless and focused upon moment-to-moment survival.
- Transport and lack of access to resources was described as a barrier for people who have to use health services that are further away.

10.9.8 What sources of health information and advice are used by people in the above groups, and where do they find it?
- Housing Support workers and other residential staff were described as important sources of information and advice.
- For young people in this population, Connections was presented as a useful source of health information and an accessible service that can advertise health services locally.

10.9.9 What health checks, tests and illness prevention services do people in the above groups need?
- Sexual health screening service.
- Mental Health services need to be more available to carry out assessments on people who are homeless or insecurely housed. The Assertive Outreach model was suggested as an example of good practice in providing services flexibly.
- It was reported that health services need to go into short stay hostels to offer a range of screening and health checks.

10.9.10 What improvements to health services are needed for these groups?
- More accessible mental health services that are more flexible to people's   chaotic living circumstances were described as crucial in improving the health of this population.
- Health services generally being more responsive and taking an outreach strategy to target this population. The message from informants was not to expect members of this population to access services directly.
- Housing staff who work with this population being made more aware of the services that are available; such as the new Improving Access to Psychological Therapies services.

10.9.11 What services are needed to help women from the above groups who are having a baby or who have young children?
- This was described as an area of good practice due to the predictability and consistency of services.
- Partnerships between health services and housing organisations would be of further benefit.

11. Objective 5: Undertake an analysis of findings

11.1 This project has illuminated a range of the difficulties inherent in accessing groups that are defined as Hard to Reach.

11.2 General comments

11.2.1 Although directly accessing the Hard to Reach groups was beyond the scope of this report, the authors were able to access a number of different levels of information provided by key informants who have varied experience of working with/being part of Hard to Reach groups. These different levels of information can be related to differing levels of proximity to the communities. Some key informants will have been working for a relatively short time with the groups and are outsider professionals in relation to the groups. Others will have had longer-term involvement with the groups, and some may also have direct experience of belonging to one or more of the groups. Some people are working professionally with the groups and are employed in part in their capacity as group members. This variation across the sources of information given will inevitably affect the perspective that is being presented. Within any given group there are a range of perspectives that cannot all be represented by one or two key informants. There may be differing perspectives and priorities across key informants that will vary according to their own personal position, values, experience and knowledge. Therefore it will be important to take this information as an example of how to access the information, and as exemplars of the perspectives held within the communities, rather than as generalisable or representative of the whole communities.

11.2.2 As outlined above, this project did not aspire to comprehensiveness in representation of the communities addressed. Rather, what has been achieved is a broad collection of perspectives to inform how to move forward in working toward the aim of engagement across all sections of the communities served by NHS GYW. With the degree of diversity within and across communities, it becomes readily apparent that any attempt to catalogue this diversity would be an enormous, and potentially never-ending task due to the dynamic nature of populations, cultures and the individuals within them. There are questions regarding how useful it would be to undertake such a task, particularly in the light of other, more pressing needs as expressed by key informants in this project.

11.2.3 However, what remains is the problem of initiating changes to healthcare provision that reflect the specific needs of particular groups or individuals from Hard to Reach communities. When considering what these may be it will be important recognise that consistent, predictable and person centered care models are the most successful for Hard to Reach communities.

11.3 Commonalities and differences

11.3.1 Across the groups that are described in this report, there are a range of areas of commonality, and also significant areas of difference.

11.3.2 One of the unexpected findings of this project was the extent to which many key informants focused on the mental health of people in Hard to Reach groups. When asked about health issues, many key informants had a great deal to say about their own struggles in working with people in Hard to Reach groups who had unmet mental health needs. This was the case for Looked After Children, individuals in the criminal justice system, members of Lesbian, Gay, Bisexual and Transgender communities, homeless and insecurely housed people and people with long term mental health problems.

11.3.3 It is important to note that the groups identified as Hard to Reach, are not exclusive categories, of which any individual will only belong to one. Talking to key informants in this project has shown that these areas of overlap are not always random or accidental. In many cases there may be a direct relationship between categorisation within of one Hard to Reach group leading to further exclusion and disadvantage, and subsequently joining another Hard to Reach group. In other cases there may be additional, underlying factors that lead to a person becoming a member of more than one group, and which will vary between individuals. For example, a boy growing up in a series of unstable foster placements may lead to distress being channelled into anger and criminal activity, with dependence on drugs and alcohol as means of

self medicating. Such a boy may move from being a Looked After Child to being an individual in the criminal justice system, and perhaps homeless or insecurely housed. For another child, for example a girl growing up in a series of unstable foster placements, distress may be expressed and managed through self harm and entry into the mental health system and becoming a person with 'long term mental health problems'.

11.3.4 These ways of becoming Hard to Reach are far removed from belonging to an ethnic or racial identity group within a relatively supportive community that may be excluded from access to services because of a mismatch between cultures and assumptions. This is different again from escaping from persecution or a war-torn country to seek asylum in the UK, or being born with a chromosomal disorder such as Down's Syndrome that affects physical and cognitive development. Hard to Reach as a categorisation to describe all of these experiences, identities, and situations is overly simplifying, and potentially contributes to the problem.

11.4 Hard to Reach?

11.4.1 Although this report has used the language of membership of Hard to Reach groups, it is apparent that 'Hard to Reach' is a construct that should be subject to further consideration.

11.4.2 The state of being Hard to Reach is expressed from a particular perspective – it places people in groups at a distance from 'us' (often professionals) within our own organisations. Indeed people described as Hard to Reach have been so, from the perspective of a commissioning NHS Trust, or a group of university-based academics and healthcare professionals. In actuality, those groups are not so Hard to Reach for many of the people who have been consulted as key informants during this project. This raises questions regarding the idea of defining others as Hard to Reach, or 'Seldom Heard', 'Socially Excluded' or 'Easy to Ignore', by whom people are so defined, and whether this is an unhelpful way of approaching the possibility of inclusion and engagement. To illustrate this, the term 'Hard to Access' may be applied to certain services – this would challenge us consider what the barriers might be from a different perspective.

To locate the Hard to Reach as being far removed from our organisations places us in a particular dynamic, a perception which may not be unidirectional. For example, from the project with people with long term mental health problems, it is also apparent that particular services are hard, if not impossible to reach from their positions as service users.

11.4.3 The authors' experiences of attempting to reach the people in the defined groups showed that in order to reach, movement from where we are is essential. It was primarily through existing connections and going out to community places that attempts to make contact and gather information were most successful. The people who were easy to reach were those who were already close, such as other professionals working with those groups, or who had themselves become closer by stepping toward a professional identity or representative role from within their Hard to Reach group. Access to informants enabled us to access the views of the hard to reach.

11.5 Existing good practice

11.5.1 When considering accessing the views of the Hard to Reach, we can cite examples of best 'systems' practice and examples of individuals who we consider to have qualities of excellence.

11.5.2 With regard to best 'systems' practice we would re-emphasis the importance of consistent, predictable and person centered care models which have emerged through our investigation as most successful for Hard to Reach communities.

11.5.3 To provide examples of good or best practice in individuals encountered by the project team would not do justice to those who were not included in this project. What has become evident is that there is a community of professional and dedicated people working in the Hard to Reach sectors who have established effective models of practice and engagement with their communities in often emotionally difficult or potentially threatening and dangerous circumstances. It is safe to say that all of those contacted during the course of this project demonstrated a level of commitment and dedication to their roles and the communities they served that was highly effective and in many cases inspirational.

11.5.4 The relationships that the NHS GYW have already established with these key people can only serve to provide a better understanding of how to promote and nurture health and well being throughout the Hard to Reach communities. The following recommendations are designed to support systems and individuals in this purpose.

12. Recommendations

12.1 NHS GYW has expressed its intentions as follows:

'We are preparing for an improved and more formalised way in which to engage with the population, ensuring we listen to all groups of the population, especially the 'seldom heard' which have previously been less influential. (pp28)'

With this objective in mind, the following recommendations arise from the content and experience of conducting this project. (repeated from section 1 of this report)

1.7 Recommendations from this project are that;

A   the NHS GYW use the Hard to Reach contact database (provided as a separate document from this project) and continue to develop and maintain it;

B   suggestions within this report regarding models of engagement with Hard to Reach communities be piloted Section 9.3.1, 10.2.5, 10.3.13, 10.4.4, 10.5.8, 10.6.3, 10.7.3, 10.8.4, 10.9.4;

C   decisions be made regarding other Hard to Reach categories (i.e. men of working age, single parents, elderly) and methods of engagement with these groups be sought out;

D   an easily accessed community engagement fund be established to sponsor activities that engage with the Hard to Reach communities..

E   changes to healthcare provision for Hard to Reach groups be developed through the recommended consultation approaches (as per B above);

F   examples of best practice for GPs to engage with Hard to Reach communities be communicated;

G   NHS GYW consider the engagement of members of Hard to Reach communities in the evaluation of these changes (i.e. expert patient or advocacy exercises)

H   NHS GYW develop methods for communication with Hard to Reach groups within the trust communication strategy;

I   consistent, predictable and person centered care models are the most successful for Hard to Reach communities and NHS GYW should consider these as key qualities in healthcare provision for these groups.

Appendices

Appendix A:

Plain Language Statement - Surveying Hard to Reach Groups

The National Health Service in Great Yarmouth and Waveney would like to hear the views of those people who are described as 'Hard to Reach' about the health services in the region. Services find some people 'Hard to Reach' for a variety of reasons and so this means that a special effort needs to be made to understand how to provide health services for them.

These people include;

- Travellers
- Migrant Workers
- Looked After Children
- Individuals within the criminal justice system
- Asylum seekers and refugees
- Black and Minority Ethnic (BME) Groups
- People with Learning Disabilities
- People with long term mental health problems.
- Gay and Lesbians
- Homeless

The health service would like to know;

1. How people in the above groups use health services, and
2. What do they say, prevents them from doing so
3. What sources of health information and advice are used by people in the above groups
4. Where do they find this information
5. What health checks, tests and illness prevention services do people in the above groups use.
6. What health checks, tests and illness prevention services do people in the above groups say they need.
7. What improvements to health services would people in the above groups like to see (to help people in their position)
8. What services are needed to help women from the above groups
   who are having a baby or who have young children

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Appendix B: Literature Review

Methodology and findings

The literature survey was carried out using Internet search engines such as Google scholar and UEA library resources and databases such as MetaLib. The search terms that were used were 'hard-to-reach' AND 'healthcare' AND UK. From the MetaLib search engine, three databases were chosen. These included ASSIA, the Applied Social Science database, which generated 16 hits; Biomed Central generated 262 hits, and the Cochrane library 190. Additionally, Google scholar was searched, using the same search terms. It was assumed that journals such as Social Science & Medicine, Quality in Primary Care, Journal of Public Health Medicine, BMJ and The Lancet are searched by those three main databases, so these were not searched separately. The literature survey is by no means exhaustive and is not a systematic review.

Out of the 16 articles that were found using the ASSIA database, four used the term 'hard-to-reach' as an umbrella term; four were concerned with ethnic minorities and access to health care; equally, four were concerned with children and their health care needs. The rest was concerned with substance abuse and people with severe mental health problems. Biomed Central mostly covers the British Medical Journal and Public Health journals. The search engine did not discriminate between articles that had a geographical focus on the United Kingdom. The articles that were generated covered the whole world, with a leaning towards the United States and were thus not considered for this report, as the authors tried to keep the search locally or UK-focussed. The Cochrane Library, a database which focuses only on systematic reviews, had no reviews that focused only on Hard to Reach groups and their access to health care. Only the publications which have a focus on hard-to-reach groups as an umbrella term were chosen. They were deemed as representative for the current state of research on this topic. A snowballing technique for literature search was also used, (i.e. the list of references of published and unpublished papers from each publication was searched for additional useful material.)

The analysis of the publications revolved around four categories: Firstly, why is research on Hard to Reach groups an issue? Secondly, what is the definition of Hard to Reach groups? Thirdly, which methodologies are seen as useful in researching and evaluating the needs of Hard to Reach groups? And lastly, which recommendations and suggestions have been made?

In addition to the peer-review material, the briefing papers of the Department of Health on addressing inequalities and the reports of other PCT were scrutinized using the same analytical categories as outlined above. Four randomly selected reports from primary care trusts across the UK were selected and analysed accordingly, and one county council report (Nottingham) was taken into consideration. The South Somerset Primary Care Trust has published their report on patient and public involvement strategy in 2003 online, and even though it is not a specific report on Hard to Reach groups, `vulnerable groups´ have been taken into consideration.

The following observations can be drawn from these published articles and from the unpublished reports:

Why is research on Hard to Reach groups an issue?

There is an overall acknowledgement that the provision of health care to hard-to-reach groups is a challenge to primary care trusts (Pfeil & Howe 2004; Aggett & Goldberg 2005; Thompson & Phillips 2007). Hard-to-reach groups not only suffer from higher morbidity, but there is an overall expectation that the users of health care should play a more central role in the delivery of services. The Department of Health (DOH) states that "infant mortality in social class 5 is double that for social class 1' (DOH, Addressing Inequalities, 2). However, some of the hard-to-reach groups are deliberately found in this rather artificial category: Aggett & Goldberg state that people with mental illnesses, who are supposed to be cared for in the community, 'have little or no social contact, are highly reclusive and hide from personal intervention' (2005: 83). Sometimes the onus is however on the health care system: Pfeil & Howe e.g. have found that in 2004, only one GP in Norwich registered homeless people or prostitutes. There is also the issue of 'lobbying': whilst people with HIV might be members of a group whose advocates are very skilled at lobbying and making their views and needs heard, some members of hard-to-reach groups are not at all capable of making their views and needs heard in the public domain or with the representative primary care trusts. These might include children or mentally ill people or people with learning disabilities.

A common theme was that getting people to respond to queries of participating in research was a 'hit and miss affair', and that, usually, there is a lack of demographic data. Indeed clustering hard-to-reach persons into any groups

is a controversial task because of the potential stigma, but gaining demographic data is sometimes nigh impossible (Thompson & Phillips 2007: 1297). There are thus limits to reaching and enlisting hard-to-reach individuals. Trevor and Phillips especially point to the ethical considerations of recruiting hard-to-reach individuals because 'the potential for harm through breaching confidentiality is ever present in all research initiatives but especially so on a broader level when the focus is on a stigmatized group, whose members might not be well served by the publication of research findings that portray them as vulnerable victims or that focus on negative issues and experiences' (ibid: 1301).

Definition of 'hard-to-reach' groups

The definition of 'hard-to-reach' groups is rather elusive because there are only a few common denominators that link the members of these groups. Researchers should keep in mind that the concept is an artificial one, which helps the researcher to structure the data, but the researched people would hardly ever describe themselves as 'hard-to-reach', unless they deliberately want to be hard to be reached. A report published by the Institute of Social Research (Swinburne University of Technology, Victoria, Australia) entitled `Who is Hard to Reach and why´ by Nicola Brackertz argues that there is a lack of clarity about what the term actually means. The term is used inconsistently, and can sometimes be an euphemism for hidden populations, i.e. people who do not really want to be found or contacted (2007, online paper). Brackertz emphasises the sentiment that underlies a critical social science approach to research on Hard to Reach groups. She claims that the term in itself `implies a homogeneity within distinct groups, which does not necessarily exist´ (ibid). The perceived, or constructed, problem that these groups represent are thus seen as lying within the group, rather than within a definition that comes from outside i.e. the researcher or the commissioner.

The reports by the primary care trusts such as the report by South Somerset PCT and the report on patient and public involvement in Sutton and Merton PCT tend to define Hard to Reach groups as a subgroup of other groups and they tend to refer to them as `vulnerable and marginalised groups´ rather than Hard to Reach (see South Somerset PCT report and Sutton and Merton PCT report). Alternatively, they group Hard to Reach together as people with mental health problems (see Join Lancashire PCT recommendations).

Nottingham county council makes a specific claim that 'hard-to-reach' groups cannot be defined as a homogenous group, but they vary according to geographical area, urban or rural, and policy of the local authority. They suggest that hard-to-reach groups 'may include homeless people, drug users, refugees, economic migrants and asylum seekers, Travellers, disabled people, people with mental health problems, minority ethnic groups, young people and those who live in relative rural isolation' (Nottingham County Council online paper).

Methodological approaches

A second issue was that researching these groups might contribute to the problem itself. Some of the groups for instance do not want to be 'reached', or their cultural background makes it very difficult to acknowledge any kind of disease as they would be stigmatised within their groups. This has an impact on the research methodology: For instance, Bradby et.al (2007) found that interviewing British Asian families on child and adolescent mental health services was very challenging because for a family afflicted with mental disorder, the acknowledgement would lead to stigmatisation within their social environment. Bradby et.al. thus suggested the use of focus groups, followed by semi-structured interviews. The focus group discussions were stimulated using a hypothetical vignette about mental illness which allowed the participants to voice their views in an 'as-if' situation. The preferred research method by most authors was focus groups, as it allows the participants to remain immersed in their natural environment and it is less 'intense' than face-to-face interviews.

In the social sciences and urban planning, focus groups allow interviewers to study people in a more natural setting than a one-to-one interview.
 http://en.wikipedia.org/wiki/Focus_group - September 2009

Sampling strategies are also not straightforward: Thompson & Phillips, distinguish in their research on non-associative members of a hard-to-reach groups, for instance fathers of newborn babies, and researching members of an associative group, such as men who have sex with other men, i.e. the gay community. They criticise the fact that the snowballing technique, which is often used in the latter group, might make people known who would prefer to stay under cover and 'hard-to-be-reached'. Yet, they argue that snowballing is the most effective research method because despite

its pitfalls, such as 'social distance between pairs of individuals […], different subsets that might or might not be connected, overlapping acquaintance circles, increasing likelihood of being sampled, and affiliation and "force field" biases; whereby some people have greater presence and visibility in the community than others' (2007: 293).

Aggett & Goldberg (2005), on the other hand, distil five themes that link members of hard-to-reach groups and that will have to be overcome if one wants to research them: isolation, inaccessibility, invisibility, antagonism, and a rigidly patterned lifestyle (at least in people with severe mental illness). Whilst not all of their suggestions for overcoming these hurdles might be applicable to all members of hard-to-reach groups, some of their tactics in sampling and getting in touch are worthy of mention: knowledge base, i.e. being informed about the sometimes 'weird' behaviour of the researched; building rapport with people: 'communication needed to be warm, facilitative, open and respectful' (2005:87). They also suggest that one needs 'cognitive flexibility' i.e. the ability not to get caught up in anger bouts of the researched which then leads to blaming and scapegoating. Time management, persistence and pacing were some other strategies they employed. They conclude that 'building and maintaining relationships with reclusive clients […] is a highly and variegated task' but necessary because otherwise the researcher might lose his or her professional knowledge base and professional conduct.

How can these individuals and groups be heard and engaged?
Some of the articles make suggestions on 'ensuing that primary care reaches the hard-to-reach' (Pfeil & Howe 2004) but also state that some of hard-to-reach groups, especially young children, are 'consulted but not heard' (Curtis et.al. 2004).

Pfeil & Howe evaluated a local service that was set up by the Norwich PCT in 2002. This initiative, called 'City Reach', opened in 2002 to provide access to health care for hard-to-reach groups. The authors of the article thus researched the health care providers. They found that despite the difficulties of overcoming barriers in accessing the hard-to-reach, the representatives of hard-to-reach advocacy groups were content that City Reach provided 'easy access to by bringing clinics to homeless hostels, travellers site's, and women's refuge, and with the help of a specially designed van, the 'red light district' (2004: 187). They also point out that the attitude displayed by health workers is of utmost importance to the members of hard-to-reach groups. Humiliation by GPs and other health workers was often perceived as detrimental to the rapport.

A multi-agency co-operation, i.e. the establishment of a reference group, consisting of representatives of all agencies working with clients was seen as a criterion for success, so was the constant improvement of City Reach by clinical governance as well as by developing the service further according to the needs of the clients (e.g. the introduction of podiatry and dentistry). In conclusion, Pfeil & Howe point out that reintegration into the mainstream health care services was not a major issue for all groups. There was diversity according to the defining identity of the group members. Homeless people were more interested in being reintegrated than travellers (Pfeil & Howe 2004). Humiliation was also an issue in the research on children who are 'consulted but not heard' (Curtis et.al. 2004).

This literature seems to have been taken into account by some PCTs and some county councils. Nottingham county council for example suggests three steps towards engaging members of Hard to Reach groups: Firstly, identify the groups you need to include, secondly, learn something about them, and thirdly, identify the obstacles (Nottingham County Council, online). Aggett & Goldberg, also suggest that the personal approach works best. However, this personal approach needs time: 'Parachuting in, asking a few questions and then never being seen again' is not the way to approach consultation with Hard to Reach groups. Nottingham CC also recommends not to use IT or email. They also warn policy makers and researchers not to rely too much on self-appointed spokespersons as a substitute for a whole community. The South Somerset PCT recommend in their report that the researched society should not be split into several sub-groups, but that members should be involved on several levels: as `an individual persons, as expert patients, as a group with common issues, an organisation representing vulnerable groups, or a representative of a statutory agency or a member of the general public´ (online report, p.6).

Implications for this Project

Differences between and within the groups:

Broadly speaking, there are two different groups within the Hard to Reach category: On the one hand, there are people who are not 'heard', and on the other hand, there are groups of people who do not want to be 'reached'. The first groups feel that they are consulted and over-researched, but that nothing is done for them, whereas the second groups feels that research on them is an intrusion into their lifestyles.

Methodology:

Focus groups are sometimes quoted as the best way of reaching and surveying members of Hard to Reach groups, and so are online consultations via email or blogs. However, Nottingham county council contests this approach. They argue that members of Hard to Reach groups very often need the personal contact. Time and timing has to be taken into consideration: Members of Hard to Reach groups need time to get used to people who want to listen to their opinions. They also suggest that a multi-agency approach seems the best way of contacting members of 'hard-to-reach' groups. A multi-agency approach is also recommended by Pfeil & Howe`s evaluation of the City Reach services in Norwich (2003: 34). Likewise, inappropriate language, technical descriptions and jargon should be avoided.

Recommendations:

Pfeil and Howe suggest that the 'doctor-patient' relationship is of utmost importance when it comes to establishing a working contract with members of Hard to Reach groups. That means that respecting their choices and giving them autonomy is a necessary underlying principle that should influence all aspects of the relationship (see Pfeil & Howe 2004, DOH 2002). The DOH publication mentions specifically that 'those with learning disabilities have particular problems including staff attitudes, waiting times, fear of clinical settings and communication/literacy problems´ (DOH 2002: 2).

Nottingham County Council goes a step further and suggests the adoption of the social model of disability: they consider it as the 'responsibility of all individuals and organisations to make the environment, systems and activities inclusive and accessible for everyone. It is not the responsibility of individuals to 'fit in' to a system or environment that excludes them and not their fault if they cannot participate because an event, information, building or environment is not accessible' (Nottingham County Council, online publication). This should lead directly to an avoidance of stigmatisation of some Hard to Reach groups: the term `hard-to-reach´ is already perceived as a stigmatising terminology, which might only exacerbate the problem of people being invisible, not wanting to be heard or not wanting to be identified in the first place as `hard-to-reach´ (see Brackertz 2007; Freimuth & Mettger 1990).

Gender issues:

Gender issues are not a primary issue in research, policy and recommendations for practice of Hard to Reach groups. The DOH report is amongst the few that make a specific claim, arguing that over twice as many men die of cardio-vascular diseases than women, that 63% of men are overweight, compared to 53% of women, and that suicide rates are three times higher for men than for women. However, overall, two and a half-times as many women as men are treated for depression in England in Wales (DOH publication 2002). Women consult doctors much more often than do men and speak about their ailments more openly.

Ongoing methods of involvement:

The South Somerset PCT report is among the few that recommends an ongoing involvement of people, such as for instance regular listening events and an ongoing annual evaluation of the independent complaint and advocacy services as well as from voluntary and statutory organisations and from organisations that represent Hard to Reach or vulnerable groups (online report, p. 12). This is also recommended by Pfeil & Howe. Ongoing surveys and the need to adjust the services are amongst their recommendations (p.27) as well as an ongoing cooperation with other organisations that deal with members of Hard to Reach groups (p. 32).

The Joint Lancashire PCT report also recommends that sustaining involvement with key groups and their representatives is an ongoing process which goes beyond evaluation and research (see Joint Lancashire PCT report).

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Appendix C:

Further detailed information on consultation with key informants regarding Black and Minority Ethnic groups

In what capacity did key informants have contact with the group?
Each of the contacts can be considered to be both of this group and also working directly with other members of this group. They each said that they felt able to participate in the project both as representatives of this group and as professionals providing a service to other members of this group.

The respondents presented perspectives on the views of several Hard to Reach groups identified by this project. This reflects their work roles but also the interconnectedness and overlap of the groups themselves. Each of the respondents spoke about their work with BME groups and these included migrant workers, asylum seekers and refugees, and travellers. The respondents also commented that the BME groups they worked with also included people who could also be considered to be part of other Hard to Reach groups such as people with long term mental health problems; Lesbian, Gay and Bisexuals; and people with Learning Disabilities.

The information provided by respondents often pertained to all groups under the BME umbrella but often there were important distinctions, differences and issues that principally affected a more specific Hard to Reach group. Therefore each group is presented here as discrete even though respondents were reporting on the views of several groups.

Is there any existing information about this group?
There is a wide range of health related policy documents available locally and nationally on migrant workers who have moved to the UK. I will include here only work that has been commissioned locally.

Two reports conducted by Community Connections relate to the demographic make-up of migrant workers in Great Yarmouth, as well as an analysis of their needs. These both include information about health related issues:

Community Connections (2008)- Survey on perceived issues and needs of the black and minority ethnic (BME) communities in Great Yarmouth

Carlos Antunes, Community Connections (2008)- Building a picture of migrant communities in Great Yarmouth

Both of these reports attempted to develop methodologies that could access the perspectives of the migrant worker and BME communities in Great Yarmouth directly. They both used questionnaire methods and the sampling strategy was to actively seek out people from these communities in the local area. Community Connections staff using insider and local knowledge to take an outreach approach to accessing members of these communities at sites where they congregated; shops, cafes etc. Focus group methods were also employed when people came to access support services at Community Connections. Qualitative and quantitative data was collected.

A third report focused on the mental health needs of these groups and used data from qualitative interviews with key informants and members of the communities:
Franks W, Gawn N & Bowden G (2006). 'Understanding the mental health needs of refugees, asylum seekers and migrant workers in Great Yarmouth'
This research was funded by the Neighbourhood Renewal Fund and is available to the NHS GYW on request from the first author. Many of these reports disseminate similar findings and recommendations in relation to the communities in question.

A key finding of the BME survey was; "It is clear that BME communities would like a directory of services translated in different languages." In addition two thirds of respondents said that they; "Would like some support to help to be able to live independently in their own homes."

In Waveney the Lowestoft International Support Group (LISG) published a report in 2007 entitled; The New Communities in Waveney (Bukanska & Holland).

Similarly to the Community Connections report for Great Yarmouth, the authors discuss the difficulties of compiling accurate data on numbers of migrant workers living in the area. Between 2002-2006 a total of 1,150 EU migrant workers applied for National Insurance Numbers in the whole of the Waveney area, the majority of these thought to be living in Lowestoft. However local voluntary agencies placed to actual number of EU nationals at around four times this number. The largest of these groups came from Portugal, with large numbers also coming from Poland. Other EU nationalities also moving to Lowestoft included Romanians and Bulgarians.

In addition to EU old state and new state nationals the report also listed a range of other migrant workers living in Lowestoft. These included a significant number of students from India, Pakistan and Bangladesh who attend the local Marine Studies Department at Lowestoft College.

What are the views of this group in response to the key questions?

The findings presented here are designed to present a synthesis of the responses of the various representatives to these questions. A brief thematic analysis was conducted to group together the salient themes without losing individual perspectives.

1. How do people from migrant worker groups use health services locally?
   -Respondents reported low levels of people registered with their GP and people having continuing issues about how to register with the health service generally.

   - It was reported that people often waited until they needed health care and then presented to the local A and E. This was in keeping with the hours that many migrant workers work, including long commutes to and from factories, which prevents them from accessing GP surgeries. This practice was said to be also reflective of discourses within these communities about GP surgeries being inaccessible, and A and E services being presented to newer residents as the first point of contact by other more established members of the community. Finally, it was reported that this practice may reflect the normal health-care seeking behaviour in people's countries of origin. For example, it was suggested that in some parts of Portugal it can be usual practice to access the local hospital or large clinic rather than going to a local doctor.

   - It was reported by respondents that there is generally very low levels of knowledge regarding the local health system and how to access services.

2. What do they say prevents them from accessing health services?
   - Language differences and communication problems were perhaps unsurprisingly identified as presenting the main barriers to people trying to access health services. However within this global problem a more complex picture emerged alongside potential novel solutions. Respondents reported that language barriers existed at a number of different levels and presented a range of obstacles to different groups.

   - At the most basic level respondents reported that migrant workers encountered language barriers when they tried to communicate with front line admin and clerical staff. This was reported to be off putting for some people, while others accessed support from local voluntary agencies and members of their community in order to help them with language. For others though it was reported that they would not access health services because of these problems.

   - It was reported that a greater problem was presented to people when they had to use the phone to book an appointment with their GP, as trying to talk English on the phone was perceived as more challenging than in face

to face encounters. Given that many GP surgeries also take bookings for that day appointments after 8am in the morning, there was a lack of support available at that time from local agencies (e.g. GYROS) to facilitate phone calls.

- Language issues in written form also operated as a barrier to accessing health services. Respondents reported that migrant workers often presented to their services with letters from their GP and other health agencies detailing appointment times and other information. Often simple translation sufficed, but on other occasions more nuanced problems emerged. Letters inviting women to attend for smear tests were identified as presenting particular difficulties for some people as they will often not be aware of what this test entails, what it is for and why they are being asked to attend. One respondent also reported cultural and generational sensitivies that they felt would preclude some women from attending because of a combination of the intrusive nature of the procedure and a lack of understanding of its value. It was reported that in some migrant workers' countries of origin no such screening test exists and therefore confusion is heightened for some people.

- The availability of translation services was reported to be inconsistent and patchy by several of the representatives. They said that some GP surgeries were better than others and that the local hospitals were particularly poor at providing translation services. It was noted by one representative that foreign prisoners on remand are automatically offered a translator while many migrant workers seeking health care are not. This example provides a sense of the emotive nature of the topic of translation services for a number of the representatives.

- When translation services were made available representatives reported further complexities that can arise. The insular and cohesive nature of some of these migrant workers groups meant that often the translator called in would know the family. This raised obvious difficulties around confidentiality. This was reported to be a particular issue for people accessing mental health services and was perceived by some respondents as a barrier to accessing services.

- Representatives said that they believed that some staff were not aware of patients' rights regarding translation services.

- Most representatives were aware of the phone translation service Language Line and this was perceived as a helpful service. However it was noted that there is a difference between face to face and telephone translation services.

- There were other barriers reported for people from particular cultures. For example, it was reported that Lithuanian migrant workers had particular taboos around accessing help for mental health and drug and alcohol problems. They were reported to be highly suspicious of staff who attempted to address these issues directly with them.

- It was reported that people had different expectations of health services based upon their country of origin and that this led to difficulties engaging with the NHS. For example it was reported that some migrant workers have said that they feel they have very limited access to specialist medical services and that they are often prescribed painkillers by their GP instead of being referred on to a specialist. This may be connected to some the language barriers listed above. It was reported by more than one informant that this practice by GPs led some migrant workers to return to their own country to receive medical treatment because of the difficulties they had accessing specialist medical care via the NHS.

- People from India and China were reported to access NHS services less because they rely upon their own traditional medicines, complementary therapies and people from within their community who have medial training.

- A number of representatives reported that people had bad experiences with surgery staff, particularly front line admin staff and that this put people off reusing services. It was perceived by some representatives that this was due to differences of ethnicity and language between staff and patients.

3. What sources of health information and advice are used by people in the above groups
    - Several of the representatives described how many migrant workers received most of their information from key informants within their own communities. A common theme that was presented was that migrant workers new to the area utilised local knowledge in order to access health related information and that this often came from other migrant workers who had been living in the area longer. Different representatives presented this as both advantageous and problematic. On the one hand it allowed people to access information from sources they trusted, in a language they understood and that addressed their specific needs at that time. However some representatives also felt that this resulted in migrant workers getting inaccurate and misleading information that was then passed on around other members of the community, thus perpetuating inaccuracies. One example of this was people in the Portuguese community being told that the best way to access non-emergency health care was through the local A and E department as opposed to registering with a GP. There were also other myths that built up around people needing to pay for certain types of NHS services.

    - Another reported key source of health related advice was the local voluntary organisations that migrant workers accessed early after their arrival in the local area. Organisations such as Community Connections, GYROS and the Lowestoft International Support Group were presented by representatives as the services that migrant workers and other groups would access for a whole range of information when they first moved. It was reported that these organisations have varying amounts of contact with Great Yarmouth and Waveney NHS and that they all tried to provide some health related advice, signposting and acting as mediators with local services. For example some of these groups carry out an assessment of needs for people accessing their service. This includes gathering health related information and also giving out particular types of information such as contact details for sexual health services and advice about how to register with a GP.

    - Several representatives reported schools as being a good source of health information and advice for those families who had school aged children. Information about health services would filter out to families via the services their children receive through school. In the specific case of the Lithuanian language school in Great Yarmouth it was reported that information has been intentionally disseminated by different services through children for the benefit of their relatives. Therefore in some cases, specific interface organisations can act as a portal in accessing Hard to Reach groups.

    - The final source of health related advice reported by representatives was GP surgeries. The extent to which migrant workers used these as a source of information and advice was played down by some representatives. It was reported that many people preferred face-to-face contact in order to get information and advice, and that this limited the usefulness of leaflets translated into different languages.

4. Where do they find this information
    -As discussed above the primary sources of health related information and advice for migrant workers were reported to be informal relationships in their own communities and voluntary agencies with a specific remit to work with these populations. GP surgeries were also cited.

    - Face to face contact with people was reported as being a more acceptable way of providing health related information and advice than via leaflets and other forms of media.

5. What health checks, tests and illness prevention services do people in the above groups use.
    - It was reported by some representatives that people in this group needed easier access to medical assessments and specialist medical treatments. There was a reported perception among some migrant workers that they were not able to get access to specialist services and that they were prevented from doing so by their local surgeries.

    - Sexual health checks were reported as being important for migrant workers as with the rest of the population but there was recognition that communicating these services to people from other cultures could be problematic.

- As also discussed above there was a sense from some representatives that the health checks and tests that are available are not fully taken up by some groups because of cultural differences and misunderstandings between migrant workers and services. The example of the smear test has already been detailed in the section on barriers above. Another instance of misunderstanding is around children's immunisation. It was reported that some migrant workers are reluctant to bring their children for immunisation following a standard letter being sent to the home as they are unclear about what the injections are for, as they may not have them administered as standard in their country of origin. This combination of cultural differences coupled with health service information that can be difficult for migrant workers to understand in context was cited as causing some migrant workers to not take up health checks and tests.

6. What health checks, tests and illness prevention services do people in the above groups say they need.
    - Some groups were reported as needing health promotion services around nutrition and help dealing with problems such as vitamin deficiencies. This was particularly the case for Portuguese and other continental migrant workers who may have changed their diets significantly since moving to the local area. Long working hours in factories with limited access to varied food stuffs was also cited as causing people to become unwell due to poor diet.

7. What improvements to health services would people in the above groups like to see (to help people in their position)?
    - Representatives and other staff groups who were interviewed provided novel and informed suggestions about how health services could be improved for migrant workers living in Great Yarmouth and Lowestoft.

    - One idea was to develop mechanisms of providing information to migrant workers through the voluntary agencies already working with them. This is reported to be already happening in some instances with GYROS, Mind and Waveney Community Forum reporting helpful relations with Great Yarmouth and Waveney NHS that has resulted in small pieces of work such as providing access to sexual health information and contraceptives in a drop in centre for migrant workers. It was reported that voluntary and community sector organisations as well as faith groups have an important role to play in engaging Hard to Reach communities. These groups could be involved in promoting health services, providing information and discovering the perspectives of Hard to Reach communities.

    - A more specific example was using these agencies to distribute culturally appropriate, well-translated road maps of how to navigate health services. This would very basic information that the indigenous population might take for granted but that people from other countries may find confusing. For example, providing information about GP surgeries being the primary source for accessing non-emergency health care in the UK and giving advice on how to register was reported as potentially reducing instances of people turning up at A and E. It was suggested that a road map or such like could be developed by attending to the findings of this report.

    - Representatives provided examples of improvements to local health services that they have already been implementing on a small scale. For example, GYROS has been attempting to resolve complaints made by migrant workers and BME groups in respect of GP surgeries. These complaints have been about the discrimination people have felt from the staff there, particularly reception staff and more details have been provided in the barriers section above. In response to this GYROS provided diversity awareness training for staff at GP surgeries that attempted to address the underlying problems. This could be considered as an exemplar of a targeted intervention utilising local knowledge and expertise to resolve communication difficulties. It was reported that relations with several GP surgeries and migrant workers have improved significantly over the past few years and this was in part attributed to the increased understandings that have developed as a result of small scale interventions.

    - In addition to providing details of practical steps that could be taken to improve health services for migrant workers, representatives also had ideas about the methodologies used to implement and evaluate change. Across all representatives there was an expression of fatigue, to a greater or lesser extent, at the methodologies typically

employed by a wide range of statutory services to access the views of Hard to Reach groups. These critiques also incorporated this current project and steps were taken between interviews to make the questions more meaningful to representatives and to ensure that they felt the information they provided was important and that recommendations would be made that findings should be acted upon. The main critique was that surveys carried out by large organisations are often done so in an unreflective, reactive fashion and that the findings are not visibly acted upon. There was a connected point made that some surveys done primarily serve the interests and needs of the organisation and can have little resemblance to the concerns of the groups they are trying to access. One solution to this presented by representatives was that surveys and other information gathering exercises could be done collaboratively with members or representatives of these groups and that this would provide health services that was not only more substantive but that also more accurately reflected local need. During discussion with a number of representatives a simple methodology for doing this was developed and the arising model can be seen in Section…

-Another methodological suggestion made was to invert the process of how information was collected and acted upon. One representative suggested implementing changes in how health services access Hard to Reach group[s first and then evaluate the outcome of this intervention. The process of acting upon an environment first, then observing and measuring the effects of the intervention, before reflecting upon the change and acting again can be loosely considered to be an Action Research cycle. This method of research would present a departure from mainstream models of health service research and data collection in the UK but could be easily implemented on a small scale.

8. What services are needed to help women from the above groups who are having a baby or who have young children
- Several representatives held up ante and postnatal services for women and babies as examples of good practice in health care. It appears that good communication from midwives and health visitors ensured a high level of predictability regarding what to expect from services. It was also reported that having a clear set of procedures for who women were due to see and when, as well as detailed advice about what to do in an emergency reduced anxieties and encouraged engagement with these services by migrant workers.

Appendix D: Lesbian, Gay, Bisexual and Transgender report details

From: Reducing health inequalities for Lesbian Gay and Bisexual people: Evidence
of health care needs (Ruth Hunt and Adam Minsky 2007)

Men and general health needs

There has been extensive research that examines the health needs of gay men, yet this research is predominately concerned with the sexual behaviour of gay men, and the prevention, treatment, and social policy implications of HIV and AIDS (see Sexual health needs section below). The majority of research concerned with other aspects of health care for gay men was conducted mainly in the early 1990s.

This preoccupation with sexual health and HIV can have an impact on service delivery to gay men. Gay men have health needs other than those that relate to sexual activity and HIV prevention. This preoccupation, however, can sometimes affect health service delivery. For example, a gay man might be celibate, or in a monogamous relationship, yet his GP might continually give him information about safe sex because it is assumed that this is the individual's only health care need. This emphasis on sexual health also perpetuates the notion that gay health needs are concerned with what men "do" rather than who they are. This also has an impact on people's perceptions of gay relationships. The narrow focus on sexual activity can sometimes demonstrate to young men, or men who are discovering their sexuality, that being gay is just about sex. This can have an impact on relationships, and on an overall sense of well-being. It is important that the health sector does not perpetuate this narrow understanding of gay male sexuality.

Research indicates that gay men would prefer to disclose their sexual orientation to health care professionals but are reluctant to do so because they are anxious about discrimination. Research also suggests that some gay men are concerned about issues relating to mental health, sexual behaviour and safety, weight issues and eating disorders, a lack of role models, and relationships. Some are also concerned about smoking, drinking, drug and alcohol abuse. For some, gay men just want to be able to be themselves when engaging with a health care professional. If patients do not feel able to be fully open, this may affect the accuracy of the information given to a health care practitioner, and the validity of any history that is taken. A patient's circumstances, living arrangements, income and lifestyle can have a direct impact on their health needs. Knowing more about a patient improves delivery of care. (pp7)

Women and general health needs

The health needs of lesbians are one of the most neglected research areas in health care. There is however increased recognition by some researchers that lesbians do have unique health care concerns, and are generally underserved by the health sector. Research suggests that lesbians do not respond to preventive health care messages, and do not seek intervention or support from the health sector. Lesbians also have specific health issues relating to fertility, pregnancy, sexual health, and mental health. Some are also concerned with weight issues, eating disorders, relationships, smoking, drinking and drug use. Research suggests that lesbians want to disclose their sexual orientation to their GP, but are reluctant to do so because they think that they might be discriminated against. This can lead to inappropriate delivery of services, for example, a woman may continue to take the contraceptive pill rather than indicate that they are lesbian. Research suggests that lesbians are generally unhappy with the level of service they receive from the health sector.

Research also suggests that lesbian identity does not necessarily reflect a lifetime of same-sex only relationships. Some women who identify as lesbian do have sex with men, or have had sex with men in the past. Furthermore, previous sexual relationships with men have an impact on a lesbian's health care needs.

America and Australia are both conducting further research into lesbian health needs, and some work has been conducted in the UK. There is still, however, distinctly less research into lesbian health needs in comparison to gay men's health needs. A thorough national needs assessment would help fill this gap. (pp12)

Appendix E: Homelessness Report Recommendations

The Queen's Nursing Institute , Homeless Health Initiative, Service User Consultation Report, February 2008 , Groundswell UK

3.1. Training for Staff. Training should be developed on the particular health care issues faced by homeless people, particularly their mental health needs. This should be made available for health care professionals, particularly for frontline staff in A&E, nurses, GPs and A&E receptionists. This training should be developed with people experiencing homelessness and health professionals.

3.2. Training for Homeless People. Training should be developed for homeless people about the range of health services on offer to them and on how to approach services. This training should be developed with people experiencing homelessness and health professionals.

3.3. Hospital Discharge. That all Primary Care Trusts are made aware of the Department of Health (DOH) guidelines for hospital discharge procedures (DOH, Homeless Link: 2006), and that there is a formal audit of their use.

3.4. A&E Signposting. Good practice relating to how homeless people can be signposted to other more appropriate support services when departing A&E, developed by Health Link (health-link.org.uk), should be adopted and disseminated.

3.5. Intoxication. Protocols should be adopted recognising that while a person may be drunk, intoxicated, or displaying signs of mental illness, they should still be able to be treated for their other physical health needs.

3.6. GPs & Walk in centres. Walk in centres offer a good access point for homeless people to reach health care and these should be supported. However they are not a substitute for GP registration and homeless people should be encouraged and supported to register with GPs. Clear protocols should be developed for GPs for registration of homeless people.

3.7. Health Records. Clear protocols need to be developed on access to health records: who should have access (eg medical professionals), who should not (eg. ancillary staff), and in what circumstances they can be accessed without the client's consent. Clear information on this protocol and on how individuals can access their own records should be produced and disseminated to homeless people. (Recommendations from Service User Consultation Report, February 2008 , Groundswell UK)

Hidden Homelessness: Britain's Invisible City
www.crisis.org.uk/pdf/SONreport_HHBIC.pdf

A high proportion of Hidden Homeless people have more complex problems including mental ill health and addiction. They are urgently in need of specialist help including psychiatric assessment and care, detox and rehabilitation support. Many are not in touch with specialist drug or mental health workers and few are even registered with a GP. (Hidden Homelessness: Britain's Invisible City pp11)

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