Groups at Risk of Disadvantage

Health Needs Assessment

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This needs assessment was prepared in July 2015 by the Public Health Action Support Team on behalf of Suffolk County Council.
Introduction

In 2008 the title of the Suffolk public health report was ‘Health inequalities and diversity in Suffolk’ and reviewed the health of; prisoners, street sex workers, family carers, asylum seekers and refugees, migrant workers, Gypsy and Travellers, Afro-Caribbeans and south Asians. Since then Public Health and other key partners have worked together to improve the health of these communities by establishing a number of relevant initiatives such as; the Suffolk prostitution strategy; the Healthy Living Project model and the extended Health Outreach Project.

This health needs assessment revisits the health of some of the communities identified previously as well as looking for the first time at some emerging communities.

The original title of this health needs assessment was to be ‘vulnerable groups’ but was deemed to be unrepresentative of how the communities to be reviewed feel about themselves and was rejected in favour of ‘groups at risk of disadvantage’.

Initial discussions about who to review identified a large number of communities who fell under the category ‘at risk of disadvantage’. However some have been the subject of their own health needs assessment recently (e.g. carers and those with a learning disability), or are captured in broader health needs assessment such as mental health, hidden harm and children and young people and were excluded from the list.

The final list of communities to be reviewed were agreed as; migrants from Eastern Europe; asylum seekers and refugees; women with female genital mutilation; Gypsy, Roma and Traveller communities; homeless community; communities that live in rural deprivation; transgender community; sickle cell community; communities who use psychoactive substances ‘legal highs’; ex-offenders; and sex workers¹.

Due to timing and the complexity of their needs the last two on the list; ex-offenders and sex workers will be reviewed as individual health needs assessments at the beginning of 2016.

Executive summary

The 2008 public health report ‘Health inequalities and diversity in Suffolk’ (reviewed the health of; prisoners, street sex workers, family carers, asylum seekers and refugees, migrant workers, Gypsy

¹ To be looked at in a separate report in more detail
This needs assessment was prepared in July 2015 by the Public Health Action Support Team on behalf of Suffolk County Council.

and Travellers, Afro-Caribbeans and south Asians) and showed these groups had the following in common:

- Users sometimes had limited knowledge of their rights to services or how to access them appropriately.
- For some, language and communication poses difficulties when English is not spoken as a first language. Absent or inadequate interpreting services can compound the problem.
- Incomplete data collection by the health sector e.g. for ethnicity, means that the specific health needs of each community group cannot easily be assessed.
- Limited joint working between the health sector and community or advocacy groups means there are fewer chances to reach out to specific communities.
- The perception of some communities is that staff have a limited awareness of important cultural issues.
- Specific health issues are seen within some groups, which significantly contribute to health inequalities in Suffolk.

What has changed?

This complex health needs assessment considers the health of nine different communities and presents evidence that health inequalities are being perpetuated within Suffolk. It is concerning to find that many of the issues identified in the 2008 report ‘Health inequalities and diversity in Suffolk’ have not progressed adequately. If the Health and Wellbeing Board are serious about supporting the health needs of all communities in Suffolk and reducing health inequalities, system leaders need to work together to implement the key recommendations set out below:

**Key recommendation 1**: A strategic group should be established to oversee the implementation of all recommendations in this report and ensure there is systematic and regular review of communities with the highest health need.

**Key recommendation 2**: System leaders should ensure that data sharing agreements between services are effective and support the health needs of populations that have the highest health need.

**Key recommendation 3**: The quality and quantity of Language support for non-English speaking residents in Suffolk should be improved and consideration given to developing an integrated language support system commissioned as one service for the whole statutory sector.

**Key recommendation 4**: The Health Outreach Project is a valuable service that supports the health
needs of the most vulnerable individuals within Suffolk. There is evidence that it should increase its scope by considering new groups, improve its presence in other parts of the county and improve the way it collects and analyses data. Great Yarmouth and Waveney Clinical Commissioning Group should consider the benefit of a similar service in their locality.

**Key recommendation 5:** Good quality information about health and social care provision including General Practice registration, self-care and referral to secondary care or mental health services needs to be widely available to endure appropriate access to healthcare services by the whole Suffolk population.

**Key recommendation 6:** Data collection about ethnicity, gender reassignment, sexual orientation and disability needs to be improved in all health and care services. The authors of this report struggled to access good quality data against all of these dimensions.

**Key recommendation 7:** Training is required to improve cultural capability amongst health and care services to better meet the needs of groups at risk of disadvantage.

Specific recommendations for each community reviewed are for multiple audiences and require consideration by Clinical Commissioning Groups (CCGs), Suffolk County Council, District and Borough Councils, NHS England, the Home Office, General Practices, Health Outreach Project, Public Health Commissioned Services, Mental Health Services and Acute Trusts.

**Specific recommendations for asylum seeker and refugees**
1. NHS England and the CCGs should collaborate to ensure continued capacity and capability in primary care is available for asylum seekers and refugees.
2. The CCGs should support the Health Outreach Project to improve their monitoring and reporting of activity and outcomes so that the full scope of their work is recognised.
3. Suffolk County Council and the NHS should explore options for improving access to services including NHS services which are particularly challenging to those who experience language barriers.
4. The Home Office should be informed that G4S is not meeting the minimum standards set out in their accommodation contract, so that accommodation for this group can be improved.
5. Asylum seekers and refugees can be at risk of Vitamin D deficiency. Young children (under 5 years) and mothers who are pregnant or breastfeeding should be informed of Healthy Start vitamins. Those who are over 65 years; have low or no exposure to the sun either for cultural reasons (covering their skin); are housebound or confined indoors for long periods; have
darker skin should be encouraged to take Vitamin D supplements.

Specific recommendations for migrants from Eastern Europe
1. Health messages should be available in appropriate languages and visible in areas that are accessed by the Eastern European population.
2. Services, particularly stop smoking, drug and alcohol, mental health and sexual health services, should be able to meet the needs of Eastern Europeans’ taking account of their culture, language, and lifestyle.
3. The formation of social groups should be encouraged to reduce social isolation which is a problem particularly for young, single males.
4. Eastern European migrants need access to appropriate housing advice.
5. Improving the understanding of migrants about local health and care systems including GP registration, self-care and referral to secondary care, would promote appropriate use of health and care services and also improve access to services.
6. Ensure professionals in all services understand how to access translation and interpretation services, and that they are widely available. This should decrease the practice of children and others interpreting for family members or friends, when personal information is being discussed.
7. Use contracts to strengthen the collection of ethnic group data, to enable better understanding of the health and well-being needs of local communities.

Specific recommendations for Female Genital Mutilation (FGM)
1. The FGM multiagency group should continue its work in Suffolk with a particular focus on training, workforce development and the dissemination of good practice, take into account risk, safeguarding, and legal requirements. It should continue to encompass health, social care, education and early years services, and engage communities.
2. The FGM group should consider ways to engage partners and the wider community in raising awareness, agreeing priorities and supporting joint work on FGM. It should use information from interviews and focus groups which have already taken place to develop a picture of the views of groups affected in Suffolk.
3. Training should cover awareness-raising and cultural competence and also support frontline staff to develop skills and competence in raising and discussing questions around FGM and responding to safeguarding concerns.
4. FGM should continue to be part of mandatory safeguarding training. Training should take into account the views and knowledge of communities in Suffolk who are affected by FGM.
5. Consistent guidance should be promoted across Suffolk. This should include agreed risk assessment frameworks, how to record and report FGM as well as information about local
arrangements.

6. All frontline staff working with children and families in any setting should know how to recognise and respond to safeguarding concerns in relation to FGM and this should be part of mandatory safeguarding training and covered in local guidelines.

7. NHS England and Suffolk CCGs should clarify responsibilities for commissioning and provision of services for women and girls with physical and psychological health needs as a consequence of FGM.

Specific recommendations for Gypsy, Roma and Traveller communities
1. A strategy is needed to create a multiagency approach to supporting the health needs of Gypsy, Roma and Traveller (GRT) communities. Services should provide consistent advice and support. Smoking in pregnancy and refusal of immunisations and vaccinations are particular areas to be tackled.
2. Members of the GRT groups could be trained as advocates to work alongside the Norfolk and Suffolk Gypsy, Roma and Traveller Service (NSGRTS) and The Health Outreach Project to build further bridges with the community.
3. Cultural competency among health and social care workers is appreciated by gypsies and travellers and staff training should be developed and encouraged.
4. Appropriate information to encourage the use of NHS services should be available to increase understanding of waiting times, queuing procedures, referrals, signing-in at clinics and response to letters from NHS authorities on topics such as such screening and hospital appointments. However funding for English language and integration lessons stops September 2015 and opportunities to carry on this work need to be developed.
5. The Health Outreach Project should be supported to improve their monitoring and reporting of activity and outcomes and needs to record data about GRT communities in real time.
6. Suffolk County Council may wish to include “New Travellers” and “New Age Travellers” in a future health needs assessment.

Specific recommendations for homelessness
1. The Health Outreach Project support General Practices who register homeless people but currently relatively few practices are involved. NHS England and the CCGs should encourage other General practices to offer registration to homeless people.
2. The CCGs should consider a training and education remit for The Health Outreach Project, for staff from mainstream services.
3. The CCGs should support the Health Outreach Project to improve their monitoring and reporting of activity and outcomes so that the full scope of their work is recognised. This needs assessment lacked the data necessary to support clear recommendations that would
lead to service improvement.

4. The public sector should facilitate data sharing agreements with partners to improve understanding of the state of health of the local homeless population.

5. Homelessness can be reduced by the health and care system being alert to the known risk factors such as having a learning disability, being a care leaver, needing to use emergency accommodation and/or having a criminal record. Multiagency work is recommended to find ways to influence those at greatest risk of becoming homeless.

6. After October 2015 Public Health should review the local adherence to the new Tuberculosis NICE guidance and highlight areas for action with the relevant agencies.

7. The CCGs, The Health Outreach Project and GPs with significant numbers of people who are homeless on their lists, should co-operate to decrease ‘do not attend’ (DNA) rates, and maximise preventive measures to encourage Accident and Emergency avoidance.

8. Acute Trusts need to ensure that discharge planning for the homeless is appropriate and if required involve local voluntary services as well as health and social care.

9. Prevention or early intervention of homelessness should be considered to reduce the number of individuals requiring supported housing from Suffolk Co-ordination Service (SCS).

**Specific recommendations for new psychoactive substances (NPS)**

1. There should be a partnership approach to tackling all aspects of NPSs which is integrated into current substance misuse partnership arrangements. This should draw in a wide range of partners including healthcare providers (both specialist substance misuse and non-specialist services), children’s and adults’ social care, teams working with those who are not in education, employment or training and Young Offenders, schools and colleges, youth services and various third sector organisations, the police, trading standards, and the criminal justice system including prisons and community rehabilitation. The Recovery Forum could develop into a partnership which takes a proactive approach to this work.

2. There should be consideration of what further information is needed to develop a better understanding of current and potential users of NPSs in Suffolk including those in prison settings.

3. Accurate, up-to-date information and advice about the harm of NPSs should be developed. Appropriate routes should be identified to reach particular target groups (such as users of the night-time economy, men who have sex with men (MSM) and those in the criminal justice system) as well as broader approaches for young people through schools and other settings.

4. Work with schools across Suffolk should support and develop Personal, Social and Health Education programmes which include information about NPSs as part of substance misuse awareness raising.
5. Steps substance misuse services could take to ensure they are accessible and seen as appropriate for users of NPSs should be explored. The scope should include risk groups such as young people, prisoners, MSM, and those from socially deprived areas. The potential benefits of outreach to target groups and environments where there is increased risk of NPS use such as clubs and festivals should be examined.

6. Specialist services should provide effective support for users of NPS. This should include; harm reduction where appropriate e.g. needle exchange for people who inject NPSs and interventions to reduce dependence for users of NPSs (who will often be multiple substance users). Any provision needs to underpinned by detailed information about these users, including demographic details, risk factors and interventions in order to determine and evaluate outcomes.

7. Stronger links and pathways between specialist services and generic services such as sexual health, Accident and Emergency, paramedics and primary care should be developed. Ensuring that these workforces feel confident and competent to identify and deal with problems relating to NPSs (including acute reactions) and are able to provide information and to signpost people appropriately.

Specific recommendations for rural deprivation

1. Suffolk County Council should review the findings of the “Hidden Needs” report (Fenton 2011) and ensure that the findings are used to inform interventions aiming to prevent increasing isolation of rural communities.

2. Mental health services should ensure that their provision is accessible to those who are rurally isolated, both the indigenous population as well as migrant labour.

3. There is little known how Suffolk residents without cars who live in rural areas access GP, dental, optician and hospital appointments. When appointments are offered to people living in rural areas, patient’s travel arrangements should be taken into account and a survey to find out more information should be considered.

4. The studies available for this needs assessment have included a review of the voluntary sector and its input, some information on health services, and some information on health need, but these different analytical perspectives need to be brought together in order to reveal and allow analysis of the gaps. This is the joint responsibility of the CCGs and SCC Public Health.

5. SCC in conjunction with the district and borough councils should identify the most deprived rural wards and make firm plans on improving the life chances of the residents in those areas.

6. In taking decisions on budget allocation, SCC should consider the high value of the voluntary sector in reducing rural social isolation and support the sector to improve their performance.
Specific Recommendations for Transgender
1. More awareness raising and specific training are required in primary care. The previous training was limited to only a fraction of Suffolk practices. There is a need to improve knowledge and attitudes about how to treat trans-people in primary care, and also about referral and support of those who seek treatment.
2. Providers of mental health services in Suffolk should designate a consultant psychiatrist or clinical psychologist to see patients referred with symptoms of gender dysphoria. This will improve the quality of the service.
3. These services should also provide better access to people being seen at a gender identity clinic who need support with other psychological problems such as anxiety and depression, or just emotional support in dealing with the difficulties of gender transition.
4. The specialist services need, at the least, to explain to patients and parents why the correctness of their diagnosis and their commitment to treatment require such frequent testing.
5. Support for trans-people and their families’ needs to be increased. The Gender Xplored support group should continue, but with more involvement by the County Council to ensure its long-term viability and effectiveness. At present it attracts only a small fraction of the Suffolk trans-community. More active marketing and publicity and wider availability of meetings might increase the use and impact of the group.

Specific Recommendations for Sickle Cell
1. Awareness of sickle cell disease in ethnic communities and in primary care needs improvement.
2. Information and education for primary care staff about Sickle Cell should be available.
3. The County Council should continue to support Thalassaemia and Sickle Cell Support Group. Important priorities are promoting awareness of the disease, countering stigma and overcoming the possible under-diagnosis of sickle cell disease.
4. Hospitals in Suffolk should continue their present efforts to improve sickle cell services. This should include consideration of a single tertiary hospital as a service partner, a clearer clinical pathway, better staff training and awareness, and clinical audit, including use of the National Haemoglobinopathy Register. They should signpost people to the Thalassaemia and Sickle Cell Support Group.
5. The changing population profile in Suffolk is likely to see an increasing number of patients with sickle cell and it may become appropriate for tertiary services to be provided locally, with specialist teams traveling to district hospitals rather than vice versa.
Chapter 1
Asylum Seekers and Refugees
Summary

Asylum seekers and refugees introduction

- Ipswich was receiving refugees prior to its designation by the Home Office as a dispersal centre for asylum seekers and refugees. Since that time there have always been approximately 70 to 90 people in the County in this category applying for a decision, appealing a decision or being designated a refugee for five years prior to applying for indefinite leave to remain.
- Asylum seekers and refugees have very distinct needs and need appropriate services. Once leave to remain has been granted ("a positive decision"), the individual acquires the status of refugee and has the same rights as other UK residents, free to live anywhere in the UK, take a job and apply for benefits. Once a refugee has leave to remain, he has to leave the Home Office dispersal accommodation in Ipswich. At this point, a new asylum seeker will be moved into the dispersal accommodation and the refugee may choose to remain in Ipswich as well, resulting in an increase in the migrant population. The burden of care on health services is always being renewed.

Asylum seekers and refugees key points

- Asylum seekers include unaccompanied minors, usually aged between sixteen and eighteen years but sometimes younger, as well as single adults, couples and families.
- They may not all be new arrivals in the UK. People may have lived in the UK under other circumstances but find they need to apply for asylum.
- An increasing number have no recourse to public funds and may become destitute.
- Many arriving to seek asylum are strong and well but others may be emotionally and physically damaged.
- Norfolk Suffolk and Cambridgeshire is designated by the Home Office to receive a maximum of 450 asylum seekers at any one time, 150 each in Ipswich, Peterborough and Norwich.
- New arrangements are in place for tuberculosis screening which mean less treatment is required in the UK. Asylum seekers are tested pre-entry and can only apply if they are clear of the disease. This process will exclude people already resident in the UK and making a new claim to asylum, people who are trafficked to the UK, and illegal immigrants.
- Many asylum seekers find the NHS system difficult to understand; the GP’s role as gatekeeper to other services is not usual in other countries. Even though the system is
explained to them, they still worry that they will be charged for services. Their access to services may depend on them having a clearer understanding of their entitlements and the way the system works.

- The regular statutory services in primary and secondary care work well mainly because of the significant additional contribution made by the Health Outreach Project and the voluntary Suffolk Refugee Support.
- Data recording issues and the time of year requests were made to the Health Outreach Project resulted in minimal data sets being available from this service.
- Although some asylum seekers and refugees in Suffolk come from countries with a high burden of Tuberculosis (TB), there is no local data that demonstrates local services do not manage this adequately.
- Language and communication affects service access and efficient usage and is vital to integration and good health.

**Asylum seeker and refugees recommendations**

1. NHS England and the Clinical Commissioning Groups should collaborate to ensure continued capacity and capability in primary care is available for asylum seekers and refugees.
2. The CCGs should support the Health Outreach Project to improve their monitoring and reporting of activity and outcomes so that the full scope of their work is recognised.
3. Suffolk County Council and the NHS should explore options for improving access to services including NHS services which are particularly challenging due to language barriers.
4. The Home Office should be informed that G4S is not meeting the minimum standards set out in their accommodation contract so that accommodations for this group can be improved.
5. Asylum seekers and refugees can be at risk of Vitamin D deficiency. Young children (under 5 years) and mothers who are pregnant or breastfeeding should be informed of Healthy Start vitamins. Those who are over 65 years; have low or no exposure to the sun either for cultural reasons (covering their skin); are housebound or confided indoors for long periods; have darker skin should be encouraged to take Vitamin D supplements.

Throughout this document the asylum seeker is described as “he” and “him”. This is for ease of language and the content applies equally to male and female asylum seekers though the majority are male.
Who are asylum seekers and refugees and why is this important for Suffolk?

Introduction

Asylum seekers are people who are making a claim to stay in Britain because of fear of persecution in their home country. Many have suffered threats, imprisonment, torture, injury or threat of death. This makes returning to that country extremely dangerous. The 1951 United Nations Convention relating to the status of refugees defines a refugee as a person:

“who is outside his or her country of nationality or habitual residence; has a well-founded fear of being persecuted because of his or her race, religion, nationality, membership of a particular social group or political opinion; and is unable or unwilling to avail him or herself of the protection of that country, or to return there, for fear of persecution” (UNHCR 2011).

Asylum applications in the UK were at a peak of over 80,000 in 2002. Since then, this has reduced and remained at approximately 25,000 per year (ONS May, 2015).

Those claiming asylum are first housed in ‘initial accommodation’ under section 98 of the Immigration and Asylum Act. It is here where health screening should take place, with the results forwarded once they are dispersed under section 95. There is no initial accommodation in the East of England.

Asylum claims are handled by a branch of the Home Office known as UK Visas and Immigration. Asylum seekers are supported with accommodation and subsistence (a room and £36.95 per week for a single person over the age of 18) if they are destitute, but they may not take a job unless it is one on the shortage occupation list and if their asylum claim has not been decided within twelve months, nor access formal ESOL\(^2\) classes. There are others who are supported only with subsistence as they find accommodation with family or friends.

Once asylum seekers have received a positive decision on their application, they may be granted refugee status and given leave to remain for five years in the UK after which they can apply for indefinite leave to remain. The refugee\(^3\) may decide to settle in Ipswich, the place to which he was dispersed, or may travel to be nearer friends. He has the same rights as other residents in Britain and can look for work, claim benefits, reside in the place of his choice and apply for British

\(^2\) English for Speakers of Other Languages

\(^3\) Once an individual has received the right to remain in Britain, he is no longer an asylum seeker and is generally referred to as a refugee. (Suffolk Refugee Support)
citizenship. Other positive decisions for asylum seekers include discretionary leave to remain of one to three years or humanitarian protection.

Whilst not all obtain a positive decision, there are many reasons why some may not be able to return to their countries of origin, perhaps because of war or other instability, or there being no viable route of return (no flights to the country nor embassy in the UK from which to obtain a visa), or permission has been obtained to proceed with a judicial review against the decision, or he is too ill (or a woman in the late stages of pregnancy) to travel. Possibly the country that he claimed to have left does not recognise him as one of their citizens, so while he may be declined leave to remain in the UK he is also refused leave to return to the country which he claimed as his origin. Whilst awaiting deportation, which can take many months, a small support package is available through the National Asylum Support Service.

Failed asylum seekers have been unable to establish to a reasonable degree of likelihood that they would suffer persecution if they were to return to their home nation. It is estimated that there may be as many as half a million failed asylum seekers remaining in the UK.

The majority of initial applications are unsuccessful. For example, in 2006 only 10% of applicants were granted refugee status. Of those who were able to launch an appeal against this decision, 73% were dismissed (Taylor 2009).

Unaccompanied minors also arrive seeking asylum. These are generally aged between 16 and 18 years though they may be younger. They are looked after by Social Services and placed in private foster care whilst their application is decided.

Not all asylum seekers are new arrivals. They may have been in the UK when conditions in their country of origin changed and it became unsafe to return. One family cited as living in Ipswich with two children had been in the UK for a number of years, but had not renewed their visas so were seeking asylum. A single Libyan man had entered England to undertake a university course but during that time the Libyan civil war commenced and he could not return home so is also seeking asylum.

This needs assessment includes current and failed asylum seekers, and refugees. It does not include undocumented migrants, people who arrive on valid visas but become undocumented because they overstay, or people who have entered the country illegally and not by the asylum seeking or visa processes.
No Recourse to Public Funds (NRPF)
This is a condition imposed on someone due to their immigration status. The public funds include a large number of mainly out-of-work benefits.

People are subject to immigration control if they:

- have leave to enter or remain in the UK with the condition 'no recourse to public funds'
- have leave to enter or remain in the UK that is subject to a maintenance undertaking, for example, an adult dependant of a person with settled status (possibly a spouse of a refugee), or
- require but do not have leave to enter or remain (for example, visa overstayers, illegal entrants, or failed asylum seekers who claimed asylum after entering the UK, rather than at the port of entry).
- When subject to immigration control, a person is prohibited from accessing public funds. This contributes to the public health problem since it is possible for people affected in this way to become destitute.

There is some redress. For example if lack of recourse to public funds affects a family with children, they can be referred to social services for a human rights assessment under the duties that social services have under the Children Act. A vulnerable adult may be entitled to support under the Care Act. Those families found to have need would receive housing and support from the social services department. In Suffolk, training is being arranged for housing providers and advice agencies since they need to know who to refer to social services. People have already presented in a destitute state so action needs to be planned. There has always been the potential for this – as with failed asylum seekers who overstayed, but they often are part of a community with friends to help.

NHS treatment is subject to overseas visitors charging regulations. All refugees and asylum seekers are exempt.4

Why this is an important public health problem
Asylum seekers and refugees, within a wide spectrum of vulnerability, have health needs which are more complex those of the general population. Research undertaken by City University (2014) found that most asylum seekers arrive in the UK in good health; a minority arrive in considerable distress, sometimes with a number of complex physical and mental health needs, especially if they have experienced torture and organised violence.

Some asylum seekers experience mental health problems that cannot be addressed by the GP but fail to meet the criteria for receiving psychiatric treatment, meaning that many receive no treatment. They may have been self-medicating for anxiety and depression in their country of origin and be unable to access similar medication in the UK. The impact of exile on refugees is evident in many physical illnesses such as tuberculosis (TB) as a result of poor living conditions; and HIV undisclosed because asylum seekers fear that it will jeopardise their asylum application.

They may experience difficulties in accessing GP services and an increased reliance on Accident and Emergency or other direct access services. They may not understand how to use NHS systems (Stagg et al 2012).

Unaccompanied asylum-seeking children are vulnerable; some are under 16, though most are older, and the fact that the majority have no parent or guardian in the UK. Taylor (2009) found that “in almost all indices of physical, mental, and social wellbeing, asylum seekers and refugees suffer a disproportionate burden of morbidity.”

Refused asylum seekers awaiting voluntary return or removal receive minimal support (accommodation and shopping vouchers) but this is not available to those who decide not to leave the UK and consequently have no recourse to public funds and only limited healthcare. Care from a GP or in Accident and Emergency would be available, but admission to a ward or visit as an outpatient would be charged. Other services which may be accessed by someone with NRPF include an NHS walk-in centre, family planning services, diagnosis and treatment of specified infectious diseases, or of sexually transmitted diseases, or treatment required for a physical or mental condition caused by torture, female genital mutilation, domestic violence or sexual violence.

Up to half in this population are suffering from depression (Aspinell 2014). In 2007, this group was estimated to number 510,000 across the UK.
Some Asylum Seekers and Refugees can be at risk of Vitamin D deficiency (NICE guidance PH56). Vitamin D is essential for skeletal growth and bone health. Severe deficiency can result in rickets (among children) and osteomalacia (among children and adults). Dietary sources are limited. The main source of Vitamin D is from sunlight on skin. However, from mid-October to the beginning of April in the UK there is no ambient ultraviolet sunlight of the appropriate wavelength. Infants and children under 5; pregnant and breastfeeding women, particularly teenagers and young women; people over 65; people who have low or no exposure to the sun, for example, those who cover their skin for cultural reasons, who are housebound or confined indoors for long periods and people with darker skin, for example, people for Africa, African-Caribbean or South Asian family origin are at risk groups. These groups should be encouraged to take Vitamin D supplements.

Links to other PHAST needs assessments
Although the groups are discrete, some aspects of health status and access to health services may have common features with the needs assessment on Eastern Europeans and also on Gypsy, Roma and Traveller People.

Asylum seekers and refugees are an important public health problem in Suffolk because of the numbers who are regularly dispersed to Ipswich, their needs and care while they seek asylum, and the growing numbers who may settle in Ipswich and the surrounding areas following receipt of a positive decision to remain.

What is the local picture?
Asylum seekers and refugees were a significant minority in Suffolk even before Ipswich was designated a dispersal centre under Home Office rules. In 2000, Iraqi Kurdish men began to arrive in Ipswich seeking asylum and from 2004 Iranian Kurds joined them. There is now a population of about 1,000 Kurdish men who were given positive decisions on asylum applications with leave to remain in the UK and are now settled with their families.

Suffolk is in the East and Midlands Home Office region and is takes about 10% (450) of asylum seekers housed in this region. Other centres in Norfolk and Cambridgeshire are Norwich and Peterborough. There is an agreement by which each of these towns can take a maximum of 150 Home Office supported asylum seekers at any one time. However there are rarely more than 90 in Ipswich as there is insufficient affordable, quality accommodation for more. Management of the accommodation services contract by G4S was criticised by the National Audit Office (NAO 2014) for

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5 Dispersal is the process by which the Home Office moves an asylum seeker to accommodation outside London and the South East. They are first moved to initial accommodation while their application for asylum support is processed. Once the application has been processed and approved they are moved to dispersal accommodation elsewhere in the UK.

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poor standard of quality in the housing provided for asylum seekers, and for delay in acquiring new properties. This situation still pertains, although a decent standard of accommodation for people who have fled unsafe and threatening conditions is a basic requirement for physical and mental health.

There are also small numbers of people who stay with friends or family while making their asylum claim – so called ‘subsistence only’ applicants. Their access to services will be informed by their hosts’ awareness of local provision.

Advice and support to asylum seekers in Ipswich is provided by a voluntary agency, Suffolk Refugee Support (SRS). In the year to March 2015 79 asylum seekers known to SRS were settled in Ipswich. These came from sixteen countries; the largest contingents are detailed in Table 1.

Table 1: Asylum seekers in Suffolk by country of origin, April 2014 to March 2015

<table>
<thead>
<tr>
<th>Country of origin</th>
<th>Asylum seekers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Iraq</td>
<td>21</td>
</tr>
<tr>
<td>Iran</td>
<td>14</td>
</tr>
<tr>
<td>Pakistan</td>
<td>8</td>
</tr>
<tr>
<td>Eritrea</td>
<td>4</td>
</tr>
<tr>
<td>Albania</td>
<td>4</td>
</tr>
<tr>
<td>Zimbabwe</td>
<td>5</td>
</tr>
</tbody>
</table>

Source: Suffolk Refugee Support

In addition there were another 23 asylum seekers from 12 other countries, a total of 79 people.

Table 2: Asylum seekers, unaccompanied minors, 1 June 2013 to 30 June 2015

<table>
<thead>
<tr>
<th>Period</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>1/06/13 – 31/12/13</td>
<td>4</td>
</tr>
<tr>
<td>01/01/14 – 31/12/14</td>
<td>24</td>
</tr>
<tr>
<td>01/01/15 – 30/06/15</td>
<td>19</td>
</tr>
<tr>
<td>Total</td>
<td>47</td>
</tr>
</tbody>
</table>

Source: SCC Fostering service

This needs assessment was prepared in July 2015 by the Public Health Action Support Team on behalf of Suffolk County Council.
These young people arrived from Eritrea, Iran, Albania, Sudan, Vietnam and Afghanistan. Young men often enter the UK on lorries, and in that case will be registered in the County where they are found. Some of these will have arrived at Felixstowe.

There is a comprehensive service available in Ipswich. Suffolk Refugee Support provides information, help with form-filling, language skills, companionship and caring, advice and advocacy. They comment “we can easily overlook just how resilient, positive and creative” the asylum seekers can be. The Health Outreach provides health and social care support in identifying problems and signposting to solutions, in providing a good start as asylum seekers and refugees arrive in Ipswich, and making themselves known as a service to which those people can return. These additional services complement the clinical work in primary care. If they were not there, the offer that primary care alone could make would be much less effective.

**What is the evidence base for interventions? What is best practice?**
The key question approached by a number of studies is how access is gained by vulnerable migrants to primary care and to secondary care.

Primary care is often not available in migrants’ country of origin, and they may expect to go to hospital for initial assessment of a problem. They also lack knowledge about payment for health services, and anecdotal evidence suggests that some NHS Trusts are also unclear. Access is related to accurate understanding of points of entry to the NHS and confidence about charges which might be levied in the system.
Aspinell (2014) reviewed the payment structure for health services available to vulnerable migrants:

- There is no required minimum period of stay in the UK before a person - including asylum seekers, refugees, and failed asylum seekers - can be registered with a GP. GPs can only decline such people if their list is closed or on other non-discriminatory grounds.
- GPs have a duty to provide emergency treatment free of charge regardless of migrants’ residential or registration status.
- Charging regulations in secondary care have frequently changed. Since May 2012, a person seeking asylum or granted asylum, temporary or humanitarian protection under immigration rules is exempt from NHS charges and should be recognised as a refugee.
- Failed asylum seekers are generally liable for NHS hospital treatment charges, although there are exemptions for those continuing to be supported by UK Visas and Immigration.

All primary care services are available without cost to asylum seekers and refugees. The debate continues on the best way to structure primary care services for asylum seekers and refugees (Feldman 2006). Three models are proposed:

- “Gateway services” facilitate entry into primary care by identifying unregistered patients and carrying out health assessments.
- “Core services” provide full registration and may be provided by dedicated practices or by mainstream practices.
- “Ancillary services” are those that supplement and support core services’ ability to meet the additional health needs of this group. They include language and information services, close links with community-based organisations, specialist mental health services and services for survivors of torture and organised violence, as well as targeted health promotion and training of health workers.

The discussion is limited by lack of evaluation of different models, but stresses the importance of ancillary services to successful mainstream provision.

Aspinell further considers registration rates of newly arrived refugees and asylum seekers. “The most robust estimates suggest that only about a third of all generic new entrants to the UK were registered”, and only 19% of asylum seekers. This varied across the UK, with rates approaching 100% in London. Aspinell notes: “the evidence was based on those entering the UK from countries with a high risk of TB who underwent port health tuberculosis screening”; this introduces a potential bias.
The question of how primary care should meet the challenge of newly arrived asylum seekers was the subject of a national survey of primary care (Eling 2010). There was insufficient data to evaluate the different models that had been developed in response to local need around the UK. However, factors were identified which influenced the configuration for a local service:

- local health service factors – enthusiasm to prepare for sudden large influxes of new entrants and the consequent resource implications,
- demographic and geographic factors – the ratio of new entrants to the established population, and the expected disease epidemiology in the new arrival group,
- local enthusiasms and politics, how much support could be expected from commissioners to engage with the agenda of including and supporting asylum seekers and refugees, and whether there should be specialist GP surgeries.

A brief introduction to this discussion is included here as there are similar questions to be answered in Ipswich. However the model which is in place in Suffolk is The Health Outreach receiving referrals on all newly dispersed arrivals through the asylum service, then arranging certain screening and healthcare advice before facilitating registration with a GP. This fulfils the “Ancillary services” (Aspinell) requirement. Compared with the total number of asylum seekers entering the UK, East of England does not receive many. However systems have to be in place both for proper access and use of the services, and also for health risks such as TB. The level of this risk should reduce as new screening procedures are implemented in the country of origin of asylum seekers prior to application being made.

Tuberculosis (NICE, 2011), is an infectious but treatable disease. It is the second most common cause of death globally. In 2012 there were 8,751 new cases in the UK, an incidence of 13.9/100,000. Since 2004, people arriving from countries with an incidence of tuberculosis of over 40/100,000 are screened on arrival. More recently, people applying for asylum in the UK from the 22 WHO high burden countries for the disease are screened before they leave their country. If they are infectious they can seek medication and can re-apply when they are well. This is both cheaper and more effective. (UKBA, 2012).
What is the pattern of services in Suffolk at present?
This section is arranged following the asylum seeker’s route from arrival.

Port Health
TB screening is no longer carried out at Heathrow and Gatwick airports. Those resident in one of the 22 WHO high burden countries for TB will be tested before being allowed to commence an asylum seeking journey.

On arrival in Ipswich
Outreach and preventive work is provided by the Health Outreach, which works at all stages of the prevention, treatment and care pathway, providing treatment, information and advice on health and social issues and facilitating access to GPs and other mainstream health and social services.

It is specifically commissioned to provide health and social care advice and support to refugees and asylum seekers as well as other specific groups of marginalised and vulnerable adults.

The Health Outreach also has a geographic spread across Suffolk, a main static base located in Ipswich and visiting arrangements with the mobile clinic to a number of the market towns in the County.

The Health Outreach provides initial contact treatment and advice widely in Suffolk. The Health Outreach team consists of general nurses, mental health nurses, and a blood-borne virus nurse specialist, social workers, a GP, a physician’s assistant, support workers and administrative staff encouraging links with health services. The team also liaises with and support other organisations such as the Suffolk Refugee Support.

On arrival in the UK, a new asylum seeker is placed in UK Visas & Immigration temporary initial accommodation, where there are health teams that provide health checks. Once his support application has been granted, he leaves this accommodation and is transferred into dispersal accommodation until he receives a decision on the asylum application, or his support needs or circumstances change.

The Health Outreach in Ipswich is notified of all new arrivals directly by secure email, as a first point of contact with health services in Ipswich. Two formal systems are employed, one for unaccompanied young persons and one for adults and families.
Unaccompanied young persons are brought to The Health Outreach by social care with either their care provider or foster carer.

Adults and families are notified to The Health Outreach by the Home Office and the housing provider G4S. The Health Outreach makes direct contact with the new arrival(s) to begin the assessment as soon as possible, usually immediately after arrival.

The Health Outreach will ensure the person has a GP, dentist, optician and referral to Suffolk Refugee Support and elsewhere as appropriate.

Where there is anxiety and depression, The Health Outreach will provide counselling. The system is efficient and few if any are missed, but it depends on sufficient GP practices being able and willing to absorb the potentially heavy new additional workload.

The Health Outreach also has strong links with the other dispersal sites in the region (particularly with City Reach in Norwich) so if there are any changes of location during dispersal, a new referral can be made quickly.

Asylum seekers and refugees receive free primary and secondary care and are entitled to free prescriptions for medication, dental care, eye tests and spectacles.

**Primary care**

In Ipswich, new arrivals join one of the town centre practices. Barrack Lane Medical Centre is not a specialist practice but receives many asylum seekers and refugees. A new patient check is carried out by the practice nurse, as for any newly registering patient, and leaflets are available in a number of languages. There are probably no previous notes, except those from screening in initial accommodation and language is a problem so the process of registration may take extra time. It can be straightforward or the person may present with very distressing and complex problems.

Barrack Lane Medical Centre holds a monthly multidisciplinary team meeting attended by external professionals including adult social workers, a link worker from Norfolk and Suffolk Foundation Trust (NSFT), the community cancer care team, community matron and The Health Outreach Team. Any input from other professionals on the needs of particular patients, including new asylum seekers and refugees, are discussed at the meeting. In this context, The Health Outreach is providing most of the “ancillary services” mentioned in the last section, with specialist mental health service from NSFT and English classes and information and social support by Suffolk Refugee Support.
**Secondary care**

Despite the documented high incidence of mental health problems amongst asylum seekers and refugees, there are no dedicate services at Norfolk and Suffolk Foundation Trust Hospital though there is a plan to look at whether these are needed. Counselling is provided at The Health Outreach and in interviews with asylum seekers this service was commended.

**Service user opinion**

Two visits were made, one to a group of overseas women who were mostly interviewed separately as they did not want to break up the activity they were engaged in to form a focus group. The second was a lunch club of people from a range of nationalities who participated in a focus group.

The women had all had contact with The Health Outreach so all were registered with a GP and knew how to get appointments, and to see that their children’s health needs were met. A common problem was waiting and queuing for services, it was not in their experience. If medication was needed, they had to wait at the doctor’s surgery for a prescription whereas at home they would have gone to the pharmacy and bought it over the counter. If they wanted a doctor, they would go to the hospital.

They knew how to get access to language line, though some said they did not think it was their responsibility to ask for it; it should be automatically provided.

They had been comprehensively introduced to different health services by The Health Outreach.

Their children were up-to-date with immunisations and vaccinations, and the women had had cervical screening. One man wanted to know why he could not have screening for diabetes as he knew it was a risk for him.

They cooked together as one of their activities, but one woman expressed her frustration that when she was newly arrived, she didn’t recognise the food in the shops and for example, had no idea how to cook broccoli.

They found it difficult to keep warm in winter and the fuel bills were high; this may only have applied to those with positive decisions who were responsible for their own bills.

Although many were alone in the UK they seemed to have made relationships together and were sharing child care for example. They liked meeting together and they were pleased that halal food
was easily available.

What additional information is needed?
- The Health Outreach was unable to provide specific quantitative analysis of its dataset. The work of The Health Outreach is commended by professionals and clients alike but in this needs assessment, only qualitative description can be offered as The Health Outreach was unable to provide statistical information relating to its service. As all budgets are under threat The Health Outreach should find a way of presenting its activity in a way that will stand scrutiny.
- A two year audit by a GP practice of registrations of new patients arriving from non EU countries cross referenced to referrals for specialist mental health services is underway but not currently available.

What can be concluded?
Asylum seekers are brought together by the most difficult of circumstances. In 2006, only 10% of asylum claims were successful and three-quarters of appeals were rejected.

They are effectively homeless, placed where they are told and open to being moved by the housing provider if the needs of another client would more closely fit the size of the accommodation. The interviews with asylum seekers show the level of anxiety and depression, possibly linked to the insecurity of their situation of whether a positive decision is to be obtained (the Home Office aims to complete enquiries in six months) and if so, whether after five years, indefinite leave is granted. The possibility of detention and deportation remains for a long time.

They are often alone without family or friends; some having moved to different countries before and if they have family, they may never see them again.

In interviews some negative comments were expressed. Some less common languages or dialects were not available on Language Line. Asylum seekers and refugees found it very difficult to understand queuing and waiting. Most come from different health systems and may not expect to have to get a prescription for drugs which they just used to go out and buy at home.

The pathway of services available in Ipswich, the main receiving centre for the asylum seekers and refugees arriving in Suffolk, is comprehensive. Having been received by The Health Outreach, the new arrivals are then provided with health screening and advice and enabled to register with a GP. This makes the Suffolk population of asylum seekers and refugees different from those in some
other parts of the UK. The GP is then able to use Language Line for consultation with the patient. Social life, language skills and integration into British life is supported by Suffolk Refugee Service. We conclude that supported by the additional services, and subject to an audit to clarify the capacity of GP practices to continue to accept all new comers, a satisfactory service is available to asylum seekers and refugees.

References

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Vitamin D: increasing supplement use among at-risk groups NICE guidance PH56 [https://www.nice.org.uk/guidance/ph56]
Chapter 2

Migrants from Eastern Europe
Summary

Migrants from Eastern Europe introduction

- The exact boundaries of Eastern Europe are not well defined and each nationality has its own identity, culture and language.
- At the 2011 Census, Poles were overwhelmingly the largest group of Eastern Europeans in Suffolk. The next largest was Lithuanians; these two nationalities, together with Latvians and Romanians (the next two most numerous), made up 79% of Eastern Europeans resident in the County.
- In Suffolk, Ipswich has by far the highest number of Eastern Europeans, followed by St Edmundsbury and Forest Heath. Both Ipswich and Forest Heath had a higher proportion of residents from Eastern Europe than the East of England and England as a whole.
- The predominance of Poles is corroborated by an analysis of main language as reported in the Census. Polish was also the most common non-English language spoken as a mother-tongue in Suffolk schools.
- The majority of Eastern European people in Suffolk are young adults of working age. There are also children and some middle-aged and older people. The pattern with Romanians is similar to that seen for Poles, but is less pronounced.
- In the five years to 2013, the rate of inward migration to Suffolk was broadly constant.
- The number of non-UK nationals working, planning to work legally or claiming benefits in Suffolk is consistently lower than elsewhere in the region or in England.

Migrants from Eastern Europe key points

The main health problems for Eastern European migrants include:

- Mental health problems. The main mental health problems facing economic migrants are loneliness, anxiety and depression, along with the effects of excessive drinking.
- Obesity. Central and Eastern European countries have a higher prevalence of obesity than those in Western Europe, especially among women. Eastern European populations have had a particularly high mortality rate from cardiovascular disease.
- Sexually transmitted infections. Migration is associated with the ending of previous sexual relationships and the establishment of new ones. It can lead to high-risk sexual behaviour, so migrants from Eastern European countries are at an increased risk of developing sexually transmitted disease.
• Drug and alcohol consumption. Excessive drinking and the use of illicit drugs are reportedly common amongst Eastern European men. Alcohol specifically is a major cause of ill-health in the Eastern European region, with binge drinking a special threat.

• Smoking. Eastern European countries have high rates of smoking. In consequence, lung cancer incidence is higher there. Migrants to the UK have higher rates of smoking.

• Poor housing. Many economic migrants lack access to good housing advice, often due to language barriers, uncertainties about entitlement and the opening hours to the services.[21] They often occupy poorer quality private rented housing.

• Lower understanding of the British health system. Migrants often lack knowledge of the UK health system and specifically of the role of the general practitioner (GP) and primary care.

• Barriers to accessing healthcare. Limited English, rural locations and lack of GP registration can make it harder for migrants to use the NHS.

Migrants from Eastern Europe recommendations

1. Health messages should be available in appropriate languages and visible in areas that are accessed by the Eastern European population.

2. Services, particularly stop smoking, Drug and Alcohol, mental health and sexual health services, should be able to meet the needs of Eastern Europeans’ taking account of their culture, language, and lifestyle.

3. The formation of social groups should be encouraged to reduce social isolation which is a problem particularly for young, single males.

4. Eastern European migrants need access to appropriate housing advice.

5. Improving the understanding of migrants about local health and care systems including GP registration, self-care and referral to secondary care, would promote appropriate use of health and care services and also improve access to services.

6. Ensure professionals in all services understand how to access translation and interpretation services, and that they are widely available. This should decrease the practice of children and others interpreting for family members or friends, when personal information is being discussed.

7. Use contracts to strengthen the collection of ethnic group data, to enable better understanding of the health and well-being needs of local communities.
**Which migrants from Eastern Europe live in Suffolk?**

When the term Eastern Europe is used it at its simplest means countries in the eastern part of the European continent. It is often taken to mean the countries which were under communist rule until the end of the Soviet Union. However, the exact boundaries of Eastern Europe are not well defined (see Appendix B).

In this report, we mostly discuss Eastern Europeans as a single group. However, this is a simplification; each nationality has its own identity, culture and language. Some Eastern Europeans would prefer not to be labelled in that way, just as British people might not see themselves as Western Europeans.

Migrants to Suffolk do not come equally from all of the countries in Eastern Europe. Table 2 shows the countries of origin of the 11,220 respondents to the 2011 Census in Suffolk who gave countries of origin in Eastern Europe, as defined as present in at least one of the lists in the Appendix B.
Table 1: Numbers of migrants from Eastern Europe, Suffolk, 2011

<table>
<thead>
<tr>
<th>Country of origin</th>
<th>Bulgaria</th>
<th>Czech Republic</th>
<th>Estonia</th>
<th>Hungary</th>
<th>Latvia</th>
<th>Lithuania</th>
<th>Poland</th>
<th>Romania</th>
<th>Slovakia</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>235</td>
<td>249</td>
<td>71</td>
<td>398</td>
<td>690</td>
<td>1452</td>
<td>6106</td>
<td>652</td>
<td>411</td>
<td>9</td>
</tr>
<tr>
<td>Proportion (%)</td>
<td>2.1</td>
<td>2.2</td>
<td>0.6</td>
<td>3.5</td>
<td>6.1</td>
<td>12.9</td>
<td>54.4</td>
<td>5.8</td>
<td>3.7</td>
<td>0.1</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Country of origin</th>
<th>Czechoslovakia</th>
<th>Albania</th>
<th>Armenia</th>
<th>Azerbaijan</th>
<th>Belarus</th>
<th>Bosnia and Herzegovina</th>
<th>Croatia</th>
<th>Yugoslavia NOS*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>9</td>
<td>89</td>
<td>4</td>
<td>17</td>
<td>36</td>
<td>11</td>
<td>37</td>
<td>31</td>
</tr>
<tr>
<td>Proportion (%)</td>
<td>0.1</td>
<td>0.8</td>
<td>0.0</td>
<td>0.2</td>
<td>0.3</td>
<td>0.1</td>
<td>0.3</td>
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<table>
<thead>
<tr>
<th>Country of origin</th>
<th>Georgia</th>
<th>Kosovo</th>
<th>Macedonia</th>
<th>Moldova</th>
<th>Montenegro</th>
<th>Russia</th>
<th>Serbia</th>
<th>Ukraine</th>
<th>USSR NOS*</th>
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</thead>
<tbody>
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<td>7</td>
<td>274</td>
<td>84</td>
<td>198</td>
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</tr>
<tr>
<td>Proportion (%)</td>
<td>0.1</td>
<td>0.9</td>
<td>0.1</td>
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<td>0.1</td>
<td>2.4</td>
<td>0.7</td>
<td>1.8</td>
<td>0.1</td>
</tr>
</tbody>
</table>

Source: Office for National Statistics, 2011 Census

* Not otherwise specified

Poles were overwhelmingly the largest group, constituting 54% of the total. The next largest was Lithuanians (13%). These two nationalities, together with Latvians and Romanians (the next two most numerous), made up 79% of Eastern Europeans resident in the County on Census night. In England as a whole, Poland (8.7%) is among the top three countries of birth for foreign-born individuals in the UK, along with India.
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(9.1%) and Pakistan (5.8%). Poland represents the largest proportion of foreign-born people living in the UK who have retained their original nationality, with 14.9% of the total (Office for National Statistics, 2013).

Table 2 shows the number of these four most frequent nationalities in each local council district in Suffolk and for the County as a whole. Ipswich has by far the highest number of Eastern Europeans, followed by St Edmundsbury and Forest Heath. Both Ipswich and Forest Heath had a higher proportion of residents from Eastern Europe than the East of England and England as a whole; this was 2.1% in both cases.

Table 2: Numbers of migrants from Latvia, Lithuania, Poland, Romania and total Eastern European, by local authority, Suffolk, 2011

<table>
<thead>
<tr>
<th>Local authority</th>
<th>Latvia</th>
<th>Lithuania</th>
<th>Poland</th>
<th>Romania</th>
<th>Other Eastern European</th>
<th>Total Eastern European</th>
<th>Total Eastern European as a proportion of overall population</th>
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</thead>
<tbody>
<tr>
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<td>44</td>
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<td>330</td>
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<td>149</td>
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<td>Forest Heath</td>
<td>79</td>
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<td>1204</td>
<td>66</td>
<td>334</td>
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<td>2367</td>
<td>219</td>
<td>838</td>
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<td>74</td>
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<td>1266</td>
<td>79</td>
<td>448</td>
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<td>1.9</td>
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<td>339</td>
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<td>132</td>
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<td><strong>Suffolk</strong></td>
<td><strong>690</strong></td>
<td><strong>1452</strong></td>
<td><strong>6106</strong></td>
<td><strong>652</strong></td>
<td><strong>2320</strong></td>
<td><strong>11,220</strong></td>
<td><strong>1.5</strong></td>
</tr>
</tbody>
</table>

Source: Office for National Statistics, 2011 Census
Figure 1 shows the proportions of the Suffolk population from these four nationalities. Although numbers of Eastern Europeans were higher in St Edmundsbury than in Forest Heath, the lower total population of the latter local authority means that they represent a higher proportion of residents.

**Figure 1: Proportions of population from major Eastern European nationalities, by local authority, Suffolk, 2011**

[Bar chart showing proportions of population from major Eastern European nationalities by local authority in Suffolk, 2011.]

Source: Office for National Statistics, 2011 Census

The predominance of Poles is corroborated by an analysis of main language as reported in the Census. After English, Polish was overwhelmingly the most common main language, used by 5762 people. The next most common was Lithuanian, used by 1275 people. No other main language was reported by more than a thousand people.

In more recent data from 2014, Polish was also the most common non-English language spoken as a mother-tongue in Suffolk schools, with 1146 speakers. Lithuanian with the third most common, with 397 schoolchildren, after Portuguese with 679 schoolchildren (Office of National Statistics, 2014).
More detailed analysis is available for the Polish and Romanian population of Suffolk. Figures 2 and 3 show the age structure in 2011 of Suffolk residents born in Poland. The analyses for males and females show a similar pattern, with the majority of people being young adults of working age. There are also children and some middle-aged and older people.

**Figure 2: Age structure of males born in Poland and resident in Suffolk, 2011**

![Age structure of males born in Poland and resident in Suffolk, 2011](image)

Source: Office for National Statistics, 2011 Census
Figure 3: Age structure of females born in Poland and resident in Suffolk, 2011

![Age structure of females born in Poland and resident in Suffolk, 2011](chart)

Source: Office for National Statistics, 2011 Census

Data on Romanians in Suffolk are only available for Ipswich Borough because of small numbers elsewhere. The pattern is similar to that seen for Poles, but is less pronounced: there are proportionately more children of school age and middle-aged adults (Figures 4 and 5).
Figure 4: Age structure of males born in Romania and resident in Ipswich, 2011

Source: Office for National Statistics, 2011 Census
We found no other data specific to Eastern Europeans in Suffolk. However, there are broader indicators of inward migration which are relevant. Figure 6 shows three indicators for the five years to 2013, the most recent year for which data are available. They suggest that the rate of inward migration to Suffolk was broadly constant over this period. The rate may have risen after Bulgarians and Romanians gained the right to work in the UK in 2014.
This needs assessment was prepared in July 2015 by the Public Health Action Support Team on behalf of Suffolk County Council.

NINo: The number of new National Insurance Numbers (NINos) registered by migrants in the UK provides an indication of the number of economically active foreign nationals entering the country. NINos are issued to all non-UK nationals aged 16 or over working, planning to work legally or claiming benefits in the UK, regardless of how long individuals intend to stay. Figure 7 compares the rates of new National Insurance Numbers (NINos) registered by migrants in Suffolk, the East of England and England as a whole for the same five year period. It indicates that the number of non-UK nationals working, planning to work legally or claiming benefits in Suffolk is consistently lower than elsewhere in the region or in England. NINo data do not indicate the number of people who may have registered elsewhere before coming to Suffolk.
What are the health problems for Eastern European migrants?
We reviewed the literature to identify the most important health problems affecting Eastern Europeans resident in the UK. The answers are not always clear-cut, because the research may not be focused on migrants of the same nationalities as are seen in Suffolk, may be concerned with groups defined by ethnicity not nationality, or may be in settings which are dissimilar to Suffolk. However, their general conclusions are likely to be relevant (Tobi et al, 2010, Centre for Public Health 2014, City of Bradford 2014).

Many migrants from Eastern Europe have good health, and the worst health problems are concentrated in a small minority.

Mental health
Research on the mental health of migrants to the UK is largely concerned with asylum seekers and refugees. Eastern European communities in the UK are however known to have poor mental health, attributable to a combination of underlying risk, experiences in migrants’ home countries and the stresses of immigration and of adaptation to and living conditions in
the new country (Tobi et al 2010, Patel 2012, Lindert et al 2008). Migrants from Eastern Europe may be socially isolated and vulnerable, for example living in multiple occupancy houses, which can exacerbate mental health problems. Paradoxically, those with the greatest needs are therefore least likely to use services.

The main mental health problems facing economic migrants are loneliness, anxiety and depression, along with the effects of excessive drinking (Moore 2007).

**Obesity**

After the end of communist rule in Eastern Europe, a high fat and high sugar diet became more common (Webber 2012). Alcohol consumption also rose substantially. As a result, Central and Eastern European countries have a higher prevalence of obesity than those in Western Europe, especially among women. Eastern European populations have had a particularly high mortality rate from cardiovascular disease (Rabin et al 2007).

**Sexual health**

Sexual health is an important issue for migrants from Eastern Europe:

The collapse of communism was followed by a marked deterioration in public health services, including the surveillance and treatment of sexually transmitted infections. Awareness of these illnesses and of their consequences are low, and antibiotic resistance is high in Eastern European countries. The use of intravenous drugs and needle sharing also contributed to a high prevalence of HIV infection (EuroHIV, 2007).

Migration is associated with the ending of previous sexual relationships and the establishment of new ones. It can lead to high-risk sexual behaviour, so migrants from Eastern European countries are at an increased risk of developing sexually transmitted disease (Patel 2012, Burns et al 2008). Eastern European migrants, especially males, report high rates of risky behaviours associated with increased transmission of HIV and other sexually transmitted infections; these include excessive alcohol consumption, recreational drug use, anal sex and paying for sex (Burns et al (2011).

Migrants often have limited knowledge and experience of the British health systems. This means that they may access services late or not at all, and not take up contact-tracing
opportunities (Tobi et al 2010). Eastern European women are more likely to attend genito-urinary medicine clinics than their male counterparts (Burns et al 2008).

There is less cultural acceptance of homosexuality in some Eastern European societies. Lesbian, gay, bisexual and trans-gendered people face stigma and discrimination and may therefore emigrate to a more tolerant society (Burns et al 2008).

**Drugs and alcohol**

Excessive drinking and the use of illicit drugs are reportedly common amongst Eastern European men. Alcohol specifically is a major cause of ill-health in the Eastern European region, with binge drinking a special threat (Bobak et al 2004, Nemtsov 2002, Bunting 2010). People from Poland and the Baltic states are said to drink more than those from Romania and Bulgaria. Needs assessments have reported higher rates of alcohol use in migrant populations (Patel 2012); however, an analysis of alcohol-related hospital admissions in the UK found no excess of people of Polish origin (Collinson et al 2010).

Alcohol dependency is linked to homelessness and is a significant health problem amongst the homeless Eastern European population in London (Haringey 2014). In Haringey, Eastern Europeans form part of the visible street-drinking population, and a street outreach programme is in place to target individuals from Poland and Eastern European communities (Malvezzi et al 2013).

**Smoking**

Eastern European countries have high rates of smoking (Moore 2007). In consequence, lung cancer incidence is higher there, with rates of 55 to 80 per 100,000, compared with rates in Western Europe of 35 to 40 per 100,000 (Eida 2010).

Migrants to the UK have higher rates of smoking than the indigenous populations (Patel 2013). Most started smoking before coming to the UK, with prevalence highest in those in routine and manual jobs or with weaker language skills (Eida 2010).

This is compounded by language difficulties. Smoking cessation services involve counselling which depends on linguistic compatibility between the smoker and the advisor. Migrants are
therefore unlikely to use or benefit from smoking cessation classes conducted in a language in which they are not proficient; there is evidence that this deters people from accessing mainstream services (Eida 2010). To overcome this, smoking cessation classes have been organised in some places with the local Polish Society – an example of this is Crewe (Webber et al 2012, Kofman et al 2007).

**Housing**

Overcrowded, poor housing damages health. Many economic migrants lack access to good housing advice, often due to language barriers, uncertainties about entitlement and the opening hours to the services (Kofman et al 2007). They often occupy poorer quality private rented housing (Shelter 2008, Ricketts 2008, Spencer et al 2007). If their employment is linked to their accommodation, the disadvantage from poor housing can be compounded by excessive working hours (Ricketts 2008). Agricultural work is sometimes seasonal, leaving migrants not only unemployed for part of the year, but also without accommodation.

**Understanding of the British health system**

Migrants often lack knowledge of the UK health system and specifically of the role of the general practitioner (GP) and primary care (Tobi et al 2010, Lindert et al 2008, Collis et al, 2010). This affects what they expect from services and how they use them (Duckworth et al 2012). Those with fluent English tend to have more understanding of the NHS (Collis et al 2010).

Lack of information can lead to inappropriate use of services. For example, some Eastern European patients attend emergency departments because they do not understand the UK health system and may find it hard to register with a GP because of language difficulties (Webber et al (2012). There is conflicting evidence about migrants’ registration with and use of primary care (Duckworth et al 2012). Those unregistered cited lack of knowledge about the process, lack of need or inclination and language as the main obstacles (Tobi et al, 2010). Some researchers have suggested that migrants need information on health services when they enter the UK (Collis et al 2010).

This lack of understanding of the system can lead to dissatisfaction and frustration with the UK health system. In many Eastern European countries, patients consult specialists without
referral from a GP. They may be used to direct access to hospital services and a lower threshold for investigations than in the UK – for example, more scans in pregnancy (Webber et al (2012). The concept of a GP as a gatekeeper to other services is unfamiliar, and may be experienced as a denial of care or cost-saving manoeuvre.

There are also different expectations about prescribing and availability of medicines, which may be due to variations in the health care systems in participants’ countries of origin (Duckworth et al 2012). Many Eastern European women believe that they cannot access any gynaecology services without referral to a specialist by the GP, including genito-urinary medicine and contraception services.

A London GP provided an anecdotal account of her experience of Polish patients (Greenhalgh, 2006). They believed that, compared with Britain, GPs in Poland take illness more seriously and make more specialist referrals, postnatal care continues for longer periods and sick children can access a paediatrician immediately as opposed to having to wait for several weeks. Her experience was that Polish immigrants brought with them “memories of a healthcare system in which general practice is often the last refuge of the failed physician”.

Some Eastern Europeans choose not to use NHS services, but instead consult doctors from their country privately, or return there for dental care or other forms of treatment. This is more consistent with their previous experience of unmediated access to specialist care, and may provide culturally and linguistically accessible healthcare. After returning to the UK, they may develop complications which require treatment here. However, some of these patients may not have full knowledge of what NHS services are available and why, or may be deterred by concerns about the availability of an interpreter; with better information, they might make more use of the NHS.

**Barriers to accessing healthcare**

Limited English is a significant barrier to Eastern Europeans making use of the NHS. We were not able to obtain any data on the language proficiency of migrants in Suffolk, and language skills tend to improve with time spent in a new country. However, there are anecdotal reports of the inadequate availability of interpreters. Language Line is an NHS
interpretation service available in Suffolk, but it is not adequately publicised and in some cases we were told that it is used inappropriately. INTRAN provides translation services at West Suffolk Hospital and TIP does so for the marginalised and vulnerable adults service. Some Eastern Europeans live in remote rural locations with limited public transport. Some work long hours. These are also barriers to use of services, including the NHS.

Entitlement to health care and benefits depends on migration status (Jayaweera 2010). Eastern Europeans are not always aware of their entitlements. The proportion who hold this card is 5% to 10% (Jayaweera 2010). Cultural insensitivity and associated taboos (for example sexuality and domestic violence) means that it is often difficult to discuss these issues with Eastern European patients, especially for women consulting a male practitioner (Tobi et al 2010). We heard that only one in five migrants from Eastern Europe known to Migrant Help, a charity which assists migrants, is registered with a GP. Some do not access NHS services or register with a GP because they believe that a fee would be payable. From 2016, the introduction of the habitual residence test may reduce access to some NHS services for migrants who lose recourse to public funds.

Accessing mental health services is particularly difficult. Ethnic minorities and migrants may be affected by

- different understandings of mental health problems
- lack of acknowledgement and discussion of, and priority for, mental health problems
- lack of knowledge of services
- stigma, fear of authority and lack of trust
- previous negative experiences of accessing NHS services
- lack of interpreting and translation services

In Suffolk and elsewhere, many migrants from Eastern Europe work in agriculture and food-processing in rural areas. This is different from previous waves of immigration, where newly arrived people were concentrated in cities. Healthcare resources may be more thinly spread in rural areas, less flexible and with fewer resources to accommodate specific needs. There are also poor health and safety practices in some industries which employ migrants.
Occupational health arrangements are often limited or absent, staff do not usually have union representation and may be engaged via an agency rather than directly employed.

**Suffolk County Council’s survey in 2010**

In 2010, Suffolk County Council published a survey of migrants (Suffolk County Council 2010). It was based on 400 face-to-face interviews. Two hundred and eight of the respondents were Polish and most of the rest were Eastern European. Although the survey is no longer current, it corroborates and reinforces many of the findings of this report. In the 2010 Suffolk survey, 88% of migrants rated their health as good or very good. This compared to 76% of the adult population in Suffolk.

Overall, 18% of migrants had not used primary care, 42% had not used a dentist and 34% has not used a local hospital. Of those that had used these services, 88% were at least satisfied and 8% dissatisfied with primary care, 73% were at least satisfied and 6% dissatisfied with dentist services and 76% were at least satisfied and 5% at least dissatisfied with their local hospital.

Eighty per cent of migrants in this survey had registered with a GP. Lithuanians were less likely to be registered (59%). There was also some variation by district, with 61% registered in Babergh and 91% registered in St Edmundsbury. Fifty-one per cent of those who had been in the UK for under a year had registered with a GP, compared with 91% of those that have lived here for over a year.

**What is the pattern of services in Suffolk at present?**

**General health services**

Eastern Europeans have access to the full range of local health services.

We wished to analyse routine NHS activity datasets to understand in more detail patterns of utilisation of Eastern European residents of the County. However, the ethnicity data groups all Eastern Europeans into the “any other White” category, along with all White patients not categorised as British or Irish. This group will include other European migrants and residents in Suffolk, as well as White people from North America and Australasia. It is therefore not helpful for the present analysis.
Specific services

The Marginalised and Vulnerable Adults (MVA) service (Health Outreach Project) runs health outreach throughout East and West Suffolk, offering a drop-in service for people from marginalised and vulnerable groups. It is not commissioned for the population of Waveney. The service offers immediate help, and signposts people to GPs and other services. The service’s database is a potentially rich source of information about the health needs of users, including people from Eastern Europe, and about how those needs are met. It records service users’ ethnicity. Unfortunately, the database could not be analysed for this project. We were told that two to three Eastern Europeans attend the service each day, and that there are about a dozen Eastern Europeans among the homeless people known to the service.

Migrant Help is a charity which assists migrants by providing resources and support to find safety, access appropriate services and information, develop greater independence and become successful, active and contributing members of the community. Funded by the Big Lottery until September 2015, it provides services in Ipswich, Newmarket and Brandon. It is not clear whether it can continue after this grant ends.

Keystone Development Trust aims to build community capital by empowering individuals, groups and communities to tackle needs and issues by creating their own solutions, organisations or enterprises. It numbers Eastern Europeans among the groups it supports. We held a focus group with a senior manager from Migrant Help and the Keystone Development Trust.

What is the evidence base for interventions? What is best practice?

We searched for evaluated interventions aimed at improving the health and wellbeing of Eastern European populations in the UK. We found one which had been subject to evaluation. The Smokefree Northwest project developed a service in Central and Eastern Cheshire aimed at smokers in the Polish community in Crewe (Eida et al 2010). It was based on a mainstream smoking cessation model, but with language-related adaptations to suit the target audience.

The evaluation showed that the service was successful. Sixty-five people accessed the service, with a 40% quit rate achieved. Ninety per cent of service users said that they would
recommend the service to a friend. Most service users became aware by word of mouth; referrals from health service providers and self-referrals from paper and internet publicity were low.

There are other examples of projects which indicate the approaches taken elsewhere. Although they have not been evaluated, they are still of interest:

- The Highland region of Scotland has a Polish community of 4,500. NHS Highland provided leaflets in Polish and translators were available at clinics attended by large number of Polish people. The leaflets covered topics specific to pregnant Polish women, such as routine blood and screening tests, which may not be familiar from the Polish healthcare system. This intervention received positive feedback (Moore et al 2007).
- NHS Scotland’s website describes the Scottish health service and how to access it. It is available in different languages and covers subjects from the need to register with a GP to where to go for marriage guidance.
- In Norfolk, a former primary care trust commissioned an interpreter to run sessions at GP surgeries. Medical practices had access to a communicating/interpreting service and frontline healthcare staff, were given language cards so migrants could point to the language that they speak (Moore et al 2007).
- This primary care trust held a Migrant Workers Day to provide advice on diet, lifestyle, sexual and mental health, and social care. The feedback from the migrant community led to changes in the Trust's service-level agreements with providers to help ensure migrant workers receive appropriate care (Moore et al 2007).
- In Reading, the former primary care trust worked with local agencies, including the Catholic Church, to inform the Polish community about the health system. It also used health advisers from within the community, based on a scheme developed with its local black and minority ethnic community (Moore et al 2007).

What additional information is needed?
It was disappointing that the MVA service's dataset was not available for analysis. The dataset needs to be analysed so that its value for health needs assessment and service evaluation is fully realised.
More generally, the recording of ethnic and nationality data is far from complete in the NHS. It may not be practical to record data showing details of national origin in every case, but the absence of any data constrains what can be learned of the use which Eastern Europeans make of services.

**What can be concluded?**

The twenty-first century arrival of Eastern Europeans in the UK is fundamentally different from previous waves of immigration to the UK. Most Jewish, Afro-Caribbean and South Asian people arriving here saw themselves as moving to Britain permanently. They concentrated their settlement in urban areas, creating mutually supportive communities where they could live, work, trade and worship together. Although they were, and sometimes still are, marginalised and victimised through racism and restricted social and economic mobility, their visibility, clustering and distinctiveness from indigenous White Britons conditioned how they interacted with wider society, the extent of their integration and the benefits and harms of UK residence.

By contrast, Eastern European migrants to the UK are:

- widely dispersed, many in rural areas. They may lack the sense of community and have limited opportunities to support one another.
- less visibly different to White British people. This mitigates the risk of active racist discrimination, but does not abolish it. Many people from Eastern Europe face substantial discrimination in the UK.
- mostly younger adults, rather than larger family groups. They may lack accessible support from wider families.
- likely to return temporarily or permanently to Eastern Europe. This provides them with recourse to resources in their country of origin, which is a safety valve but also sometimes a deterrent to deeper engagement here.
- less united by a common faith, a source of cohesion and strength to minority communities.
- arriving in a more multicultural and less discriminatory country, although one in which immigration, especially from Eastern Europe, is politically controversial.

Some of these factors reduce the risks that Eastern European migrants face, others exacerbate them. However, these migrants are far from uniformly vulnerable. Many come to
the UK out of a desire to better themselves economically and aim to work hard before either returning to their country of origin or settling in the UK. They will tend therefore to be energetic and entrepreneurial.

We identified a number of specific issues for Eastern Europeans in Suffolk which give rise to important health needs or limit services’ ability to respond effectively:

**Adverse health factors**
Migrants bring with them lifestyles and behaviours from their country of origin. In the case of Eastern Europe, these include patterns of tobacco and alcohol consumption that pose a threat to health. These interact with the risks created by their migrant status, which include adverse mental health, a risk of sexually transmitted infections and occupational health threats from unsafe or unsatisfactory places of work.

**Dispersal**
In Suffolk, as in Norfolk and Lincolnshire, many Eastern Europeans work in the production and processing of food. Their workplaces are often rural and remote, ill-served by public transport and isolated from other resources and facilities; they may be unpleasant with inadequately mitigated hazards. The migrants may live in accommodation tied to their employment.

These factors are likely to place migrants at higher risk of physical and mental health problems. They will also make it harder for migrants to access health care and other resources to help them deal with these problems.

**Lack of knowledge and understanding of UK resources**
Eastern Europeans arrive from countries with a distinct culture, attitudes to and expectations of health and health care, and with healthcare and allied systems which reflect those factors. They understandably lack awareness of the systems in the UK, and may not accept readily the basis on which those systems are built, such as the centrality of primary care, the concept of screening and different approaches to prescribing.
As a result, Eastern European migrants may not be able to make good use of the NHS and other public services. Changes in entitlements add to the uncertainty about what is available. The inverse care law is at work here, with the most marginalised and disadvantaged migrants least able to make good use of the NHS.

**Language**

Problems with access to services are exacerbated by language difficulties. We found no data on the language proficiency of Eastern Europeans in Suffolk, but many arrive with only limited English. Language skills improve with time, but remain a constraint on migrants' ability to engage, integrate and make use of local resources and facilities.

**Limited data**

From the review of routine datasets, it was apparent that none comprehensively captures the extent of the migrant population or their main health issues. Ethnicity is often used as a proxy for analysing migrant data, as migrant status is rarely recorded unless the service is specifically for migrants. Most computer systems only collect ethnicity, not capturing whether a patient is of Eastern European origin. Improving monitoring would allow increased understanding of the population using their services, where they are not meeting the needs of specific groups and where they need to target.

**References**


Chapter 3
Female Genital Mutilation
Female Genital Mutilation introduction

- Female genital mutilation (FGM) refers to all procedures involving partial or total removal of the external female genitalia or other injury to the female genitalia for non-medical reasons.
- It has no medical benefits and serious potential harms including both short-term and long-term physical and psychological problems.
- Over 125 million women and girls are thought to have undergone FGM worldwide. It has been documented in 28 African countries and is also thought to occur in other countries in Africa, the Middle East and Asia.
- It is usually carried out on girls aged between 0 and 15 and is linked to cultural beliefs. Reasons given for the practice include social acceptance, beliefs about preserving virginity, cleanliness and hygiene, and religious beliefs.
- It is illegal to carry out FGM in the UK, or overseas on a permanent or habitual UK resident.
- There is no comprehensive information on how many women and girls in the UK are affected by FGM. Recent estimates suggest that there are over 127,000 women aged 15 and over in England and Wales who are likely to have undergone FGM, and almost 10,000 girls aged 0-14 at risk of FGM.
- Recording of FGM is now mandatory within many NHS services in England and Wales. Almost 4,000 newly identified cases were reported between September 2014 and March 2015.

Female Genital Mutilation key points

- Maternity services serving the Suffolk population identified fewer than 10 women with FGM between September 2014 and March 2015.
- Estimates based on school census data suggest there may be at least 115 girls aged 5-16 in Suffolk schools who are from FGM-practising countries.
- Estimates based on census data suggest there may be at least 470 women and girls of all ages of African or Kurdish origin in Suffolk who have undergone, or may be at risk of,
FGM. This figure is a very rough guide only as a number of assumptions had to be made due to the limited information available on the populations at risk.

- It is also estimated that less than 15-20 women with FGM are likely to deliver in Suffolk per year.
- There do not appear to be large communities from countries which practise FGM in any particular area of Suffolk apart from the Iraqi Kurdish community in Ipswich and the surrounding area.
- A number of women in Suffolk have disclosed that they have undergone FGM. Interviews carried out with women and men who were from FGM-practising countries known to Suffolk Refugee Support identified views on and experience of FGM similar to those found in larger research studies. None of those who had undergone FGM expressed support for the continuation of the practice.
- Interventions to reduce the risk of and mitigate harms resulting from FGM fall into three main areas, and there is recent guidance on many aspects of these:
  - Girls who are at risk of FGM
  - Women and girls who have undergone FGM
  - Reducing the prevalence of FGM.
- There has already been some work on FGM in Suffolk including training, work with individuals and communities and local guidelines on safeguarding.
- A stakeholder group has recently started to develop joint work on training, guidelines and sharing resources, and a project run by Suffolk Refugee Support aims to address a number of aspects of FGM.

**Female Genital Mutilation recommendations**

1. The FGM multiagency group should continue its work in Suffolk with a particular focus on training, workforce development and the dissemination of good practice, take into account risk, safeguarding, and legal requirements. It should continue to encompass health, social care, education and early years services, and engage communities.
2. The FGM group should consider ways to engage partners and the wider community in raising awareness, agreeing priorities and supporting joint work on FGM. It should use information from interviews and focus groups which have already taken place to
develop a picture of the views of groups affected in Suffolk.

3. Training should cover awareness-raising and cultural competence and also support frontline staff to develop skills and competence in raising and discussing questions around FGM and responding to safeguarding concerns.

4. FGM should continue to be part of mandatory safeguarding training. Training should take into account the views and knowledge of communities in Suffolk who are affected by FGM.

5. Consistent guidance should be promoted across Suffolk. This should include agreed risk assessment frameworks, how to record and report FGM as well as information about local arrangements.

6. All frontline staff working with children and families in any setting should know how to recognise and respond to safeguarding concerns in relation to FGM and this should be part of mandatory safeguarding training and covered in local guidelines.

7. NHS England and Suffolk CCGs should clarify responsibilities for commissioning and provision of services for women and girls with physical and psychological health needs as a consequence of FGM.

What is Female Genital Mutilation and why is it important for Suffolk?

Background

Female Genital Mutilation (FGM) (sometimes called Female Genital Cutting (FGC)) refers to all procedures involving partial or total removal of the external female genitalia or other injury to the female genitalia for non-medical reasons. WHO has classified FGM into four types, as shown in Figure 1 (WHO, 2008). These are shown diagrammatically in the Appendix.
This needs assessment was prepared in July 2015 by the Public Health Action Support Team on behalf of Suffolk County Council.

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**Figure 1: WHO classification of Types of FGM**

<table>
<thead>
<tr>
<th>Type 1</th>
<th>Partial or total removal of the clitoris and/or the prepuce (clitoridectomy)</th>
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<tr>
<td>Type 2</td>
<td>Partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora (excision)</td>
</tr>
<tr>
<td>Type 3</td>
<td>Narrowing of the vaginal orifice with creation of a covering seal by cutting and appositioning the labia minora and/or the labia majora, with or without excision of the clitoris (infibulation)</td>
</tr>
<tr>
<td>Type 4</td>
<td>All Harmful procedures to the female genitalia for non-medical purposes, for example: pricking, piercing, incising, scraping and cauterization</td>
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Source: WHO

FGM has no medical benefits and is a violation of the human rights of girls who are subjected to it. Short-term harms include severe pain and psychological trauma, and risk of infection, urinary retention and haemorrhage which can lead to death. In the longer term women may suffer chronic pain, urinary problems, infection and infertility, and have an increased risk of obstetric complications including obstructed labour, lacerations and haemorrhage. They are also at risk of long term psychological problems and sexual dysfunction which are not reduced by FGM being a culturally accepted practice within the community (FORWARD, 2014; UNICEF, 2013). Research in practising African communities has found that the majority of women have affective or anxiety disorders, and levels of post-traumatic stress disorder are similar to those of adults who have been subjected to early childhood abuse (Behrendt, 2005).

It has been estimated by UNICEF that at least 125 million women and girls worldwide have undergone FGM and it has been documented in 28 countries in Africa as well as Kurdish communities mainly in Iraq and Iran. It is also thought to occur in a number of other countries in the Middle East and Asia but there are no data about its extent in those areas. Figure 2 shows estimated prevalence of FGM among women aged 15-49 in Africa (UNICEF, 2013). The countries where the practice is known are mainly those in West, Central and East Africa, and national prevalence’s vary from over 90% (eg. Somalia, Egypt) to under 10% (eg. Ghana, Niger). There are also wide variations within some countries, for example in

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different areas of Senegal FGM prevalence varies from 1-92%, and in Iraq the practice of FGM is concentrated in the north-east and unknown in the rest of the country.

FGM is usually carried out on girls aged between 0 and 15, but in half the countries in the UNICEF study it was carried out on girls aged under 5. It is often carried out by traditional practitioners using various instruments such as blades or glass, although there is evidence of increasing involvement of health professionals in some countries such as Egypt. It is linked to cultural beliefs and reasons given for why FGM is carried out include social acceptance, cleanliness/hygiene, better marriage prospects, to preserve virginity, and in some places it is considered to be a religious requirement. While prevalence is highest among Muslim communities in many countries it is also found among other religious groups. The most commonly reported reason found by UNICEF for carrying out FGM was a sense of social obligation; social and peer pressure within a community appeared to be a strong factor, and in some cases it was reported that decisions about FGM were taken by a group (UNICEF, 2013).

The UNICEF report also found increasing awareness of the potential harms of FGM, and that it could have serious consequences. There was evidence that attitudes are changing and that support for FGM has fallen among both men and women over the last 20 years, but that practice is lagging behind changes in attitudes. Surveys have found that the proportion of both men and women who supported continuation of FGM appeared to be lower than the proportion of women who had actually had the procedure. A significant proportion of women who thought it should stop had daughters who had had FGM. UNICEF concluded that not only changes in individual attitudes, but changing social expectations about the practice of FGM across entire communities are important in changing practice.
Why is FGM important in the UK and Suffolk?
Women who have had FGM are increasingly found in the UK due to migration from countries where it is practised, but it is known that the practice may also continue in girls of families who have migrated to the UK, including those who have been born in this country.
It has been illegal to carry out FGM in the UK since the Prohibition of Female Circumcision Act 1985. This was replaced by the Female Genital Mutilation Act 2003, which was extended by the Serious Crime Act 2015, to cover procedures carried out overseas (Home Office, 2015a). It is now a criminal offence for anyone to carry out, or assist anyone else to carry out FGM in the UK on anyone, whether or not they are a UK resident or national. It is also illegal for anyone to carry out or assist FGM being carried out overseas on a UK national or permanent or habitual UK resident. The extra-territorial offences are intended to cover taking a girl abroad to be subjected to FGM. The 2015 Act also introduces a new offence of failing to protect a girl from risk of FGM, and introduces a duty on healthcare professionals, teachers and social care workers to notify the police of known cases of FGM carried out on a girl aged under 18.

However there have to date been no successful prosecutions for FGM under this law, although a number of cases have been examined by the Crown Prosecution Service in the last few years (House of Commons, 2014). The House of Commons Home Affairs Committee commented in March 2015: ‘There seems to be a chasm between the amount of reported cases and the lack of prosecutions. Someone, somewhere is not doing their job effectively’ (House of Commons, 2015).

There are three groups of women and girls in the UK with whom intervention may be needed to reduce the risk of, and harms arising from FGM:

**Girls who may be at risk of FGM**: despite the fact that it is illegal, girls may be at risk of FGM being carried out within the UK or overseas. To prevent this happening it is essential to work with communities to change attitudes to FGM, along with effective safeguarding arrangements to protect girls at risk.

**Girls who have had FGM**: FGM is dealt with as child abuse, and as well as a legal response, action is needed to try and mitigate the physical and psychological effects suffered by the child, to protect the child from any further harm, and to protect any others who might be at risk.
Women who have had FGM: the long-term health and psychological problems caused by FGM may be amenable to intervention; for example, surgical deinfibulation can reverse some of the potentially harmful physical effects and reduce the risk of problems arising during childbirth. Psychological interventions may be helpful for women who are suffering from psychological problems such as post-traumatic stress disorder, anxiety or sexual dysfunction as a result of FGM.

What is the national and local picture?
There is currently no comprehensive information on how many women in the UK are affected by FGM, or how many girls have been subjected to the procedure either in the UK or overseas.

NHS reporting of FGM – national data
A FGM Prevalence Dataset was published by HSCIC (the Health and Social Care Information Centre) on 1 April 2014 and from September 2014 it became mandatory for acute NHS Trusts in England to provide monthly returns on patients identified with FGM (HSCIC, 2014). In April 2015 this was replaced with the FGM Enhanced Dataset, which contains more data items, including patient demographic data, specific FGM information, and referral and treatment information (HSCIC, 2015). Collection of the enhanced dataset is mandatory for all acute NHS Trusts from 1 June 2015, and all GPs and mental health NHS Trusts from 1 October 2015. Clinicians are required to record in the clinical notes every time a patient with FGM is identified (whether on clinical examination or self-reported), and the type of FGM. The report on the first quarter of the enhanced dataset will be published in September 2015.

The FGM dataset reports two sets of data:

Newly identified cases: Patients who are first identified during the reporting period as having undergone FGM.

Active caseload: Patients identified as having a history of any FGM type prior to the reporting period and still being actively seen/treated for FGM-related conditions or any other non-related condition at the end of the month. This does not include patients newly identified within the reporting period.
This needs assessment was prepared in July 2015 by the Public Health Action Support Team on behalf of Suffolk County Council.

Numbers between 1 and 5 for individual Trusts are suppressed for confidentiality reasons.

Figure 3 shows the number of newly identified cases by month in the England Regions between September 2014 and March 2015. A total of 3,963 women with FGM were identified, of whom 2,040 (50%) were in London, 849 (21%) in the Midlands and East of England, 707 (18%) in the North and 367 (9%) in the South. Between 520-610 new cases were reported per month. Of all those newly identified 3,882 were aged 18 and over, 60 (1.5%) were aged under 18, and for 21 (0.5%) age was not recorded. Figure 4 shows the breakdown by Type of FGM; the majority (63%) were recorded as Type 4 or not known, and around 14% as Type 1, 12% as Type 2 and 11% as Type 3.

**Figure 3: Newly identified cases of FGM reported by NHS Acute Trusts, England Regions, Sept 2014-Mar 2015**

Source: HSCIC
Figure 4: Newly identified cases by type of FGM* reported by NHS Acute Trusts, England Regions, Sept 2014-Mar 2015

<table>
<thead>
<tr>
<th></th>
<th>Type 1</th>
<th>Type 2</th>
<th>Type 3</th>
<th>Type 4 and Not Known</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>London</strong></td>
<td>255</td>
<td>183</td>
<td>191</td>
<td>1,411</td>
<td>2,040</td>
</tr>
<tr>
<td><strong>Midlands and East of England</strong></td>
<td>181</td>
<td>171</td>
<td>163</td>
<td>334</td>
<td>849</td>
</tr>
<tr>
<td><strong>North of England</strong></td>
<td>93</td>
<td>77</td>
<td>52</td>
<td>485</td>
<td>707</td>
</tr>
<tr>
<td><strong>South of England</strong></td>
<td>42</td>
<td>47</td>
<td>20</td>
<td>258</td>
<td>367</td>
</tr>
<tr>
<td><strong>England</strong></td>
<td>571 (14%)</td>
<td>478 (12%)</td>
<td>426 (11%)</td>
<td>2,488 (63%)</td>
<td>3,963</td>
</tr>
</tbody>
</table>

*for Type descriptions see Figure 1 and Appendix
Source: HSCIC

Figure 5 shows the active caseload of women with a history of any type of FGM, who were still being actively seen/treated for any condition. This has gradually increased in all areas, but most markedly in London. At the end of March 2015 the total active caseload in England was 3,164, of whom 1,783 (56%) were in London, 686 (21%) in Midlands and East of England, 448 (14%) in the North and 247 (8%) in the South. Over the 7-month period there were 290 women nationally who underwent deinfibulation and 10 who underwent repeat deinfibulation.
The total number of care contacts (for any type of care) with acute Trusts for patients with any type of FGM were also reported. In England over the 7 months September 2014 to March 2015 there were a total of 17,875 contacts, of which 47% occurred in obstetrics, 30% in midwifery, 6% in gynaecology, 3% diagnostic imaging and 2% in genitourinary medicine (GUM). The remainder were across a wide range of other specialties. This indicator includes multiple counts for single individuals if they have more than one care contact during that time.
NHS reporting of FGM – Suffolk data

Figure 6 shows the reported figures for newly identified cases, active caseload and total care contacts for the three main hospital providers to the Suffolk population. At both Ipswich and James Paget hospitals there have been less than six newly identified cases in total between September 2014 and March 2015. The active caseload at Ipswich hospital at the end of February was less than six, and there have been a total of 11 care contacts for any woman known to have had FGM. At James Paget hospital no care contacts have been recorded, and at West Suffolk hospital no cases of FGM have been identified. The figures include the totals reported from each hospital (not only women resident in Suffolk).

Figure 6: Newly identified cases, active caseload and total care contacts for FGM reported by main hospital providers for Suffolk, Sept 2014-Mar 2015

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Ipswich Hospital NHS Trust</td>
<td>*</td>
<td>*</td>
<td>11</td>
</tr>
<tr>
<td>James Paget University Hospitals NHS FT</td>
<td>*</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>West Suffolk NHS FT</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

NB: Ipswich active caseload is for Feb 2015; March data not reported.
*number suppressed for confidentiality reasons; 5 or less

Source: HSCIC

Estimated prevalence of FGM, England and Wales

The most recent estimates for England and Wales are from research undertaken by City University, London, published in 2014, which used 2011 Census data and the most recent known prevalence of FGM in the countries involved. They estimated the number of women permanently resident in England and Wales who were born in countries where the prevalence of FGM is known and who are likely to have undergone FGM (Macfarlane et al,
2014). They also estimated the number of girls aged 0-14 permanently resident in England and Wales who were born in those countries and are likely to have undergone FGM, if they experience FGM at the same rate as girls aged 15-19 in their countries of birth. As they had access to individual records they were able to make adjustments based on individual information, for example if an individual’s religion or ethnicity suggested they were unlikely to be from a community practising FGM.

They were only able to make these estimates for women born in African countries where the estimated prevalence of FGM is known; they were not able to make estimates for women from other countries in the Middle East and Asia who may have undergone FGM because there are no data about its extent in those areas.

Figure 7 shows the estimates by age group for countries represented in Suffolk data (see below). Data are not available for the Kurdish ethnic group because the estimates are based on country of birth. There are estimated to be over 100,000 women aged 15-49 and almost 24,000 aged 50 and over in England and Wales who have undergone FGM, as well as almost 10,000 girls aged under 15 who have undergone or will undergo FGM. In addition, the authors used birth registration data to estimate that since 1993 over 76,000 girls were born in England and Wales to women with FGM.
Figure 7: Estimated number of women and girls permanently resident in England and Wales who are likely to have undergone FGM (aged 15 and over) or to undergo FGM (aged 0-14), numbers by country of birth (2011 Census)

<table>
<thead>
<tr>
<th>Age group</th>
<th>0-14</th>
<th>15-49</th>
<th>50+</th>
</tr>
</thead>
<tbody>
<tr>
<td>Iraq</td>
<td>86</td>
<td>1,256</td>
<td>459</td>
</tr>
<tr>
<td>Eritrea</td>
<td>456</td>
<td>6,286</td>
<td>1,028</td>
</tr>
<tr>
<td>Somalia</td>
<td>5,316</td>
<td>41,842</td>
<td>7,489</td>
</tr>
<tr>
<td>Sudan</td>
<td>436</td>
<td>4,421</td>
<td>846</td>
</tr>
<tr>
<td>Ethiopia</td>
<td>332</td>
<td>5,101</td>
<td>604</td>
</tr>
<tr>
<td>Kenya</td>
<td>181</td>
<td>3,270</td>
<td>969</td>
</tr>
<tr>
<td>Tanzania</td>
<td>15</td>
<td>505</td>
<td>110</td>
</tr>
<tr>
<td>Nigeria</td>
<td>1,277</td>
<td>19,451</td>
<td>5,965</td>
</tr>
<tr>
<td>Ghana</td>
<td>28</td>
<td>1,527</td>
<td>821</td>
</tr>
<tr>
<td>All other countries</td>
<td>1,637</td>
<td>19,462</td>
<td>5,628</td>
</tr>
<tr>
<td>Total</td>
<td>9,763</td>
<td>103,177</td>
<td>23,918</td>
</tr>
</tbody>
</table>

Source: City University London
This needs assessment was prepared in July 2015 by the Public Health Action Support Team on behalf of Suffolk County Council.

Figure 8 shows FGM-practising country groups as defined in the City University, London report. The African countries where there are known estimates of FGM prevalence and Iraqi Kurdistan are put in four groups, based on the prevalence and the types of FGM practised.

**Figure 8: FGM-practising country groups**

<table>
<thead>
<tr>
<th>Group</th>
<th>Definition</th>
<th>Countries and prevalence</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1</td>
<td>Almost universal FGM, over 30% FGM Type 3</td>
<td>Somalia, Eritrea, Djibouti, Sudan (north). Reported prevalence range 87%-98%</td>
</tr>
<tr>
<td>1.2</td>
<td>High national prevalence of FGM, Type 1 and 2</td>
<td>Egypt, Ethiopia, Mali, Burkina Faso, Gambia, Guinea, Sierra Leone. Reported prevalence range 74%-95%</td>
</tr>
<tr>
<td>2</td>
<td>Moderate national prevalence of FGM, Type 1 and 2</td>
<td>Central African Republic, Chad, Cote d’Ivoire, Guinea Bissau, Iraq (Kurdistan), Kenya, Liberia, Mauritania, Nigeria, Senegal. Reported prevalence range 24%-70%</td>
</tr>
<tr>
<td>3</td>
<td>Low national prevalence of FGM, Type 1 and 2</td>
<td>Benin, Cameroon, Ghana, Niger, Democratic Republic of Congo, United Republic of Tanzania, Togo, Uganda, Yemen Reported prevalence range 0%-15%</td>
</tr>
</tbody>
</table>

Source: City University, London; for FGM types see Figure 1 and Appendix

**Women and girls potentially at risk of FGM in Suffolk**

**School census**

Data based on findings from the January 2014 Suffolk school census are shown in Figure 9. The census recorded both first language and ethnicity. Recorded categories were not consistent; for example in some cases only language or ethnicity is recorded, and in some cases both.

The table shows ‘best guesses’ of FGM country group based on recorded ethnicity, language or both, for girls whose first language was not English. These data suggest that about 115 girls aged 5-16 who were in school in Suffolk in January 2014 were from countries or ethnic groups recognised to be at increased risk of FGM. Eighty-five were of primary
school age and 30 of secondary school age. Twenty-seven were from areas where there is a high or almost universal prevalence of FGM (country groups 1.1 and 1.2), 46 from moderate prevalence areas (country group 2), and 42 from low prevalence areas (country group 3). (See Figure 8, FGM-practising country groups).

Figure 9: Estimated numbers of girls in Suffolk schools in January 2014 whose recorded first language and/or ethnic group suggests they are at increased risk of FGM

<table>
<thead>
<tr>
<th>FGM country group (Fig 8)</th>
<th>Ethnicity recorded in school census</th>
<th>Mother tongue recorded in school census</th>
<th>Primary school</th>
<th>Secondary school</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1 Sudan</td>
<td>Arabic, Other</td>
<td>0</td>
<td>*</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>1.2 Ethiopia</td>
<td>Amharic</td>
<td>7</td>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.2 Egypt</td>
<td>Arabic, Other</td>
<td>12</td>
<td>*</td>
<td>&lt;17</td>
<td></td>
</tr>
<tr>
<td>1.2 Sierra Leone</td>
<td>Other</td>
<td>0</td>
<td>*</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>2 Iraqi/ Kurdish</td>
<td>Kurdish, Other</td>
<td>35</td>
<td>11</td>
<td>46</td>
<td></td>
</tr>
<tr>
<td>3 Ghana</td>
<td>Akan (Twi/Asante), Akan/Twi-Fante, Ewe, Ga, Hausa, Other</td>
<td>22</td>
<td>0</td>
<td>22</td>
<td></td>
</tr>
<tr>
<td>3 Nigeria</td>
<td>Yoruba, Edo, Igbo, Other</td>
<td>9</td>
<td>11</td>
<td>20</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td><strong>85</strong></td>
<td><strong>30</strong></td>
<td><strong>115</strong></td>
<td></td>
</tr>
</tbody>
</table>

*number suppressed for confidentiality reasons; less than 5

Source: Suffolk school census January 2014

Census data
Figure 10 shows census data on detailed ethnic group for Suffolk and Districts, for selected countries where there is known to be an increased risk of FGM. These data are only available for a limited number of countries and all the relevant ones for which the data are available are shown here; all of these are in Africa. Estimates have been made of the approximate number of females of all ages who might be affected by FGM in the Suffolk population, as follows:
1. Estimates for the number of females have been derived simply by halving the census figures, as the data were not available for women only and the gender balance within these communities in Suffolk is not known;

2. The figures for each country were adjusted by the same factor used in the City University research to allow for approximate numbers of women who might be at lower risk due to their religion or other factors;

3. The most recent reported prevalence’s of FGM in each of these countries were used to estimate approximate numbers of women affected in Suffolk (UNICEF, 2013; Macfarlane et al, 2014).

Because these estimates have been based on a number of assumptions they are intended as a rough guide only to the possible impact of FGM in Suffolk. Bearing in mind these caveats, these data suggest that an estimated 205 women and girls from African countries who are resident in Suffolk may be at risk of having had, or of undergoing FGM. The majority are from Central and West African countries, with a smaller number from East African countries.

Other research has used language rather than country of origin as an indicator of risk (London Borough of Islington, 2012), and this was explored for Suffolk using the main language recorded in the census (Figure 11). However this appears to be a less useful way of identifying FGM risk because few people in Suffolk specified a language, apart from Kurdish-speaking people. Seven hundred and twenty-eight people identified their main language as Kurdish, of whom 682 lived in Ipswich. The country of origin of all the Kurdish community is not known, but is known that there are significant numbers of people who are of Iraqi origin. Based on the prevalence of FGM in Iraqi Kurdish communities (estimated to be 72.7%) (WADI, 2010), this group may include about 265 women and girls who have undergone or are at risk of FGM. Estimates were not made for other languages because numbers recorded appear too small to be useful.
Figure 10: Detailed ethnic group as recorded in 2011 Census, Suffolk and Districts, indicating those where risk of FGM may be higher, and estimated prevalence of FGM (note: not all countries are recorded separately in the Census)

<table>
<thead>
<tr>
<th>Total pop</th>
<th>North Africa</th>
<th>Central and Western Africa</th>
<th>South and Eastern Africa</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Africa: Total</td>
<td>Ghana</td>
<td>Nigeria</td>
</tr>
<tr>
<td>FGM country group (see Fig 8)</td>
<td>**</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Average FGM prevalence</td>
<td>0-91.1%</td>
<td>3.8%</td>
<td>27%</td>
</tr>
</tbody>
</table>

| Babergh | 87,740 | 587 (0.7%) | 24 | 15 | 27 | 26 | 69 | 1 | 234 | 88 | 93 | 10 |
| Forest Heath | 59,748 | 540 (0.9%) | 31 | 25 | 25 | 31 | 26 | 0 | 196 | 131 | 68 | 7 |
| Ipswich | 133,384 | 1,563 (1.2%) | 108 | 97 | 137 | 231 | 82 | 12 | 335 | 299 | 250 | 12 |
| Mid Suffolk | 96,731 | 703 (0.7%) | 54 | 53 | 26 | 15 | 54 | 0 | 237 | 125 | 135 | 4 |
| St Edmundsbury | 111,008 | 1,163 (1.0%) | 104 | 50 | 111 | 77 | 67 | 21 | 363 | 220 | 137 | 13 |
| Suffolk Coastal | 124,298 | 1,159 (0.9%) | 83 | 47 | 80 | 33 | 103 | 2 | 470 | 151 | 178 | 12 |
| Waveney | 115,254 | 553 (0.5%) | 28 | 19 | 32 | 53 | 50 | 3 | 213 | 69 | 79 | 7 |
| Suffolk (% of total population) | 728,163 | 6,268 (0.9%) | 432 (0.1%) | 306 (0.0%) | 438 (0.1%) | 466 (0.1%) | 451 (0.1%) | 39 (0.0%) | 2,048 (0.3%) | 1,083 (0.1%) | 940 (0.1%) | 65 (0.0%) |
| Estimated no. females all ages affected by FGM | (est) 10 | 5 | 55 | 85 | 20 | 20 | (est) 10 | Est total | 205

**Most low/ no reported prevalence of FGM apart from Egypt (91.1%).
$ countries not known, but other Central/ West African countries with largest numbers in England & Wales are Gambia, Sierra Leone, Ivory Coast, Cameroon and DRC; reported prevalences range 0-76%; midpoint used.

# Most low/ no reported prevalence of FGM apart from Ethiopia (74.3%) and Tanzania (14.6%)

Source: 2011 Census; City University, London
Figure 11: Main language as recorded in 2011 Census, people aged 3 and over, Suffolk and Districts, indicating those where risk of FGM may be higher (note: not all languages are recorded separately in the Census)

<table>
<thead>
<tr>
<th>Language recorded</th>
<th>Kurdish</th>
<th>Amharic</th>
<th>Tigrinya</th>
<th>Somali</th>
<th>Swahili/ Kiswahili</th>
<th>Lingala</th>
<th>Akan</th>
<th>Yoruba</th>
<th>Igbo</th>
<th>Any other Nigerian</th>
<th>Other W African</th>
<th>Other African</th>
</tr>
</thead>
<tbody>
<tr>
<td>Likely country</td>
<td>Iraq/Turkey</td>
<td>Ethiopia</td>
<td>Eritrea</td>
<td>Somalia</td>
<td>Tanzania/Kenya</td>
<td>CAR</td>
<td>Ghana</td>
<td>Nigeria</td>
<td>Nigeria</td>
<td>Nigeria</td>
<td>W Africa</td>
<td>Most S Africa/Zimb'we</td>
</tr>
<tr>
<td>FGM country group (Fig 8)</td>
<td>2</td>
<td>1.2</td>
<td>1.1</td>
<td>1.1</td>
<td>2/3</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>1.2/2/3</td>
<td>-</td>
</tr>
<tr>
<td>Average FGM prevalence</td>
<td>72.7%</td>
<td>74.3%</td>
<td>88.7%</td>
<td>97.9%</td>
<td>14.6 – 27.1%</td>
<td>24.2%</td>
<td>3.8%</td>
<td>56.9%</td>
<td>40.8%</td>
<td>27%</td>
<td>4.89%</td>
<td></td>
</tr>
</tbody>
</table>

Babergh | 10 | 2 | 1 | 0 | 2 | 0 | 0 | 2 | 0 | 0 | 0 | 0 | 38 |
Forest Heath | 0 | 2 | 0 | 0 | 1 | 0 | 3 | 2 | 1 | 1 | 6 | 45 |
Ipswich | 682 | 2 | 1 | 4 | 11 | 0 | 15 | 13 | 5 | 5 | 12 | 123 |
Mid Suffolk | 8 | 1 | 0 | 0 | 1 | 0 | 1 | 0 | 0 | 0 | 2 | 41 |
St Edmundsbury | 16 | 0 | 0 | 3 | 3 | 2 | 3 | 2 | 10 | 3 | 1 | 44 |
Suffolk Coastal | 5 | 0 | 0 | 0 | 4 | 0 | 0 | 2 | 1 | 0 | 3 | 74 |
Waveney | 7 | 1 | 1 | 1 | 1 | 0 | 2 | 0 | 7 | 1 | 9 | 20 |
Suffolk | 728 | 8 | 3 | 8 | 23 | 2 | 24 | 21 | 24 | 10 | 33 | 385 |

Estimated no. females all ages affected by FGM | 265 |
Figure 12 shows data from a census question which allowed people to write in their ethnic group: in Suffolk 669 Kurdish people did so, of whom 626 were in Ipswich. A detailed breakdown by age group was available for the Ipswich residents only (no gender breakdown was available). Figure 13 shows that this population is predominantly young adults and children. These data suggest there may be around 49 girls aged 5-16 of Kurdish origin in Ipswich; these numbers are comparable with the school census data identifying 46 girls with Kurdish language and/or ethnicity. The language and write-in ethnic group data give very similar numbers suggesting this is a reasonably accurate estimate of the Kurdish community in Suffolk.

**Figure 12: Ethnic group: write-in responses, number stating ‘Kurdish’ by District in Suffolk (2011 Census)**

<table>
<thead>
<tr>
<th>District</th>
<th>10-19</th>
<th>0-9</th>
<th>40+</th>
<th>All ages</th>
<th>30-39</th>
<th>20-29</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffolk</td>
<td>15</td>
<td>1</td>
<td>626</td>
<td>669</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>Babergh</td>
<td>0</td>
<td></td>
<td></td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Forest Heath</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ipswich</td>
<td>626</td>
<td>106</td>
<td>40</td>
<td>669</td>
<td>181</td>
<td>234</td>
</tr>
<tr>
<td>Mid Suffolk</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>St Edmundsbury</td>
<td>9</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Suffolk Coastal</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Waveney</td>
<td>11</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: 2011 Census (supplied by Suffolk CC)

**Figure 13: Ethnicity, write-in responses where the response was ‘Kurdish’, by age group, Ipswich (2011 Census)**

<table>
<thead>
<tr>
<th>Age group</th>
<th>0-9</th>
<th>10-19</th>
<th>20-29</th>
<th>30-39</th>
<th>40+</th>
<th>All ages</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Kurdish’ (Ipswich)</td>
<td>106</td>
<td>65</td>
<td>234</td>
<td>181</td>
<td>40</td>
<td>626</td>
</tr>
</tbody>
</table>

Source: 2011 Census (supplied by Suffolk CC)
Census data records the resident population in 2011 but in addition, Suffolk is a ‘dispersal’ area for Home Office-housed asylum seekers. There are known to be a number of asylum-seeking and refugee women and girls in Suffolk who come from countries with an increased risk of FGM, this is not a fixed population and exact figures are not available.

**Maternity data**

Data on deliveries to women who were Suffolk residents over the three years 2011/12–2013/14 are shown in Figure 14. Detailed country of birth or ethnicity data are not recorded, so the ‘African: Black or Black British’ group is shown, among whom there were an average of 33 deliveries per year, almost two-thirds of whom delivered at Ipswich hospital.

However as shown in Figure 10, only around a third of the Suffolk population of African origin are from countries where FGM is known to practise, and among those the prevalence of FGM ranges from 4% to 98%. Therefore if a third of the African women delivering in Suffolk were from these countries, less than 10 women of African origin who had undergone FGM might be expected to deliver per year. In addition there will be a number of deliveries to Kurdish women and women from other countries who have undergone FGM for whom these data are not available, as well as possibly a small number of deliveries to women who are refugees or asylum seekers. A reasonable estimate might be that less than 15-20 women in Suffolk might deliver each year who have undergone FGM.
Figure 14: Suffolk resident mothers delivering 2011/12-2013/14; no. and % of Total and African (Black or Black British) ethnic group delivering at each provider.

<table>
<thead>
<tr>
<th>Provider</th>
<th>Total deliveries (% of Suffolk total by provider)</th>
<th>African (Black or Black British) (% of Suffolk total by provider)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Colchester Hospital University NHS Foundation Trust</td>
<td>211 1.1%</td>
<td>0 0.0%</td>
</tr>
<tr>
<td>James Paget University Hospitals NHS Foundation Trust</td>
<td>3,049 15.5%</td>
<td>14 14.3%</td>
</tr>
<tr>
<td>Ipswich Hospital NHS Trust</td>
<td>9,160 46.5%</td>
<td>61 62.2%</td>
</tr>
<tr>
<td>West Suffolk NHS Foundation Trust</td>
<td>5,257 26.7%</td>
<td>10 10.2%</td>
</tr>
<tr>
<td>Cambridge University Hospitals NHS Foundation Trust</td>
<td>1,372 7.0%</td>
<td>7 7.1%</td>
</tr>
<tr>
<td>Norfolk and Norwich University Hospitals NHS Foundation Trust</td>
<td>531 2.7%</td>
<td>&lt;5 &lt;5%</td>
</tr>
<tr>
<td>Other</td>
<td>103 0.5%</td>
<td>&lt;5 &lt;5%</td>
</tr>
<tr>
<td><strong>Total over 3 years (% of total deliveries)</strong></td>
<td><strong>19,683</strong></td>
<td><strong>98 (0.5%)</strong></td>
</tr>
</tbody>
</table>

Source: HES (Suffolk CC Public Health)

**Information from women in Suffolk**

A number of women in Suffolk are known to have disclosed to various staff that they have undergone FGM – figures of between 10 and 20 over the last year were reported. Suffolk Refugee Support are currently carrying out a project on FGM and the following section reports findings from interviews carried out as part of the initial phase of this work.

Over a period of seven weeks from mid-April to the end of May 2015 the FGM Project Assistant based at Suffolk Refugee Support interviewed 18 women and 4 men from countries where there is known to be a risk of FGM. In total, over 24.5 hours were spent on interviews. Countries the interviewees came from are shown in Figure 15 (listed under the ‘FGM-practising country groups’, see Figure 8).

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6 with thanks to Rohma Ullah, Suffolk Refugee Support
Eight of the interviewees disclosed experience of FGM, almost all thought to be Type 2. A number also disclosed that members of their families were living with the consequences of FGM.

**Figure 15: Countries of origin of interviewees, listed under ‘FGM-practising country groups’**

<table>
<thead>
<tr>
<th>Group 1.1 &amp;1.2</th>
<th>Group 2</th>
<th>Group 3</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Somalia</td>
<td>Nigeria</td>
<td>Ghana</td>
<td>Malawi, Pakistan</td>
</tr>
<tr>
<td>Eritrea</td>
<td>Nigeria</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sudan</td>
<td>Iraqi Kurdistan</td>
<td>Ghana</td>
<td></td>
</tr>
<tr>
<td>Egypt</td>
<td>Turkish Kurdistan</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Malawi, Pakistan</td>
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</table>

See Figure 8 for FGM-practising country groups

**Reasons for carrying out FGM**: Of the 22 people interviewed, 17 noted that the reasoning behind FGM in their countries was around controlling women’s sexuality and sexual desires. All of those interviewed said it is believed a woman is unclean and would be tempted into promiscuity if they are not cut. 3 women interviewed noted that in Iraqi Kurdistan in particular, it is ‘haram’ or forbidden to eat the food of an uncut woman. All 22 interviewees said that the practice has been justified on cultural grounds and has no place in religion.

**Attitudes towards FGM**: Of the women who disclosed having undergone FGM, all 8 were against the practice and did not want it to continue due to its harmful consequences. All 8 also noted that it is a discriminatory practice which infringes on women’s rights and seeks to assert control over them. One woman said: “The old woman [who cuts the girls] uses the same blade for many people she cuts at the same time. She doesn't clean her hands. We [Africa] are number 1 in the world for HIV. There are loads of people that are dying as a result of FGM. I am a mum. I don’t want this to happen to my baby at all.”

Many of those interviewed also considered that attitudes are beginning to change as new generations come in who are more educated.
Health Needs: None of the eight women who disclosed reported needing any physical health or medical attention as a result of the FGM. All said they experienced the FGM as children and said they have subsequently adjusted to living with it.

Conclusions: women and girls at risk in Suffolk
Estimates based on census data suggest that there may be at least 470 women and girls of all ages resident in Suffolk who have undergone, or are at risk of FGM; approximately 205 who were born in African countries where the prevalence of FGM is known, and approximately 265 of Kurdish origin. There may also be additional women and girls at risk who are not included in these figures. These could include women and girls from other countries in Africa, the Middle East and Asia where FGM is thought to be practised but the prevalence is not known; girls born in the UK to women from communities where FGM is practised among whom the risk of FGM is not known; and asylum-seeking and refugee women and girls who come from countries with an increased risk of FGM. A very rough estimate of the number of women from Suffolk who have undergone FGM who deliver is less than 15-20 per year.

These figures should be regarded as rough guide only for a number of reasons:

- The prevalences are based on countries of origin and it is not known how these relate to prevalence in this country;
- Migrant communities may not be typical of their countries of origin;
- Some of the original prevalence data in the UNICEF and other reports is from surveys several years old;
- It was not possible to adjust the local data for age distribution, level of education, socioeconomic group, etc, as individual records are not available; the adjustment factor applied by the City University researchers was used as an approximation;
- Language data alone did not appear to be useful except for the Kurdish group;
- All estimates based on census data may under-enumerate women from migrant communities;
- There are no maternity data on detailed ethnic group of women delivering in Suffolk.

Apart from the Kurdish community in the Ipswich area, there do not appear to be large communities from other countries which practise FGM in any particular area of Suffolk. Over 1,500 people of African origin were recorded in the Ipswich area in the 2011 census, as well
as over 1,000 in each of St Edmundsbury and Suffolk coastal. However these groups come from a range of different countries only some of which practise FGM.

Only a small number of women who have undergone FGM have been identified through NHS services to date but it is known that a number of women have disclosed in other settings that they had undergone FGM. In interviews carried out by Suffolk Refugee Support with women and men who were from FGM-practising countries, eight women disclosed that they had undergone FGM and others reported that they knew of other women affected. The views on and experience of FGM reported by this group were similar to those found in larger research studies. None of those who had undergone FGM expressed support for the continuation of the practice.

**What is the evidence base for interventions? What is best practice?**

Interventions to reduce the risk of and mitigate harms resulting from FGM fall into three main areas:

- Girls who are at risk of FGM
- Women and girls who have undergone FGM
- Reducing the prevalence of FGM.

Guidance has been published on many aspects of the response to FGM and key documents which are drawn on in the following section are shown in Figure 16.
Risk assessment frameworks included in the March 2015 Department of Health (DH) guidance could usefully be incorporated into local guidance and used by professionals to help assessment in different circumstances (DH, March 2015a):

- Child/young adult under 18 – to consider risk of FGM
- Child/young adult under 18 – to consider whether a child has had FGM
- Pregnant women: to decide whether an unborn child, or female children in the family are at risk, or the woman herself is at risk of further harm;
- Non-pregnant adult women over 18: to decide whether female children are at risk or the woman herself is at further risk

Figure 16: Key guidance on FGM

| Publication                                                                 |
|                                                                            |
| Commissioning services to support women and girls with FGM. (DH, March 2015) |
| FGM risk and safeguarding: guidance for professionals. (DH, March 2015)     |
| Keeping Children Safe in Education. (Home Office and DfE, March 2015)       |
| FGM: follow-up report. (Home Affairs Committee, March 2015)                |
| FGM: Guidance for Health Professionals. (Suffolk Safeguarding Children Team, February 2015) |
| Multiagency Practice Guidelines on FGM for England and Wales. (Home Office, November 2014) |
| Change: responding to FGM: a guide for key professionals. (FORWARD, July 2014) |
| FGM: the case for a national action plan. (Home Affairs Committee, June 2014) |
| Tackling FGM in the UK: Intercolligate recommendations for identifying, recording and reporting. (RCM, November 2013) |
| Eliminating FGM: an interagency statement. (WHO, 2008)                     |
Identifying girls at risk of FGM

All professionals working with children and families need to be aware of factors that indicate an increased risk of a girl undergoing FGM, which include (FORWARD, 2014; Home Office 2014; DH, 2015a):

- girls from communities which are less integrated into British society;
- families which have migrated from countries here there is a high acceptance of FGM;
- any girl born to a woman who has been subjected to FGM;
- any girl who has another family member who has already undergone FGM, particularly a sister;
- there is a female family elder who is very influential and involved in the care of the girl;
- a girl is withdrawn from Personal, Social and Health Education (PSHE) in school.

In addition, indications that FGM may be about to take place include:

- the presence of a female family elder, particularly if visiting from a country of origin;
- plans to take a girl out of the country particularly for a long period;
- the girl has attended a travel clinic or similar for vaccinations/ anti-malarials;
- a girl may talk with other children about it;
- a girl may confide that she is to have a ‘special procedure’ or to attend a special occasion to ‘become a woman’;
- a girl may request help from a teacher or another adult if she suspects she is at immediate risk.

There are many terms used for FGM in different languages and sensitivities associated with discussing it (DH, 2015a). Staff across a wide range of settings including; early years, schools and colleges, health, social care and voluntary settings, need to be sensitive to possible indicators of risk. They also need to feel confident and competent to raise the issue with children and their families. There may be only one opportunity to do this with an individual child.
Safeguarding girls at risk

DH guidance sets out different levels of response which might be appropriate depending on the level of risk identified, which should be decided on a case by case basis with expert input from all agencies involved (DH, 2015a). In outline, these are:

1. Discussions with the family and information sharing between agencies with no specific protection plan in place;
2. An ongoing safeguarding approach led by social services;
3. Urgent action if there is felt to be an immediate risk.

Where a girl is identified at risk there is a duty to safeguard her, with a legal obligation for anyone who has concerns about a child under 18 who is at risk of undergoing FGM to inform police or social services (this can be through the Multiagency Safeguarding Hub (MASH)). This can present particular challenges for professionals as the families may give no other cause for concern. Once a referral is made a strategy meeting should be called involving police, social care, health professionals and other agencies and aiming to involve the family. The least intrusive legal action should be taken but if there is no other option for keeping the child safe an Emergency Protection Order should be sought and the child removed to a place of safety. The safety of siblings and other girls in the community also needs to be considered.

Schools and colleges have a statutory requirement to safeguard girls at risk of FGM, which will be assessed in Ofsted inspections (Home Office and DfE, 2015). This includes staff training and awareness of safeguarding procedures and local arrangements, and what action has been taken in respect of particular children.

Women and girls who have undergone FGM

There are four main elements to the response for women and girls who have undergone FGM:

- a legal response if FGM has been carried out on a girl aged under 18;
- assessing and meeting needs for safeguarding for the woman or girl, and other children within the family unit and more widely;
- meeting the physical health needs of a woman or girl with FGM;
- meeting the mental health needs of a woman or girl with FGM.
Intervening if a girl has undergone FGM

Under the Serious Crime Act 2015 there is a mandatory duty on those working in regulated professions (for example, teachers, social workers and healthcare workers) to report the discovery of FGM appearing to have been carried out on a girl under 18. This applies regardless of whether FGM is thought to have been carried out in the UK or overseas. If an examination including a physical or psychological assessment is needed, this should follow safeguarding children procedures and be carried out by professionals with specialist expertise in these areas. Girls should also have access to further physical and psychological support as described below.

Indications that a girl might have undergone FGM include that she (Home Office, 2014):

- has difficulty walking, sitting or standing or looks uncomfortable;
- has frequent urinary, menstrual or stomach problems;
- has increased emotional needs or significant change in behaviour;
- avoids physical exercise;
- spends a long time in the bathroom or toilet.

Guidance makes clear that disclosure may need to go beyond the usual boundaries of patient confidentiality if it is in the public interest or a criminal act may have been perpetrated.

Safeguarding when a woman or girls has undergone FGM

If a girl has undergone FGM, the possibility of any potential further risk to the child must be considered, as well as risk to siblings or other girls in the community, and safeguarding arrangements put in place if needed. For adult women there is no requirement for referral to social services or the police, but there should be an assessment of whether the woman is at any further risk. In addition, if they are pregnant or have daughters who might be at risk, the need for safeguarding should be considered (DH, 2015a).

Services for women and girls who have undergone FGM

Guidance on commissioning services for women and girls who have undergone FGM has been issued by the Department of Health, and identifies responsibilities for both NHSE and CCGs to ensure high quality services are in place (DH, 2015b). Women and girls where FGM is found or suspected need evaluation by health professionals experienced in FGM.
who are able to determine the need for further treatment and perform a risk assessment for potential safeguarding issues. Health professionals, particularly nurses and midwives, need to be aware of the specialist care required by women and girls who have undergone FGM, particularly during labour and childbirth.

If the patient has undergone FGM, referral to a specialist FGM clinic should always be considered, and self-referral should also be available. Women who have undergone Type 3 FGM (infibulation) should be informed that deinfibulation (reversal) is an option available to them. Girls and women who have undergone FGM should also be offered psychological support to address any psychological or emotional problems they may have as a result of FGM. It is recognised that local arrangements will vary depending on the prevalence of FGM but there should be clear referral pathways wherever the services are located. Interpreters should be available if required and there should be advocacy support and links to FGM support groups.

Collection of data on FGM has been mandatory for all Acute Trusts since September 2014, and will be mandatory for all GPs and mental health NHS Trusts from 1 October 2015 (see Figures 3-6). Guidance recommends that all Trusts should have a named lead for FGM.

Reducing the prevalence

Partnerships

The need for partnership working to address the risk and impact of FGM underpins much of the recent guidance. The Government’s Multiagency Practice Guidelines on FGM are aimed principally at health and social care professionals, police, schools, colleges and universities. They advise that organisations should work together within existing arrangements, including Community Safety Partnerships, Local Safeguarding Children Boards (LSCBs), Children’s Trusts and partnerships, Adult Protection Committees, Health and Wellbeing Boards and local Criminal Justice Boards. They also suggest that LSCBs consider developing and supporting a centralised virtual team of experts (including community groups and specialist women’s groups) to advise professionals on the prevention of FGM in the community and the appropriate professional response to individual cases.

Some areas have set up dedicated FGM forums or Partnership groups, for example Greater Manchester FGM Forum (which covers both adults and children) has been in place since 2011 with the following aims (Greater Manchester FGM Forum, 2014):
• To monitor the prevalence of FGM through midwifery and children’s social care data.
• To influence the provision of FGM training and protocols/policies
• To work with CPS/police on best practice approaches to protection and prosecution
• To publicise the prevention of FGM as a safeguarding and human rights issue.
• To consult with local women affected by this issue.
• To promote a holistic approach to adult women who have been mutilated, considering referral pathways to support and knowledge of options including deinfibulation surgery.
• To report on progress annually to representatives’ Local Safeguarding Children’s Board or Local Safeguarding Adults’ Board.

Training and workforce development

All frontline professionals need the competence, knowledge and awareness to discuss issues relating to FGM, identify those at risk, and ensure protection of girls at risk and an appropriate response for girls and women who have undergone FGM (RCM, 2013). The Multiagency Practice Guidelines make clear that LSCBs are primarily responsible for ensuring that single agency and inter-agency training on safeguarding and promoting welfare is provided to meet local needs (Home Office, 2014). FGM should be a part of all staff training on safeguarding and included within training on domestic violence, forced marriage and other relevant areas.

E-learning has been developed both by Health Education England (HEE) and the Home Office. The HEE package comprises five 20-30 minute sessions aimed primarily at health professionals, endorsed by professional bodies covering General Practice, community nursing, midwifery, obstetrics and child health. It covers background about FGM, communication skills, legal and safeguarding issues, and issues in children, women and in pregnancy (HEE, 2015). The Home Office programme is intended for teachers, police, doctors, social workers and Border Force staff to help them identify and assist girls who are at risk of FGM (Home Office, 2015b).

In the past training has often focused on awareness-raising but it is clear that professionals also need the skills and knowledge to be able to raise the issue of FGM and discuss it in a culturally sensitive way (Home Office, 2014). This requires direct and simple language, recognising concerns about illegality and health risks while avoiding judgements about communities or individuals. It also requires an awareness of the variety of terms which may
be used to refer to FGM and its meanings in different languages (DH, 2015a). Training should be supported by the dissemination of guidance but guidance alone is unlikely to equip staff with all the skills and knowledge they need to be confident in addressing these sensitive questions.

As well as the professionals referred to above, training should also be offered to people working in third sector organisations who come into contact with FGM-practising communities.

**Working with communities**

Local authorities, LSCBs and all professionals are encouraged to consider how they can engage FGM-practising communities in work on FGM. An evaluation of community-based preventive work in different areas of the UK found that rejection of FGM increased in areas where this had taken place (Trust for London, 2013).

AFRUCA (Africans Unite Against Child Abuse) carried out focus groups with African communities in Greater Manchester to explore attitudes to and experience of FGM (AFRUCA, 2014). They found that some did not perceive there to be any risks around FGM. They also identified a ‘culture of silence’ whereby some participants did not want to admit to having any previous knowledge or personal experience of FGM or its occurrence in their communities, and did not admit to knowing anyone who would perform FGM, while saying everyone knew where to go if they needed a ‘cutter’. A few also said they knew that children are being taken back to their countries of origin to have FGM procedures done. However it was also said that most people would not inform others if they were going to perform the procedure on their children, as FGM is viewed as a private practice that stays within families.

Some common themes identified by AFRUCA and others working with FGM-practising communities include the need to:

- involve communities in finding their own solutions;
- develop community education programmes to help raise awareness of the law on FGM and the consequences of offending, recognising the need to address FGM in a way that does not attack people’s culture but works with and engages them as stakeholders;
- provide separate FGM awareness for men;
- work with young people, to empower and support affected girls and young women and engage boys and young men in questions around FGM;
• encourage community members to report any suspected cases of FGM, including highlighting anonymous means for doing this such as Childline and the NSPCC (Home Office, 2014);
• work with religious leaders to help challenge misperceptions about religious requirements for FGM.

What is the pattern of services in Suffolk at present?
Suffolk Refugee Support are currently undertaking a project on a number of aspects of FGM including reviewing information available, developing multi-agency approaches to reporting, risk assessment and safeguarding, training and awareness raising with professionals, and working with victims of FGM and communities from FGM-practising countries.

Girls at risk of or who have undergone FGM
Girls who are thought to be at risk are referred through the Multiagency Safeguarding Hub (MASH). Parental consent is not required although there should be an open discussion with the family unless it is thought that this might place the girls at risk. If a strategy meeting is called in relation to FGM, it will be chaired by the Suffolk Council safeguarding team and advice would be sought from the Police lead for honour based violence, forced marriage and FGM. The aim is for agencies to work together, and if there is thought to be no immediate risk but longer term involvement with the family may be needed, a decision will be made on which professional will lead on this. If a girl needs to be examined this will be carried out by specialist staff at the Ferns Sexual Assault Referral Centre (SARC) in Ipswich.

The LSCB for Ipswich and East Suffolk and West Suffolk, has adopted the national Multiagency Practice Guidelines and also produced local guidance for health professionals in February 2015, based on the national guidelines. It was distributed to all GP practices and to Trusts for dissemination to their staff. The stakeholder group plans to review the protocols and procedures of local organisations to ensure they are comprehensive and consistent in relation to requirements for FGM.

Women and girls who have undergone FGM
Ipswich maternity unit reported that a decision about whether a postnatal safeguarding referral of a woman who had a baby girl was needed would follow discussion with the woman and family, and would depend on the level of risk identified. There is a lead midwife
for safeguarding who can provide advice to other midwifery staff. It was felt that because they are used to asking sensitive questions, midwives find it easier to raise questions about FGM than some other staff. However the discussion about intentions for the baby was still considered difficult. Midwifery staff recognised that women do not always know what procedure has been done, and because there are no routine vaginal examinations during pregnancy they may only find out during labour.

Women and girls who have had FGM can be referred to specialist clinics, most of which are in London, as well as in Birmingham, Bristol, Liverpool and Nottingham (Department of Health, 2014). However while this provides access to specialist care the need to travel was considered by some in Suffolk to be potentially prohibitive, particularly if this needs to happen on several occasions. Provision for deinfibulation has now been established in hospitals in Norfolk. There is reported to be no specialist counselling currently available for FGM in Suffolk and this is one area being looked at by Suffolk Refugee Support. It is currently not clear where lead commissioning responsibilities for FGM services in Suffolk lie, between the CCGs and NHSE.

Partnerships

A Suffolk FGM stakeholder group held its first meeting in April 2015 and has agreed to start joint work on procedures and protocols, training and education and sharing resources. FGM also comes within the remit of local Children and Adults Safeguarding arrangements.

Training and workforce development

The Police lead for honour based violence, forced marriage and FGM has for several years been providing training for partner agencies including health professionals, teachers and police officers. This is sometimes carried out jointly with others such as midwives or other health professionals and is highly regarded locally because of her experience and depth of knowledge. To date the training is reported to have been mainly around awareness raising and understanding legal requirements. Training is also carried out by the Safeguarding Children Team, for GPs, hospital staff and others. Training packages have been developed by Suffolk Refugee Support and work carried out in Norfolk has included training resources as well as a pocket guide on FGM for health professionals.
Working with communities

Suffolk Refugee Support report that they saw about 500 different people from 40 countries over a year within their drop-in service, and run various services and events including women’s & men’s groups. They are actively engaging both men and women in discussions about FGM. The Police FGM lead has also delivered sessions with several community groups to discuss FGM, including men’s groups.

What additional information is needed?

There is still little robust information about views on and attitudes to FGM in the communities in Suffolk who come from FGM-practising countries. This could be addressed by further interviews, focus groups and community work. The Kurdish community in Ipswich and the surrounding area is by far the largest identifiable group, but local knowledge may indicate groups from African countries in other areas who could also be approached.

A record of more detailed information about ethnicity or country of origin in healthcare services would give a clearer indication of the numbers of women who might be at risk and could prompt further enquiry, as it is not clear whether all those affected are being identified currently.

What can be concluded about health needs?

The numbers of women and girls who have undergone FGM, and girls who are at risk of FGM, are lower in Suffolk than in many areas of the country, but there are probably still several hundred girls and women in Suffolk affected or at risk. While some may be part of well-defined communities, such as the Kurdish community around Ipswich, others may be part of smaller groups or relatively isolated.

Health needs relate to:

- Prevention: raising awareness in the wider community and among professionals, recognising when a girl might be at risk, and taking the opportunity to intervene in a proportionate way to protect them if needed;
- Identifying the physical and psychological health needs of women and girls who have had FGM, including needs which may not have been identified by the women themselves because they assume it is something they have to live with;
- Providing effective and accessible support to meet physical and psychological needs.
The relatively low prevalence of FGM and FGM risk in Suffolk presents particular challenges, as many professionals will rarely see women and girls affected so it will be more difficult for them to be familiar with the risk factors and to feel confident and competent in raising questions around FGM. Much of the work on FGM in Suffolk is still in the early stages and it appears likely that there are still unrecognised and unmet needs in all the areas above. However risk groups can be identified and many approaches can be targeted.

References
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Chapter 4
Gypsy, Roma and Traveller Communities
Summary

Gypsy, Roma and Traveller communities introduction

- Gypsies and Travellers are designated ethnic minorities. They numbered 604 (0.1%) people in Suffolk when first counted in the 2011 Census. Although the count was seen as progress in recognition for the communities, it underestimated the numbers as many, particular those living in houses, would not identify themselves for fear of discrimination.

- Estimates suggest there are about 1,500 Gypsies and Travellers living in Suffolk in either trailers or houses based on an average of four persons per unit.

- There are no transit sites in the County, but three permanent sites in West Meadows, Kessingland and Mildenhall.

- The Roma come from Central and Eastern Europe and recently arrived in the UK, mostly after 2004. An estimate from the Roma community suggests there are about 1,000 Romanian Roma and 100 Bulgarian Roma living in Ipswich.

- All three Gypsy groups have a history of suffering racism and discrimination. They have poor health, a life expectancy more than 10 years less than the general population and an attitude of fatalism to health and healthcare.

- Significant health problems include long-term illness, respiratory disease (asthma and bronchitis), chest pain, chronic cough, higher maternal and neonatal death rates, high smoking rates, and anxiety and depression.

Gypsy, Roma and Traveller communities key points

- Gypsies and Travellers can be very independent and distrustful of the wider population. The newly arrived Roma Gypsies, do not speak English and their own Romani tongue is not a written language. In South-Eastern Europe for example, only 18% of Roma attend secondary school compared with 75% of the majority community.

- Gypsies, Travellers and Roma have their own cultural health beliefs.

- The lifestyle of Gypsies and Travellers is dependent on adequate sites and pitches, both permanent and transit. This report notes that in 2013 in the UK there were 2,700 caravans in excess of the number of authorised public and privately-owned sites.

- Those who travel have overall better health than those on static sites.

Roma people live in generally poor quality housing in Ipswich, and tend to have large families.

There is a paucity of literature about Roma health.

English Gypsy children receive little education; in the UK it is unusual for them to attend school beyond the age of 11 years. We were told the boys and girls after that age enter “apprenticeships” learning from older community members the skills necessary for gypsy manhood and womanhood. The Roma boys in Eastern Europe receive approximately four years of schooling, the girls none.

Health beliefs developed during centuries in a relatively closed community are strongly held. Illness is to be avoided, so health screening is an anathema; immunisations are dangerous, fuelled by scaremongering about Measles Mumps and Rubella (MMR) vaccination; cancer and death are subjects of fear.

The Wheel of Life is a Suffolk DVD in English and Romani produced by a Gypsy filmmaker in which community leaders speak of their positive experiences of the NHS and different professionals explained their services and how they could be contacted. The DVD has been widely distributed, a good example of self-help.

Gypsies and Travellers spoke of positive experiences with GPs and health visitors who were culturally well-informed and sympathetic.

The Norfolk and Suffolk Gypsy, Roma and Traveller Service (NSGRTS) provides a good liaison, to which the Health Outreach Project adds clinical and social work support.

The community gave examples of when they had not received the help they sought from the statutory authorities; trust needs to be earned by both service providers and Gypsies and Travellers.

Groups from the mainstream population making transient or trailer dwelling a lifestyle choice are not included in this Assessment. These include “New Travellers” and “New Age Travellers”.

Gypsy, Roma and Traveller recommendations

1. A strategy is needed to create a multiagency approach to supporting the health needs of GRT communities. Services should provide consistent advice and support. Smoking in pregnancy and refusal of immunisations and vaccinations are particular areas to be tackled.

2. Members of the Gypsy, Roma and Traveller groups could be trained as advocates to work alongside the Norfolk and Suffolk Gypsy, Roma and Traveller Service (NSGRTS) and The Health Outreach Project to build further bridges with
the community.

3. Cultural competency among health and social care workers is appreciated by gypsies and travellers and staff training should be developed and encouraged.

4. Appropriate information to encourage the use of NHS services should be available to increase understanding of waiting times, queuing procedures, referrals, signing-in at clinics and response to letters from NHS authorities on topics such as such screening and hospital appointments. However funding for English language and integration lessons stops September 2015 and opportunities to carry on this work need to be developed.

5. The Health Outreach Project should be supported to improve their monitoring and reporting of activity and outcomes and needs to record data about Gypsy, Roma and Travelling communities in real time.

6. Suffolk County Council may wish to include “New Travellers” and “New Age Travellers” in a future health needs assessment.

Who are Gypsy, Roma and Traveller Communities and why is it important for Suffolk?
The Gypsy, Roma, Traveller communities are distinct cultural entities who are at risk of inequalities in health status, service access and health outcomes. English Gypsies and Irish Travellers were recognised under the Race Relations Act 1976 (Matthew 2008) which was superseded by the Equality Act 2010, and were included in the 2011 census as an ethnic minority.

Gypsies and Travellers are defined as: Persons of a nomadic habit of life, whatever their race or origin, including such persons who on grounds only of their own or their family’s or dependants’ educational or health needs or old age have ceased to travel temporarily or permanently, and all other persons with a cultural tradition of nomadism and/or caravan dwelling. (Gypsy and Traveller Strategy 2012).
The definition excludes travelling show people because they are not an ethnic group and “rarely camp illegally”.

Within the collective definition, the distinct groups are:

- English Gypsies (either travelling or on permanent encampments)
- Irish Travellers
European Roma Gypsies who are a distinct ethnic and cultural group, with their own language and lifestyles, whose nomadic traditions were made illegal in their countries of origin about 40 years ago.

However, different studies use different terminologies for groups, sometimes using terms generically (“gypsies” to include travellers or “gypsies and travellers” to include all ethnic minority groups with a transient lifestyle whatever their heritage).

The Gypsy, Roma, Traveller community is used to opposition and discrimination. This forms a constant refrain in the literature and in interviews with individuals. They feel different and ostracised and this has an effect on health. This alienation is closely linked to the placement of trailers on unauthorised sites and so the availability of transit and permanent sites is very important and is a health determinant. Successive Government policies have encouraged Gypsies and Travellers to purchase their own land but they still have to apply for planning permission; when they do, permission is often refused (Lane, Spencer and Jones 2014).

There is no national policy on integration for these groups; mainstream policy and legal mechanisms are intended to deliver inclusion. However Lane et al (2014) found that “mainstream polices in the areas of discrimination, accommodation, education, employment and health have consistently failed Gypsies and Travellers in the past”. Lane et al conclude citing an “urgent need for changes in policies in all these areas to address inequalities and promote integration”.

The aims of the Government in respect of Traveller sites are that local planning authorities should make their own assessment of need for the purposes of planning and that local planning authorities, working collaboratively, develop fair and effective strategies to meet need through the identification of land for sites (DCLG 2012). Government policy is that sites should be provided to meet the accommodation needs of Gypsies and Travellers.

This is very much needed, since in 2011, there were 18,383 Gypsy and Traveller caravans in the UK. That figure rose to 18,730 by January 2013. In 2011, there were 6,942 caravans on authorised public sites and 8,332 on authorised privately-owned sites; in 2013, the figure for public sites had barely changed at 6,930 (indeed decreased, albeit only by 12), but there were 9,100 caravans on private sites (an increase of 768). This leaves 2,700 caravans without a designated place to pull off the road.

8 Since 2006, all local authorities with housing responsibilities have been legally required to conduct Gypsy Traveller accommodation and associated needs assessments (GTANAs)
Inclusion and exclusion criteria

Included in the topic are English (Romany) Gypsies, Irish Travellers and European Roma. The Gypsies and Travellers have been in Britain for about 500 years. The Roma are present in many Central and Eastern European countries, where they have experienced harassment and racial discrimination. Some arrived as refugees in the UK from about 1999. Since 2004, when a large bloc of Eastern European countries was admitted to the European Union, many more have arrived. In the UK, they settle in permanent brick-built accommodation. There are also ‘New’ Travellers or ‘New Age’ Travellers, who started to take to the road about 30 years ago. Most New Travellers are from settled communities, although some children may have been born into a Traveller lifestyle. There is a settlement of New Travellers on a private site in Rendlesham Forest; they are not an ethnic minority, but have chosen a distinct way of life.

This needs assessment does not include New Travellers or travelling showmen and circuses. Terms used here are for English Gypsies (or “gypsies”), Travellers and Roma. “Gypsies and Travellers” is a reference to a combination of the first two of the three groups; comments may be related to either of the two. “Romani” is the language, closely related to Hindi, spoken by the Eastern European Roma, who are believed to have emanated originally from India and spread across central and Eastern European countries. Where other writers have used different terms, or made different combinations (such as Parry), this has been indicated.

A topic for Suffolk

Suffolk is an attractive county for both travelling and non-travelling Gypsies. Currently there is no transit site in the County, so Gypsies moving in this part of the East of England will either pass through Suffolk to transit sites in Essex or Norfolk, or use unauthorised (“roadside”) encampments, this can exacerbate prejudice and discrimination against the Traveller community from local permanent residents. There are a number of permanent sites in Suffolk and a significant Gypsy population.

Health of the Gypsy, Roma and Traveller community

Members of these communities have a life expectancy of less than 90% that of the general population; a recent study stated that the general population to live up to 50% longer than Gypsies and Travellers (DCLG/MWG 2012). However whilst studies show that life
expectancy is low across the group, life expectancy can vary within the Gypsy and Traveller communities.

Parry et al (2004) used the term “Gypsy Travellers” to include “Gypsies, Travellers, Romanies or the Roma people”. Parry studied these as a generic group, making specific empirical comparison between Gypsies and Travellers when necessary. The groups included those who travelled all year round, or were summer, rare or never Travellers. Whether they travelled, were living on permanent sites, or in houses, the need for secure housing is as important to the Gypsy Roma Traveller communities as to others in the wider population. “Poor living conditions are the most influential contributing factors to the poor health status of Gypsies and Travellers, and poor quality or inappropriate accommodation as a result of forced movement inevitably exacerbates existing health conditions as well as leading to new problems” (Lane, Spencer, Jones, 2014). Insecure housing is a recognised health risk particularly to mental health.

Particular health problems which were mentioned in a number of studies and in focus groups were chest pain, chronic cough, bronchitis and asthma. The prevalence of anxiety and depression were significantly higher in Gypsy women than Gypsy men, and in both genders they were significantly higher than the wider population (Parry et al 2004) (Table 1). Gypsies and Travellers reporting poorer health status for the last year were significantly more likely to have a long-term illness, health problem or disability, which limited daily activities or work. They also had more difficulty with mobility, self-care, usual activities, pain or discomfort and anxiety or depression as assessed using the EuroQol-5D health utility measure. There was a higher overall prevalence of reported chest pain, respiratory problems, arthritis, miscarriage and death in childhood. No inequality was reported in diabetes, stroke or cancer (Parry 2007).

Where accommodation types and travelling patterns were accounted for, there were significantly higher anxiety symptoms among those living in houses rather than in trailers. Travelling patterns showed a high correlation with health, those travelling rarely reporting long term illness, chronic cough, or depression. But there is no indication whether these conditions prevent travelling, or whether static living has a negative effect on health. In overall terms, the Gypsies and Travellers experienced poorer health compared with other ethnic minority groups and also compared with their white counterparts in deprived inner city

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9 ‘if you have somewhere to live all the rest seems to fall into place to be honest, your health gets better.’ Gypsy: England (Lane, Spencer, Jones 2014)
or rural locations, with the exception of self-reporting of long term limiting illness. They also demonstrated much less formal education, larger family size and higher smoking rates.

Table 1 shows differences in health experience between the Gypsy and/or Traveller populations, measured against age- and sex-matched comparators, even after controlling for socio-economic status and other marginalised groups.

Table 1: Comparisons in health between Gypsy/Travellers and the wider population.

<table>
<thead>
<tr>
<th></th>
<th>Gypsy /Traveller</th>
<th>General population</th>
<th>Note</th>
</tr>
</thead>
<tbody>
<tr>
<td>Long term illness</td>
<td>39%</td>
<td>29%</td>
<td></td>
</tr>
<tr>
<td>Asthma</td>
<td>22%</td>
<td>5%</td>
<td></td>
</tr>
<tr>
<td>Chest pain</td>
<td>34%</td>
<td>22%</td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>X3 over general population</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>X2 over general population</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Miscarriage/</td>
<td>29%</td>
<td>16%</td>
<td></td>
</tr>
</tbody>
</table>
| Maternal death       | “Possibly the highest maternal death rates among all ethnic groups”
                      |                   | During pregnancy or shortly after childbirth.                       |
| Caesarean Section    | 22%              | 14%                |                                                                     |
| Life expectancy      |                   |                    |                                                                     |
| Female               | -12 years        | Lower than general population                                      |
| Male                 | -10 years        | Lower than general population                                      |


All of these studies relate to Gypsies and Travellers. Hagioff and McKee (2000) reviewed published literature on the health of the Roma people, whom they said “originated in northern India and have been known in Europe for nearly a thousand years. For much of that time they have been the subjects of discrimination and oppression”. They found few references, and these focused on communicable disease and reproductive health, suggesting to the authors a greater concern for the populations amongst whom the Roma lived than with the community’s own health. More research was recommended.

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10 Lewis and Drife (2001). The authors acknowledge the difficulty of establishing ethnicity.
A low level of general education and literacy also affects health, understanding of health-promoting practices, recognition of poor health and symptoms of ill-health and acceptance of the value of medical intervention. Gypsy children are poor attenders at school and may have frequent changes of school when travelling. Racism and anti-social behaviour in the settled community may further alienate Gypsy and Traveller children who rarely attend beyond the age of eleven (Van Cleemput 2009).

Use of health services
Traditionally, gypsies and travellers have pursued their own health care using traditional herbs and treatment methods. Although they now use modern health services more, there are still cultural differences to the approach taken. Although the gypsies we spoke to us that their babies had received all vaccinations, there are many who do not participate in these programmes. Treatment within the community is preferred to outside support. Men are less likely to take up treatment than women (as for the settled population), but women also are slow to attend, preferring to take advice from neighbours than health care professionals. Consultation of these will be sought only when the symptoms are advanced. A stay in hospital is likely to attract large numbers of family members in attendance and especially when there is a death. However these occasions would be rare as “hospitals are seen as polluted, places of death and disease” (Okely, 1983), to be used only as a last resort.

Links to other PHAST health needs assessments in Suffolk
It is possible that health problems experienced by the Roma group are common with asylum seekers and refugees, and with Eastern Europeans, except they often lived in substandard conditions, which contributes to their poorer health, as well as experiencing additional discrimination and harassment having been the only visible minority in their countries of origin. The Roma are different from the other Gypsy /Traveller groups included here, and have their own health experience, lifestyle and culture.

Why this is an important public health problem
Gypsies and Travellers have a long history in the UK but are not integrated. They retain a distinct way of life, culture and relationships, have poor health experience. They are looking for a better way life, integration and an end to racism, discrimination, poverty and social exclusion, but not for assimilation (Lane, Spencer, Jones 2014).

“Gypsies/Travellers have low rates of GP registration, poorer general health and high rates of limiting long term illness, substantially elevated smoking rates, poor birth outcomes and
maternal health, and low child immunisation rates and commensurate elevated rates of measles, whooping cough, and other infections” Aspinell (2014).

The health status of the Roma is also poor. They generally do not speak English, adding stress to their life in the UK, are often illiterate in their mother tongue, and in their culture the role of women is to continue to produce children as long as they are able. Amongst the Roma in Ipswich, up to twelve children in a family is not unusual, with the consequent toll on the mother, the costs and a reduced standard of living in the family.

**What is the local picture?**
Romany Gypsies and Irish Travellers were included as ethnic minority groups in the 2011 census for the first time. The census for Suffolk recorded 604 in the joint category. This was 0.1% of the population, the same proportion as in England and Wales. There is a risk of underestimation as members of a frequently targeted ethnic minority group may decline to identify themselves as such.

The Norfolk and Suffolk Gypsy, Roma and Traveller Liaison Service (NSGRTS) is funded by Norfolk and Suffolk County Councils and undertakes welfare assessments on unauthorised encampments. The service estimates there are around 1,500 Gypsies and Travellers living in Suffolk. This is based on 215 pitches across the County, with an average of four people per pitch, approximately 860 people, and increasing by 50% to account for Gypsies and Travellers who now live in brick houses, giving 1,500 people.

The Department of Health does not have a code for Gypsies and Travellers in ethnicity monitoring so they are not identifiable in health datasets.

It is estimated that there are 197,000 Roma migrants in the UK from all countries in Central and Eastern Europe (Brown et al 2013). Roma people in Ipswich generally occupy houses. For some years, there had been 10 to 13 Romanian Roma families living in the Ipswich area. By 2011, there were 56 families, with an average household size of approximately 9.5 persons. However, national research suggests that actual numbers are generally around three times the identified number. These numbers are likely to increase.

In 2015, the Roma community suggested that there are 1000 Romanian Roma and about 100 Bulgarian Roma in Ipswich, which is the centre of habitation for these families in Suffolk.
Currently few Gypsies and Travellers pass through the County owing to the limited possibility of stopping. However the District and Borough Councils have a duty to provide temporary encampments locations for Travellers to avoid unauthorised roadside stopping. Suffolk Travellers currently stop in Thetford Forest, Norfolk. Lack of places to stop, poor conditions on sites, anxiety and fear of being moved on, adverse reaction by local people to unauthorised parking and allied racism and hate crimes by neighbours are all health risk factors.

The health of Gypsies and Travellers is notoriously poor. Those over the age of 50 are considered elderly.

Many factors feed into the communities’ poor health. Studies indicate high infant mortality and perinatal death rates, low birth weight, low immunisation uptake and high child accident rates. In adults there is late consultation on health issues, poor food and exercise, little education, for women many pregnancies and for men a rough outdoor life. The communities also have health beliefs not allied to the scientific base of the health services. They are fiercely independent and unlikely to attend for screening; cancer is a taboo subject which gives rise to fear and fatalism. When medical advice is sought, the visit will be postponed as long as possible. There is also a lack of divulgence between men and women. The belief is that medical services have nothing to offer and are not to be trusted. Gypsies and Travellers would consult family and friends of the same sex before health professionals.

The community approach means that if a Gypsy or Traveller is seriously ill and needs hospitalisation and especially if death is approaching, the whole extended family wishes to remain with the person. This can be difficult to accommodate in a hospital, although locally stories were told of NHS staff working hard to arrange for family members to remain with the patient.

**What is the evidence base for interventions? What is best practice?**

The Gypsy Roma Traveller communities can benefit from best practice interventions which are available to the whole population. However the minority groups often benefit less as they have limited access. This has been recognised at Government level in the “Tackling Inequalities” literature which cites the aim “to improve the health of the poorest fastest” (PHOF, 2013, Marmot 2013).
There are Government commitments to:

- reduce barriers and increase accessibility of services, specifically to the Gypsy Roma Traveller population (DCLG, MWG 2012)
- question the insistence of GPs for proof of identity and of a permanent address
- support health and wellbeing boards to ensure Joint Strategic Needs Assessments reflect the needs of Gypsies and Travellers with the worst health outcomes
- work with other institutions to include the needs of Gypsies and Travellers in the commissioning of health services, by
  - lowering mortality and increasing immunisation rates
  - identifying gaps in data and research, and
  - seeking specific interventions that produce positive health outcomes for this group.

This is a major national policy development increasing the visibility and the importance of Gypsies and Travellers and their health needs.

Best practice recommended by the Royal College of General Practitioners (Gill et al 2013) includes:

- "Outreach": helps to establish a connection to local communities, in order to build the initial relationship and raise awareness among Travellers on the range of services available.
- Mobile units and clinics: whilst bringing services directly to sites might be a way to establish some rapport, it does not ultimately help integration in mainstream services. Community building and health education are positive alternatives.
- Patient access: due to the high mobility of these patients, accessible records and interoperability of care records software will be of great benefit to the continuity of care.
- Peer-education: is a valuable means to get access to strong communities. Gaining the trust of community leaders and role models can be very beneficial to reach out to the wider group, and gradually challenge some health beliefs and behaviours."

The Faculty for Homeless and Inclusion Health (2013) emphasise that Gypsies and Travellers who are now living in settled housing do not cease to be Gypsies or Travellers and in either situation they have a legal right to access NHS and social care services. Best practice also includes care of where the Gypsies and Travellers will live since if there are insufficient sites, they "may find themselves living in irregular locations, (for instance, under
motorways or next to sewage works) so they may face unusual hazards for example, lack of sewage disposal and limited access to water”. If they are not literate, information about treatment and appointments may need to be explained. Finally, because of the high level of unmet need, fast-tracking to preventive services should be considered. The Faculty also recommends peer or community health promotion workers.

A good example of a peer intervention is the recent Suffolk production of *The Wheel of Life* (Bowers 2015), a DVD produced in both English and Romani of health experiences of Gypsies and Travellers, and interviews with local NHS staff – a GP, psychologist, cancer consultant, and midwife among others – speaking about how they can help. For each speaker, a phone number is spoken and shown on the screen. This DVD circumvents poor literacy, is of high quality, interspersed throughout with interviews of high profile members of the community recommending the services. It was made by a Gypsy journalist and filmmaker supported by Community Development Workers from Voiceability, part of Suffolk Wellbeing Service with lottery funding.

**What is the pattern of services in Suffolk at present?**

**Community care: Gypsies and Travellers**

The Norfolk and Suffolk Gypsy Roma Traveller Service (NSGRT) works with partners to help Gypsies and Travellers to get the help and advice they need for good health. In the Gypsy population there is a clear division of labour. Men and boys do outdoor work, dealing in scrap metal or laying tarmac for drives or felling trees, work not so easily available in the modern economy, while women and girls work in the trailer. The women interviewed for this needs assessment were independent, often with the partner elsewhere, so to an extent living their lives as single mothers although with female ‘significant others’ in the community.

Support workers have spent a number of years getting to know the communities, building trust, supporting wherever possible and providing links to statutory services. These support workers also liaise closely with The Health Outreach Team for marginalised and vulnerable adults.

Outreach and preventive work is provided by The Health Outreach Team which works at all stages of the prevention, treatment and care pathway, with a prime purpose of providing treatment, information and advice on health related issues and facilitating access to GPs and
other mainstream health and social services. There is more information on The Health Outreach Team in the Homelessness Needs Assessment.

The Health Outreach Team can also act in an intermediary role, of which evidence was seen in the case of a seriously ill Gypsy child whose consultant and GP had recommended should be rehoused as her condition worsened, but for whom housing was not available. The case was complicated but, for relationships to improve between the community and the statutory authorities, the community need to know that they are heard and that due attention is given to their needs as they define them. In this instance they were sure that refusal was based on their cultural background. The Health Outreach was the only organisation able to intervene. This is an example of the need for different services to work in closer collaboration towards mutually defined and agreed evidence-driven measurable ends, as knowledge about this child was only shared as a result of interviews for this needs assessment.

Collaboration is also needed in West Meadows where fly tipping is an issue. It is uncertain who is responsible, but site members are certain it includes those from the settled community (non-gypsies). Fly tipping encourages the breeding of rats such that one young mother was fearful to let her child play outside the trailer. The heap had been cleared but was restarted the next day. Managers of the site continue to try and resolve this ongoing concern.

**Community care: Roma**

The Health Outreach Team has few set clinics. It offers a “low threshold open access service”: when people arrive, they are seen. Any who did not fit the acceptance criteria would be unlikely to attend The Health Outreach Team; if any did, they would be re-directed. Many of the specific groups and clinics are not generally advertised but are focussed on those target populations.

This is the case for the Roma population. There are two clinic half days, one mixed and one for women, when an interpreter is present. She is a member of the Roma community who has been resident in the UK for about 12 years and has very good understanding of the language, the nature and structure of services, and of the people who use The Health Outreach. The clinics are staffed by health, social workers and support staff and deal with any issue the women bring.
The needs of the Roma women are great. The men may be in basic work, gathering and selling scrap metal for example, and the families are large. Management and decision-making seems to rest on the women. For newly arrived immigrants with no understanding of English and often no literacy skills in their own language, it is challenging to negotiate the education, health, welfare, financial and other systems.

A shortage of social housing may force members of these communities into expensive private rented accommodation, although migrants from the European Economic Area (EEA) are unlikely to be eligible for social housing, even if it was available. Irish Travellers who cease to travel are documented as having worse health experience compared with the rest of the community. Does this effect occur also with the Roma people? A Scottish Traveller was quoted: “I am from a travelling background and I get very ill when I am static and I really would prefer to be in a caravan with other people of my ethnicity around”. For Roma people, this effect is multiplied as Roma families from Eastern Europe were forcibly prevented from travelling by having the wheels taken off their vans and being required to settle, in the 1970s. In view of the life expectancy of Roma people, this happened a generation ago. The Health Outreach has also identified a number of clients with learning disabilities and specifically in the Roma community, a growing number of genetic conditions which also present with a learning disability.

The Health Outreach Team carries out health checks on those aged over forty years and this has been useful, yielding broader benefits over those provided in the general population and indicating where additional help may be needed. With anticipated additional numbers of Roma families moving into the area, demand is set to grow.

A report on one afternoon at the women’s clinic is included in the Appendix D.

**Primary care: Gypsies and Travellers**

For primary care, the Gypsies and Travellers use a single GP practice which is effective in providing for their needs as relationship and trust has grown. The West Meadow site is permanent, with a few spare pitches for people to pull off the road but this may be only when others are away. A report of conversations with the residents detailing compliance with vaccinations, antenatal care and health visiting services is included in Appendix D. Most of the residents smoked, did not use a dentist and had many children. Very young mothers (<19 years) are visited fortnightly by the Family Nurse Partnership during pregnancy and
until the child is two years when the health visiting service takes over. The relationship is valued and improves antenatal and child health, and the life-course of the mother, helping with planning the next pregnancy, returning to education and finding employment. However in this matriarchal society the gypsy mothers who gave interviews smoked in pregnancy, were wary of immunisations and vaccinations and lacked the security of a constant male partner.

**Primary care: Roma**

Roma women are supported in GP registration by The Health Outreach. If double appointments are made, the GPs will use language line for translation; sometimes they ask patients to bring a family member for translation or ask The Health Outreach to provide help.

**Secondary care: Gypsies and Travellers**

Secondary care is provided as for the general population. It is not possible to track use of health services by this group as the NHS has no codes for Gypsies and Travellers. Even if it had, not all would divulge this owing to negative experiences of discrimination. Health beliefs of the communities affected the use of NHS secondary care. If a gypsy is hospitalised the wish to be present all the time, especially if death is imminent can be difficult for hospital services that are concerned about infection control and want to limit the number of visitors to a bed. However one Gypsy matriarch reported how understanding a hospital had been in allowing constant presence in a recent case.

The commitment to mobility and travelling seems to be a positive health benefit to this community. However, where there are insufficient transit sites they are liable to be moved on, generally an unpleasant experience to both travellers and the settled people around them. In that situation, they also have little opportunity of a consistent relationship with a GP, or opportunity to be followed up for medical investigations, or for antenatal care. The literature demonstrates many instances of healthcare being disrupted by the need to travel either by eviction or as a desire and need on the part of the community11.

**Secondary care: Roma**

Secondary Care for Roma patients is not freely available but is as per overseas visitor charging regulations 2015.

11 'My aunt missed an important appointment about a kidney operation because she had to move before it was sorted' (Lane, Spencer Jones 2014)
What additional information is needed?

- Further information should be sought on availability of primary care services willing and able to serve this community as demand is high, and is increasing. One GP commented, “I would like to see the service work with these communities to encourage English lessons and integration lessons”. This will also apply as it is understood that Suffolk County Council will be consulting on the need for transit sites for the Traveller population passing through Suffolk. However, ESOL provision in Suffolk is diminishing.

- The Norfolk and Suffolk Gypsy, Roma and Traveller Liaison Service (NSGRTS), working closely with The Health Outreach, provides a valuable link with the communities through their liaison role, the “trusted friend”. A review of the wider network of services including Suffolk Wellbeing Service and VoiceAbility would identify the strength and consistency of the health messages and how these link to strategic public health targets.

- Recommendations elsewhere (Homelessness Needs Assessment) have been made on data collection by The Health Outreach.

- Are accessible records available so Travellers can continue to receive care? This would be for health immunisations and vaccinations and maternity care, but also for example, drug lists for people with diabetes or other long-term conditions who may need to ask for prescriptions elsewhere whilst travelling. Many travel in the summer, and for the horse fairs.

- The desire of one GP to supply information to this needs assessment suggests that an audit of GP input to these communities should be carried out to see how primary care can be supported, and other GPs encouraged to offer services to Gypsies, Roma, and Travellers. Again this is an area where The Health Outreach has been instrumental in developing relations with, and supporting primary care for the benefit of marginalised adults.

- Further research may be needed on why there are poor maternal and infant health outcomes in this community.

What can be concluded?

- The needs of the Gypsies and Travellers are different from those of the Roma. The latter are new migrants who have suffered discrimination, racism and rejection in the Eastern European countries from which they have come, with all the needs of people moving into a new community but with the additional culture
of their Roma heritage. The former have a history of British discrimination and alienation behind them.

- The most pressing health need of this group is to develop trust with the settled community and with health service providers. GPs and health visitors who were perceived to be culturally well-informed and sympathetic were highly valued. But instances were also cited where trust was threatened, for example where a child who needed rehousing and the family thought the denial, in the face of representation from hospital and GP, was because they were Gypsies. Similarly there was evidence of a serious rat infestation at a Gypsy site which was subject to fly tipping. This had been cleared but immediately more rubbish was left. So the problem was seen as intractable and the children could not play outside the trailer because of the rats. Gypsies needed to know they had the support of the authorities as much as the settled community.

- Health determinants of secure housing, education, strong relationships, lack of discrimination, and availability of good food, exercise and avoidance of smoking are as important to the Gypsy Roma Traveller communities as to the general population.

- The Family Nurse Partnership was very much appreciated with potential to contribute to the Marmot indicator of every child getting a good start in life.

- The Norfolk and Suffolk Gypsy, Roma and Traveller Liaison Service, the first line of communication, and The Health Outreach work well on the front line with the communities.

- On peer education Suffolk has taken a lead with the production of the DVD, *The Wheel of Life*. This was a great example, the idea of the community, produced within the community, and indicating links to health services with community members discussing how their own needs had been met.

- Best practice indicated that Health and Wellbeing Boards should ensure that the needs of Gypsies and Travellers with the worst health outcomes are better reflected in needs assessments and joint health and wellbeing strategies. There is evidence of this working well in Suffolk but should develop with the increasing size of the populations.
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Chapter 5
Homeless Community
Summary

Homeless community introduction

Amongst many other factors, ill health can be both a cause and consequence of homelessness. This paper reviews the topic in some depth and provides a context for understanding the services which are and could be provided.

Homeless community key points

- Homelessness can affect anyone, as a consequence of any number of factors, for example social exclusion, the loss of a job, unexpected serious illness or accident. The health of homeless people is at particular risk.
- The average age of death for homeless people is 47 years for men and 43 years for women, compared to 77 years in the general population, but those living on the streets have the highest rates of premature death.
- A study found that 30 people each year died by suicide whilst homeless.
- Homelessness is very isolating, can be physically dangerous and puts people at high risk of mental illness and of health behaviours which may provide short term relief but are hazardous in the longer term.
- An analysis was carried out of the referrals to the Suffolk Coordination Service over a 14 month period, and potential indicators of homelessness were identified. Prevention or early intervention should be considered.
- Eastern Europeans were among those needing winter night shelter in Ipswich.
- Homeless people are known to display physical ill-health, mental ill health and drug or alcohol misuse (tri-morbidity). Specialist level care may not be appropriate but given the presence of multiple morbidities, the indication may be for a more focused service than can be provided in general practice.
- The incidence of tuberculosis (TB) is increasing amongst homeless people. The National Institute for Health and Care Excellence (NICE) is due to release updated guidance on finding cases, treatment and application to marginalised and vulnerable adults, in October 2015. The provision of shelter to the homeless is strongly recommended as a preventive against contracting TB.
- NICE recommends that Directors of Public Health should provide commissioners of TB prevention and control programmes with local needs assessment information on an annual basis, and ensure that TB is part of the JSNA (NICE Guidance PH37).
• There are many voluntary organisations working in this sector and the views of some of those, and service users, are included as Appendix E.

Homelessness recommendations
1. The Health Outreach Project support General Practices who register homeless people but currently relatively few practices are involved. NHS England and the Clinical Commissioning Groups (CCGs) should encourage other General practices to offer registration to homeless people.
2. The CCGs should consider a training and education remit for The Health Outreach Project, for staff from mainstream services.
3. The CCGs should support the Health Outreach Project to improve their monitoring and reporting of activity and outcomes so that the full scope of their work is recognised this needs assessment lacked the data necessary to support clear recommendations that would lead to service improvement.
4. The public sector should facilitate data sharing agreements with partners to improve understanding of the state of health of the local homeless population.
5. Homelessness can be reduced by the health and care system being alert to the known risk factors such as having a learning disability, being a care leaver, needing to use emergency accommodation and/or having a criminal record. Multiagency work is recommended to find ways to influence those at greatest risk of becoming homeless.
6. After October 2015 Public Health should review the local adherence to the new Tuberculosis NICE guidance and highlight areas for action with the relevant agencies.
7. The CCGs, The Health Outreach Project and GPs with significant numbers of people who are homeless on their lists, should co-operate to decrease ‘do not attend’ (DNA) rates, and maximise preventive measures to encourage Accident and Emergency avoidance.
8. Acute Trusts need to ensure that discharge planning for the homeless is appropriate and if required involve local voluntary services as well as health and social care.
9. Prevention or early intervention of homelessness should be considered to reduce the number of individuals requiring supported housing from Suffolk Co-ordination Service (SCS).

What is homelessness and why is it important for Suffolk?
One definition of homelessness is: “not having a home, because you are living on the streets, or because your home is unsuitable or you don’t have any rights to stay where you live” (Shelter 2015). Service providers use more specific terms.
“Homelessness” includes a wide range of situations. Rough sleepers can be in the open air or buildings – doorways, stairwells, or tents - not intended for habitation (DCLG 2014). Those without their own current housing who squat or stay with family or friends (termed “sofa surfers”), or in temporary accommodation such as hostels, bed and breakfast, or women’s refuges are also without a fixed home. The Department for Communities and Local Government (DCLG) statistics are based on those for whom local authorities have a statutory duty, a small proportion of those who are homeless. These households may not be without a roof over their head, but this may be a strong possibility owing to imminent eviction, domestic violence or for other reasons.

Excluded from this are people not deemed eligible for assistance, those who became intentionally homeless and not falling within a specified priority need group. Priority need groups include households with a dependent child, a pregnant woman or people who are vulnerable for example by reason of mental illness or physical disability. Also included are young people aged 16 to 17, or 18 to 20 and previously in care, or people vulnerable as a result of time spent in care, in custody, in HM Forces or as a result of having to flee their home because of violence or the threat of violence.

For the purposes of this needs assessment homelessness includes:

- statutory and non-statutory homelessness, families with children, single people and couples without children
- those who are homeless (rough sleepers, ‘sofa surfers’ and those with no recourse to public funds)
- those who are temporarily housed in hostels, bed and breakfast accommodation or other short term provision
- those at risk of becoming homeless with no legal right to continue to occupy their property or for whom the risk of doing so, for example from domestic violence, means it is no longer reasonable for them to continue to live there.

The vast majority of single homeless people who are not entitled to housing, as well as those who do not apply for homelessness assistance, end up surviving ‘out of sight’. The local authority, on request, must make an assessment of their housing needs and provide advice and assistance to help them find accommodation for themselves.
Many homeless people stay in hostels. There are just over 38,500 bed spaces in hostels for single homeless people in England. They may opt for squats or bed-and-breakfast accommodation, or occupy floors or sofas of friends and family. These are described as ‘concealed’ homeless people.

Categorisation by the type of accommodation is not a helpful measure since many homeless people circulate between somewhere ‘concealed’, a prison stay, hostel, “sofa surfing”, or rough sleeping. This is a transient population.

Homelessness is a risk for the whole population. People who seem secure and well provided for may suddenly find themselves homeless. This can occur in a situation of job loss or where income is suddenly and drastically reduced, or in the case of marital breakdown, serious illness or disability. It also includes those who arrived in the UK as job-seeking migrants whose plans have not been fulfilled. Homelessness is a difficult cycle to break and people with experience of this may continue to live precarious and high-risk life styles, their stability compromised by issues of mental health, physical or learning disability, addictive behaviours or domestic violence, and they may again become homeless.

A particular group which, anecdotally, is increasing in numbers, is those with no recourse to public funds (NRPF). This relates to a person’s immigration status. The Immigration and Asylum Act 1999, Section 115, states that “a person will have no recourse to public funds if they are subject to immigration control” and as a result of this have no entitlement to certain welfare benefits, local authority housing or homelessness assistance. The frequency with which people enter this category is increasing owing to the number of asylum seekers who have leave to remain on condition of NRPF, whose leave to enter or remain in the UK is subject to a maintenance undertaking, or who require but do not have any leave to enter or remain. This is dealt with more fully in the Health Needs Assessment on Asylum Seekers and Refugees.

Homelessness is a particular risk in the winter. The crisis winter shelter provision is researched and provided through voluntary community sector in Ipswich in partnership with local and county authorities. However a number of Eastern European migrant workers sought shelter last winter. It is possible, though unverified, that they had come from accommodation available only with seasonal employment. These numbers may increase and should be accounted for.
Homelessness can affect people in any of the topic groups included in the Groups at Risk of Disadvantage, but especially in the Gypsy/Roma/traveller, asylum seekers/refugees, Eastern Europeans, and Rural Deprivation groups.

**Homelessness as a health determinant**

Homelessness is a major health risk factor in itself. Particular health risks for homeless people were identified in “Our Health and Wellbeing today” (DH 2010). These include tuberculosis (TB) which has been steadily increasing since the 1980s with 8,423 new cases in 2009, an increase of 5.7% compared with 2008. There may be 142,000 people aged 15–59 years chronically infected with hepatitis C in England only about half of whom are aware of their condition. Hepatitis C is almost always spread via blood-to-blood transmission and more than 90% of known cases in which there is information on risk factors are associated with injecting drug use. HIV rates remain relatively high, with 2,760 new diagnoses in 2009, and undiagnosed HIV is still a problem – around 26% of the estimated 86,500 people living with HIV at the end of 2009 were unaware of their infection. This means they are unable to benefit from effective treatment and risk unwittingly passing HIV on to others.

The number of homeless people is small compared to the overall population but the health effects are large and often intractable. There is also evidence that the number of homeless people is growing (DCLG 2015a, OCA 2010). Being without a home involves material hardship, social marginalisation and restrained relationships (Hodgetts et al 2007). Poverty, relative deprivation and social exclusion have a major impact on health and premature death, but those living on the streets have the highest rates of premature death (Wilkinson R and Marmot M 2003).

Marmot (2010) proposed to tackle this by “proportionate universalism”\(^\text{12}\). Public Health England included the concept in the Public Health Outcomes Framework, here stated as, to “improve the health of the poorest fastest”. The Faculty of Homelessness and Inclusion Health, (www.pathway.org.uk), published Standards for Commissioners and Service Providers (FHIH 2013) “to re-affirm the fundamental rights of all people to be treated with dignity, compassion and respect”, seeking to reduce “extremely high healthcare costs.

\(^\text{12}\)In seeking to minimise social inequalities and “to reduce the steepness of the social gradient in health, actions must be universal, but with a scale and intensity that is proportionate to the level of disadvantage. We call this “proportionate universalism.”
coupled with appalling outcomes”. Using robust methodologies and data for England, 2001-09, it has been shown that the average age of death for homeless people is 47 years for men and 43 years for women, compared to 77 years in the general population (Crisis 2011). A national clinical survey based on a four year (1996-2000) sample of people in England and Wales who died by suicide showed that a total of 131 individuals who died by suicide were reported to have been homeless at the time of death, 3% of all suicides by psychiatric patients, more than 30 suicides per year. Social and clinical risk factors for suicide were common, including drug and alcohol misuse, and recent suicidal ideas and behaviour (Bickley et al 2006).

Although homelessness can occur as a function of poor health (perhaps relating to job loss), chronic – or “entrenched” - homelessness is itself a risk factor for physical ill-health, mental ill health and drug or alcohol misuse. These are often associated with advanced illness at presentation, in the context of a person lacking social support who often feels ambivalent both about accessing care and their own self-worth. This often has its roots in histories of complex trauma, including high levels of child neglect and abuse, that impact on developmental trajectories and mental health (FHIH 2013 p7).

Aspinell (2014) identified that the particular characteristics of sleeping rough, rotating in and out of emergency hostel accommodation, having more than one indicator of vulnerability, being very young (aged 16 – 20) or a migrant rough sleeper, is to be at risk of violence, severe illness and premature death. More generally, there is a raised risk of poor mental health, including depression and other affective disorders, anxiety states, personality disorder, and schizophrenia, which together with drug and alcohol misuse, and physical illness contributes to the “tri-morbidity” commonly found in homeless people (FHIH 2014). Up to 60% of people in the hostel population in England may suffer from personality disorder. A study of consultations at a specialist homelessness practice over ten years, showed that diagnoses of heroin dependence had fallen from 37% to 28% but alcohol dependence had increased from 20% to 29% (Aspinell, 2014).

A study of homeless people in London (Bilton, 2008) found that 43% of their hostel residents had a physical illness. Respiratory problems (pneumonia, influenza, asthma, and tuberculosis, frequently latent), upper gastrointestinal disease, physical trauma (injury, foot trauma), blood-borne viruses, and skin problems (especially eczema) occurred more frequently than in the general population. Assault (17.5%) and fractures (28.6%) were
reported in consultations at a special practice for the homeless and many homeless have a lifetime experience of some form of trauma.

Aspinall also observed that significant numbers of Eastern European migrants were amongst the rough sleeping population of a number of cities, possibly homeless during the winter season of low availability of work, where accommodation was “tied” to the period of employment. This group also had high alcohol support needs, their position compounded by having minimal recourse to public funds.¹³

**Homelessness: costs and service usage**

Socially excluded groups are often invisible in national data sets, both in records of housing and homelessness and in health status and access to health services. Hospital records may record “no fixed abode” but a homeless person may use an address of a friend or a homeless charity to receive correspondence or attain registration with a GP (or to prevent identification of their real status), so cannot be identified as homeless.

The Autumn 2014 total rough sleeping counts and estimates in England (DCLG 2015)¹⁴, collected between 1 October and 30 November 2014, was 2,744, an increase of 330 (14%) on the Autumn 2013 when the total was 2,414. However the number of rough sleepers in London had increased by 37%, compared to far fewer, an increase of 7% in the rest of England.

The high costs and service usage were demonstrated by research for the Department of Health Office of the Chief Analyst (OCA 2010) which showed that single homeless people attended accident and emergency departments five times more than the local average and hospital admissions were 3.2 times the local average. The total national cost of hospital usage by this client group was conservatively estimated to be £85m (in 2010), four times the level of the general population and inpatient costs (the bulk of the usage for this client group) was eight times higher than for the housed population in the same age group. In fact this is likely to be a considerable underestimate, as many homeless people will give a hostel or “care of” address and are not identified in this type of analysis.

¹³ The 2004 A-8 accession states: Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Slovakia and Slovenia, plus the 2007 accession states, Bulgaria and Romania.

¹⁴ “Rough sleeping counts and estimates are single night snapshots of the number of people sleeping rough in local authority areas. Local authorities decide whether to carry out a count or an estimate based upon their assessment of whether the local rough sleeping problem justifies counting.”
What is the local picture?
There is no available total number of homeless households in Suffolk. Those in priority need for whom there is a Local Authority Statutory duty are recorded, but these are only a proportion of the total. “The vast majority of single homeless people are not considered statutorily homeless” (IHAG 2014), and of these there is no record.

Figure 1 shows the trend in homelessness where the local authorities have accepted a duty of care. It is based on numbers rather than rates related to the population, so larger authorities will have higher numbers. The increase in recording by St Edmundsbury may be an artefact, but the service manager is “confident that those who present here as homeless or threatened with homeless are dealt with appropriately under the legislation and the figures we report are an accurate record of the numbers that we have a duty to accommodate”.

Figure 1: Number of households accepted as being homeless and in priority need, 2007/08 – 2013/14, Local Authorities, Suffolk

Source: DCLG Table 784. Local authorities’ action under the homelessness provisions of the Housing Acts.\(^\text{15}\)

Figure 2 presents the data on households accepted as eligible for Housing Related Support, in Suffolk and compared with England, as a rate per 1,000 households. There is no discernible trend.

The Hostel Accommodation Recording Project (HARP)\(^\text{16}\) showed that between January 2011 and December 2012, there were 1,060 individuals a year applying to hostels for the homeless in Ipswich. In 2012 the 365 single person hostel bed spaces in Ipswich were approached for housing by 1,108 individuals (IHAG 2014).

Table 1 shows the DCLG record of an annual count of rough sleepers. Local authorities may carry out a count or an estimate based upon their assessment of whether the local rough sleeping problem justifies counting.

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\(^{16}\) HARP recorded every individual applying to the single person hostels in Ipswich, delivered on behalf of the Ipswich Hostel Liaison Group by Ipswich Housing Action Group
Table 1: Street counts and estimates of rough sleeping in Suffolk, Autumn 2014

<table>
<thead>
<tr>
<th>District</th>
<th>People</th>
</tr>
</thead>
<tbody>
<tr>
<td>Babergh</td>
<td>0</td>
</tr>
<tr>
<td>St Edmundsbury</td>
<td>3</td>
</tr>
<tr>
<td>Suffolk Coastal</td>
<td>2</td>
</tr>
<tr>
<td>Ipswich</td>
<td>8</td>
</tr>
<tr>
<td>Forest Heath</td>
<td>2</td>
</tr>
<tr>
<td>Mid Suffolk</td>
<td>0</td>
</tr>
<tr>
<td>Waveney</td>
<td>3</td>
</tr>
</tbody>
</table>


However, in a one year period (01/02/2014 to 31/01/2015), 85 clients applied for accommodation to Suffolk Coordination Service (SCS) as ‘rough sleepers’ in Ipswich alone. These are self-defined and it is possible that some presented themselves as such in their hope of increasing their chance of being housed.

The most complete dataset on statutorily accepted homeless people in Suffolk currently is held by SCS. The service links individual applicants for housing with available resource. Approximately 80% of those accepted and assessed by local authorities as having priority need would be referred to SCS, the remainder would be housed through other routes, but others can also refer to SCS. The comprehensive referral form allows analysis of the characteristics of the anonymised referrals. In the fourteen month period April 2014 – May 2015 there were 3,557 acceptances of which 75% were male.

Figure 3 shows the trend of homeless applications since the SCS began (14 months). The ratio of male to female has increased owing to a greater increase in the number of male referrals. It is possible that the increase in the number of applicants over time is due to the establishment of a new service in the Suffolk Co-ordination Service. There is no discernible seasonal trend.

Figure 3: Applicants to SCS for accommodation by gender April 2014 – May 2015

Source: SCS

Figure 4 shows the area from which the applicant presented for referral to SCS, rather than where he was before he became homeless. Figure 2 shows the homelessness rate per 1,000 households, Figure 4 shows the actual number of referrals.

Figure 4: Applicants to SCS, by area referred, by gender, April 2014 – May 2015

Source: SCS

*includes 81 discharges from prisons
Figure 5 show the main reasons for referral to SCS, being relationship breakdown, family disputes and eviction. Leaving prison is also significant, and is a more predictable event. Analysis of these reasons by age group is show in Appendix E.

**Figure 5: Main reason for referral, by gender, April 2014 – May 2015**

Source: SCS

Applicants to the SCS for housing related support were asked to give their medical needs. Of the 1,278 who responded to this question, the conditions most frequently mentioned were depression (285), anxiety (144) and asthma (111). It is possible that these were related to the problem of homelessness being experienced. Other frequently cited health problems were ADHD (77), back problems (57), mental health (57), and epilepsy (42). Fewer, but significant in people applying for housing were people with Asperger’s, autism, stroke, psychosis, cerebral palsy and cancer. A complete table is in Appendix E.

Drug users were asked what substances they used. The most frequent, in order of magnitude were Cannabis (457), Heroin (214), Methadone (131), Cocaine (107), and Crack (88). A further 124 applicants listed other substances used.
The referral form requested information about having a criminal record (1,831), learning disability (437), or being a previous occupant of emergency accommodation (836).

The great majority of applicants were white British (2,983), with nine white Irish and 244 White Other. All other ethnic groups were very small. Of the 967 young people applying for housing aged between 15 and 19 years, 183 were care leavers.

The answers to the questions were not entirely surprising, but give a clear indication in terms of prevention of homelessness, the interventions that would have the greatest effect on health.

A number of the questions refer to relationships; these are difficult to control. Other factors such as having a learning disability, being a care leaver, needing to use emergency accommodation and having a criminal record indicate that more developmental programmes are needed before the homeless reach the SCS. Male gender and drug misuse are also risk factors.

It is important to remember that these findings relate to a group of people who had already been found eligible for Housing Related Support. They are among the most vulnerable, but are only a proportion of the total homeless population in Suffolk, most of whom will not have such eligibility.

What is the evidence base for interventions? What is best practice?
There is little evidence of best practice in prevention and management of homelessness from routine information sources. One forum for development of evidence based interventions for the homeless in the UK is the Faculty of Homelessness and Inclusion Health.

The National Institute for Health and Care Excellence (NICE 2013) published guidelines for Local Authorities on best practice management of tuberculosis (TB), a major risk factor of which is homelessness. A recommendation is “providing shelter for homeless people with tuberculosis: just one way local government can help tackle TB”, and for a whole systems approach. The risk of spread of infection is greatest in the areas of greatest concentration of at-risk groups, such as London and the West Midlands. However it is associated with new arrivals from countries of high TB prevalence and the guidance should be adhered to in Suffolk. New national arrangements mean that people wishing to seek asylum must be
tested in their home country and be clear of the disease before applying for asylum in the UK (PHE 2013, UKBA 2012).

NICE PH37 gives guidance on identifying and managing tuberculosis among hard-to-reach groups. Under this guidance, Directors of Public Health should provide TB prevention and control programme commissioners with local needs assessment information on an annual basis, and ensure that TB is part of the JSNA in areas of high need (NICE 2012). The guidance also recommends use of a mobile digital x-ray unit which in London screens almost 10,000 high risk people every year.

NICE is in process of producing an “Update of CG117 Tuberculosis” which deals with clinical diagnosis and management of tuberculosis, and measures for its prevention and control, incorporating PH37 “Tuberculosis - Hard to reach Groups”. On publication which is anticipated in October 2015, this should be reviewed for evidence on the most efficient way of providing TB screening in Ipswich.

NHS Health Checks are a nationally approved screening programme to help prevent the onset of heart disease, stroke, and type 2 diabetes and kidney disease and is being offered to people between the ages of 40 and 74. Its effectiveness is still being evaluated but it has been found to be a useful screening tool for homeless people. We were told that homeless people do not present for healthcare until their condition is advanced and more difficult to treat. These people may not be registered with a general practitioner so an NHS health check is appropriate until registration can be completed. NICE notes that where delivery and uptake are sub-optimal and the lifestyle advice offered does not meet the person's needs, then there is a risk of the programme being ineffective (NICE 2014). However participation by those at greatest risk, including the homeless, is especially encouraged and at The Health Outreach it has been found to be a valuable tool in identifying latent or active disease as well as instituting preventive measures.

What is the pattern of services in Suffolk at present?
Providing care services to people who are homeless can be difficult. We were told they “often need help with: using services, behavioural issues, attending appointments, having to wait, having to attend, having to organise, taking treatments and tablets. They need help controlling their “chaos” (a Suffolk GP).
The service to marginalised and vulnerable adults delivered in Suffolk, The Health Outreach Project works at all stages of the prevention, treatment and care pathway providing treatment, information and advice on health related issues and facilitating access to GPs and other mainstream health and social services.

Services are provided to people who are either:

- Homeless
- Refugee and asylum seekers
- Gypsies and Travellers
- Other Black Minority and Ethnic (BME) individuals
- Migrant workers
- Ex-offenders

These groups are heterogeneous and will have individuals with multiple health inequalities such as people with learning disability, mental health problems, sensory loss, physical disability, a few in older age and many with co-morbidities.

The Health Outreach also has a geographic spread across Suffolk (excluding Waveney), a main static base located in Ipswich and visiting arrangements with the mobile clinic to a number of the market towns in Suffolk, as well as regular support provided in the 20% most deprived lower super output areas in the County, and other places as needed. The service also works with people on the street on a regular basis.

People with learning disability (currently about 5% of the caseload), have been identified;

- as a target group for NHS health checks and seeing a very poor level of access to primary and secondary care
- as a group turning up to crisis services (food banks, soup kitchens, night shelters) with very complex needs and often significant safeguarding issues

The Health Outreach provides initial contact treatment and advice widely in Suffolk. The team consists of general nurses, mental health nurses, a blood-borne virus nurse specialist, social workers, a GP, a physician’s assistant, support workers and administrative staff who visit a number of venues for the homeless (the Chapman Centre, The Salvation Army, Cavendish Lodge and others), encouraging links with health services. Please see Appendix E for a map showing coverage by this service.
Clients initially present with a wide range of problems such as head wounds, infection, and a crisis with a service, a personal relationship or other concern, pain, depression, foot problems. All patients have their presenting problem addressed first, but are offered health screening and access to treatment including physical health assessment, screening for dental/oral problems, BBV (blood borne viruses), smoking, drug and alcohol problems, TB (tuberculosis) screening, screening for mental health problems, diet and exercise.

TB screening is offered at Ipswich Hospital, but this does not work well for homeless people because of the distance and the problems of their chaotic lifestyles which result in high rates of non-attendance (DNA). The National Institute for Health and Care Excellence is due to publish revised guidance in October 2015, and when available this should be reviewed for cost effective measures of offering screening for TB amongst marginalised and vulnerable groups.

The Health Outreach partners with NHS treatment services at many levels. Initially links are made with the GP surgeries. People who are homeless can require additional time and effort, particularly if people have a history of homelessness or rough sleeping, and some GPs are unwilling to engage with this, expressing concern that if they take one or two, others will follow and they will not be able to cope. There are six practices which will take these homeless patients, three work comprehensively with them.

Recording and enumerating is a serious challenge when working with homeless clients. A frequently used GP surgery told us that if a new patient is homeless, rather than “No Fixed Abode”, they are normally registered with an address as the Chapman Centre, in this way letters by post can be sent to them. Some will give friends’ or family addresses that they can access.

A coding for No Fixed Abode will not identify the majority of the homeless in primary or secondary care.

A Health Outreach support worker attends the primary care practice if necessary to help with registration. But they cannot provide ongoing personal care: the objective is to enable the individual to access mainstream services.
We were told that homeless people normally require many more GP appointments than other patients, some weekly. They often require weekly prescriptions. Some have been violent, so will need to be looked after by the violent patient scheme. Accurate data collection is almost impossible. The Health Outreach has devised a patient record card to be completed with each new client attending their service. The Health Outreach Project manager acknowledges that written records are something they need to improve on. Each patient now is entered on SystmOne unless this has already been completed.

Secondary care is most often accessed by the homeless via Accident and Emergency (A & E), attending only when a problem has become an emergency. Patients are not recorded as NFA (No Fixed Abode) at the hospital, as most give a past address or the day care centre, so they cannot be identified through routine data searches. None of the hospitals serving homeless patients can provide this information.

The Health Outreach has made the following estimates:

- Approximately 3,500 patients have been seen over two years.
- Many clients have co-morbidities, each at a lower level than to attract specialist attention but with a cumulative effect of serious disadvantage, both to themselves and to NHS staff who must treat them. Specialist level care may not be appropriate but the indication may be for a more focused service than can be provided in general practice.
- Most attend The Health Outreach with no record of NHS engagement but 90% are registered with a GP by the end of the care episode.
- Each Health Outreach episode is targeted to be completed in 6 weeks however the range can be from one week to 7 years.
- “We do know that the interventions we are delivering are evidence based and have raised the average age of death from 40 to 49 in ten years but we know we still have a long way to go” (Manager, The Health Outreach)
- There are few set clinics. This is a “low threshold open access service”: when people arrive, they are seen. Any who did not fit the target groups would be unlikely to attend here but if any not meeting the acceptance criteria did seek to attend, they would be re-directed. Many of the specific groups and clinics are not generally advertised but are focussed to the target populations.
The Health Outreach refers to a number of agencies as well as into the NHS care pathway. Clients can be referred, and assisted in making the links. They routinely work with:

- 7 foodbanks
- 200 housing providers, housing associations, private rented landlords
- 6 Local Authorities and Norfolk, Essex, and Cambridgeshire County Councils.
- 120 GP practices
- Several hundred health visitors.
- Children’s centres
- Job centres
- Benefits advice
- Welfare services
- Home Office
- Acute hospitals: Ipswich, West Suffolk, Norfolk and Norwich, Colchester General, and Papworth.
- Mental Health – crisis, and Integrated Drug and Alcohol services.
- Members of the Ipswich Locality Homelessness Partnership (ILHP)
- The Chapman Centre and the ILHP’s Assertive Street Outreach Service
- Police and probation who also refer into The Health Outreach Project.
- Roma adults often come with a number of children, so safeguarding is an issue and they refer into social work teams.
- The MASH (Multi agency Safeguarding Hub) centrally organised for Suffolk
- The Ropes Trust providing small grants to help the people of Ipswich. For The Health Outreach it provides for clients’ travelling, fridges for medication and housing deposits.

Most clients are supported and referred onwards. Little prescribing is done by The Health Outreach.

There are 10,000 – 15,000 interventions to 1,500 clients in one year. Interventions might mean organising supported housing, providing food parcels, dental prevention services, immunisations (flu vaccines) and going out to rural areas. They see drug users, do health checks, provide wound care, and support harm reduction (needle exchange), giving education on overdose training so clients will be able to help a peer in that situation. Homeless people tend to have more blood clots (pulmonary embolism and deep vein
thrombosis) and infection (skin infection and pneumonias), also poor condition through self-neglect. A GP told us he would like The Health Outreach to accompany the homeless people to NHS appointments as the DNA rate is very high, and costly. He would also like GPs to partner with Turning Point, the mental health services and to work with The Health Outreach on some joint management of patients.

Information on homeless clients is shared on SystemOne which supports quality of care for The Health Outreach clients. It could be used to better support The Health Outreach’s need for recording their output.

Admission to secondary care is traumatic and difficult for homeless people. Early self-discharge is known, or patients might be discharged with little notice and nowhere to go. It is not uncommon for homeless people to be discharged by ambulance to the Chapman Centre (see Client interviews). Some patients will have their discharge delayed until they have registered with a GP practice, which can be valid, as continuity of treatment and care needs to be safely provided in the community, which would only be possible if the patient was registered with a practice.

**Comparator services in East Anglia**

Homeless services are provided in other towns but the need is marked in Ipswich as it is a dispersal centre for asylum seekers and has cheaper property which attracts people with less disposable income including migrant workers.

Cambridge provides a GP surgery specifically for the homeless\(^\text{18}\). The distinction between this and The Health Outreach is that The Health Outreach goes to where the need is. Suffolk covers a large area, and services are truly inventive in being provided in such a wide range of venues. Many of the care group seen in Suffolk also have limited literacy and technological skills, for whom the Cambridge approach would be less suitable.

A service similar to The Health Outreach, although much more restricted in its geographical reach, exists in Norwich. City Reach\(^\text{19}\) offers clinic services and outreach services, facilitating

\(^{18}\) [http://www.mhcambridgeaccess.co.uk/the-practice/about-the-practice/](http://www.mhcambridgeaccess.co.uk/the-practice/about-the-practice/)

attendance at hospital appointments, and offering shower facilities at their premises. It has a wider number of target groups – including sex workers and people leaving prison, and a Freephone telephone number for people to call them. Like The Health Outreach it is a five day service and GPs provide out of hours at the weekends, but it offers a number of links with other statutory and voluntary services.

**Surveys of service user opinion**

Conversations were held with clients at the soup kitchen, the Chapman Centre, Christchurch House and with providers at a winter planning session and the women’s refuge (The Lighthouse). Some notes are included in the Appendix E.

Key points were:

- The precariousness of the lifestyle as the night before we attended the soup kitchen, one of the clients had died, making everyone unsettled and easily upset.
- That the clients, whatever their current living arrangements, would rather live a more secure life, though the revolving style of life through different sheltering arrangements suggested that settling was quite difficult. It was not the provision of a roof but enabling clients to value and retain it.
- The soup kitchen provided hot food but as important, companionship. Some of the exchanges were angry, but there was human interaction.
- The requirement to conform to regulations in order to keep a place in the hostel was a matter of contention.
- The ever-present personal danger. This was evidenced by the anger and disturbance expressed that evening as one of their group had died the night before. A young woman present who by the age of 24 had given birth to 7 children who were all now in care, was living a precarious lifestyle. All the group spoken to carried fear of attack from one’s fellows.
- We had two conversations with men who had been rehoused; one to a one-bedroom flat and was lonely; and one to sheltered accommodation who had settled well.
- One man complained that after a 999 phone call and treatment in A&E he was returned to the streets after a few hours with no support. Others joined in with similar stories.
- Use of the Chapman Centre as an address for mail and to register with the GP was a benefit, but this may be the cause of ambulances returning people to the centre after hospital admission.
• Homeless people had well developed skills in keeping warm and dry, a basic requirement for health protection and promotion.
• The difficulties of getting help were emphasised. Being homeless somehow “allows others (nurses, paramedics) to feel able to abuse and ignore you”.
• Young people in a hostel, all of whom have had an independent life, were now being retrained, and all wanted to move on but were all nervous about it. A home is fundamental to security.
• Ill health and homelessness are closely linked, with high levels of mental ill health openly displayed.
• There were two emergency beds at Cavendish Lodge. These were unpopular amongst the group. If one was taken and two friends were looking for somewhere for the night and only one could be admitted, the two would prefer the streets together for safety.
• People were in and out of prison on short sentences. Currently there was a couple rough sleeping in a tent by the swimming pool and one who was in the door way of the Methodist church.
• There were normally about 12 people who were roofless, circling between sofa surfing then into temporary accommodation then back to prison and on to more temporary accommodation.
• Discharge from hospital was also raised in different forums. The Chapman Centre said they received a call each week from Ipswich hospital asking if they could send someone “home” to the Chapman Centre. But about once in six weeks the hospital would simply put a patient in an ambulance and send him to the Chapman Centre. It was agreed that a better discharge arrangement was needed.

What additional information is needed?
• The Health Outreach manager acknowledges that written records are something they need to improve on. The impression is that the service provides a very useful support to other NHS services whilst delivering a good quality service to the most vulnerable people. This is evidenced by effective working relationships with other professionals, and the network of partners who use The Health Outreach for patients and clients who otherwise would fall through a gap in services.
• The Health Outreach needs a stronger brand since clients do not always realise that the services they receive at the Chapman Centre, at Cavendish Lodge, or other centres, are The Health Outreach staff.
A consistent multidisciplinary team (MDT) approach might help to pull services together such as A&E, Ambulance Service paramedics, additional GPs, and members of the Ipswich Locality Homelessness Partnership (ILHP), The Chapman Centre and the ILHP’s Assertive Street Outreach Service. There was evidence of one MDT initiated by a GP surgery and attended by The Health Outreach, but this is not in effect uniformly across the system.

Additional research is needed on homeless families.

NICE is in process of producing an Update of CG117 Tuberculosis (incorporating PH37), anticipated publication date October 2015. On publication this should be reviewed for evidence on the most efficient way of providing TB screening in Ipswich.

**What can be concluded?**

There is a significant group of homeless people mainly in Ipswich but also in other centres in Suffolk. They cannot be categorised in terms like rough sleepers or sofa surfers as they move from prison, to a hostel, to the streets, a different hostel, a tent, someone’s floor and back to prison or a spell in hospital.

Through negative life events it is possible for anyone to become homeless and homelessness is both a cause and may be an effect of ill health. Single men only obtain statutory help with homelessness if they have additional needs.

The analysis showed many had traumatic backgrounds, addicted to drugs and alcohol, time in prison, and time in care as children. Many gave relationship breakdown as the cause of their homelessness.

Common health needs were head wounds from falling or aggression, depression and anxiety, increased suicide risk, personality disorder, foot problems, diabetes, blood clots and alcohol-related conditions.

Even when someone is housed, he may return to the streets through lack of cooperation on regulations, not managing the budget, or relationship breakdown.

Winter and very cold weather are a particular risk to people without permanent accommodation. They should be accommodated during the day and night when temperatures drop. Additional migrant populations may also need accommodation.

Record keeping was difficult owing to lack of coding for the homeless, and the temporary situations in which health care was sometimes carried out.
To an extent homeless people do defy organisation but they have their own way of managing life and have a loyalty to the group.

The Health Outreach Project played a major role in support of the homeless, as evidenced by staff in other parts of the NHS who were dependent on the organisation to sort out GP registration, immunisations, cold weather interventions, and drug advice and support, referrals for TB screening and hepatitis screening.

Other parts of the service would like them to do more to support the reduction of DNA rates; The Health Outreach would like to do more in capacity building with mainstream services by training primary and secondary care staff how to manage homeless people better, and by training more staff for the Outreach Team, a specialist role which requires special training.

Life expectancy among The Health Outreach clients rise from 40 – 49 years in ten years of operation.

References

Bickley H et al. (2006). Suicide in the homeless within 12 months of contact with mental health services: a national clinical survey in the UK. *Social psychiatry and psychiatric epidemiology*. 41 (9), 686-691.


Healthwatch Suffolk. Engagement Report


Chapter 6

New Psychoactive Substances ‘Legal Highs’
Summary

New Psychoactive Substances introduction

- New Psychoactive Substances (NPSs) are psychoactive substances which are newly synthesised and/or newly available, designed to mimic the effects of ‘traditional’ illicit drugs and to be outside the scope of the Misuse of Drugs Act 1971. As they become brought under legal control, new ones have been manufactured often by slight changes in chemical composition.
- NPS use appears to be increasing nationally, while there has been a downward trend in the use of illicit drugs overall over the last decade.
- Patterns of use change; for example there is some evidence that the use of mephedrone increased until around 2012/13 and has fallen since then, while the use of nitrous oxide has increased in the last few years.
- The commonest routes of supply have been through head shops\(^2\) and online, but new legislation outlaws the distribution of NPSs in this country. The impact of this on NPS use has yet to be seen.

New Psychoactive Substances key points

- Users of NPSs tend to be people who also use other illicit drugs, and different groups of NPS users have been identified including participants in the night-time economy, men who have sex with men (MSM), some groups of young adults, ‘psychonauts’ who experiment with psychoactive drugs, and vulnerable young people living in socially disadvantaged environments.
- There is limited evidence on the effects of NPSs but because they often contain a mixture of substances, or unknown substances, health effects can be unpredictable and idiosyncratic.
- Currently NPS users comprise only a small proportion of users of substance misuse services, although many users may not regard NPSs as substances with which they need help.
- There are no specific interventions to reduce demand for or manage dependence on NPSs and approaches used for other substances also apply to NPSs. These include

\(^2\) Head shops are high street outlets which often sell paraphernalia related to the growing, production or consumption of cannabis and other drugs, alongside NPSs or ‘legal highs’.
information giving and resilience building for young people (including in schools), and psychosocial interventions using a stepped care approach to manage dependence.

- There is little information on NPS use in Suffolk. The proportion of substance misuse service users citing NPS use appears relatively low compared with other areas and the services in Suffolk do not perceive NPSs as a big problem.

- A survey of young people at New College, Ipswich found that almost a quarter had tried NPSs, and 11% reported using them frequently. Most of the respondents appeared to be aware that these drugs are no safer than illegal drugs and many said they would not use them even if recommended by a friend. However few appeared to be aware of local sources of information and advice about them.

- Anecdotal information suggests there may be particular concerns about substance misuse, including NPSs, in the Lowestoft area.

- There is evidence of a dramatic increase in use of synthetic cannabinoids (‘Spice’) in prisons over the last 5 years, including those in Suffolk.

- The Suffolk Recovery Forum has not encountered particular concerns about NPSs to date.

**New Psychoactive Substances recommendations**

- There should be a partnership approach to tackling all aspects of NPSs which is integrated into current substance misuse partnership arrangements. This should draw in a wide range of partners including various healthcare providers (both specialist substance misuse and non-specialist services), children’s and adults’ social care, teams working with those who are not in education, employment or training and Young Offenders, schools and colleges, youth services and various third sector organisations, the police, trading standards, and the criminal justice system including prisons and community rehabilitation. The Recovery Forum could develop into a partnership which takes a proactive approach to this work.

- There should be consideration of what further information is needed to develop a better understanding of current and potential users of NPSs in Suffolk including those in prison settings.

- Develop accurate, up-to-date information and advice about the harm of NPSs, identifying appropriate routes to reach particular target groups (such as users of the night-time economy, men who have sex with men (MSM) and those in the criminal justice system) as well as broader approaches for young people through schools and other settings.
• Work with schools across Suffolk to support and develop Personal, Social and Health Education programmes which include information about NPSs as part of substance misuse awareness raising.
• Consider what steps substance misuse services need to take to ensure they are accessible and seen as appropriate for users of NPSs, particularly considering risk groups such as young people, prisoners, MSM, and those from socially deprived areas. Including development of outreach to target groups and environments where there is increased risk of NPS use such as clubs and festivals.
• Ensure that specialist services provide effective support for users of NPS. This should include; harm reduction where appropriate eg needle exchange for people who inject NPSs and interventions to reduce dependence for users of NPSs (who will often be multiple substance users). Any provision needs to underpinned by detailed information about these users, including demographic details, risk factors and interventions in order to determine and evaluate outcomes.
• Develop stronger links and pathways between specialist services and generic services such as sexual health, Accident and Emergency, paramedics and primary care. Ensuring that these workforces feel confident and competent to identify and deal with problems relating to NPSs (including acute reactions) and are able to provide information and to signpost people appropriately.

Most of the information collection and interviews for this needs assessment were carried out before the Psychoactive Substances Bill was published on 29th May 2015.

**What are New Psychoactive substances?**

New Psychoactive Substances (NPSs) are substances which:
• are newly synthesised and/or newly available;
• are psychoactive and designed to mimic the effects of ‘traditional’ illicit drugs;
• may cause a threat to public health and/or the health of individuals;
• are designed to be outside the scope of the Misuse of Drugs Act 1971 (although many are now controlled under the Act), and not covered by the UN Drug Conventions;
• have become more widespread in use in the UK in the last 6-7 years.

‘New’ NPSs are constantly being manufactured, so there is no definitive list of substances, but their actions fall into 4 main categories, similar to the drugs they are designed to mimic; stimulant, hallucinogenic, depressant, or synthetic cannabinoids.
Figure 1 gives examples of NPS by their effect. Although sometimes referred to as ‘legal highs’ many have been controlled under the Misuse of Drugs Act 1971 and many more are covered by Temporary Class Drug Orders which apply to specific compounds. The Psychoactive Substances Bill published on 29th May 2015 will make it illegal to produce, distribute, sell or supply (although not to possess) ‘any substance intended for human consumption that is capable of producing a psychoactive effect’ (tobacco, alcohol and caffeine will be excluded). This effectively covers all NPSs which are available now or might be manufactured in the future.

**Figure 1: The main types of NPS and examples of each type**

<table>
<thead>
<tr>
<th>Type of NPS according to their effect</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primarily stimulant effects</td>
<td>Mephedrone (meow meow), Benzo Fury, MDAI, ethylphenidate, NRG-1, BZP</td>
</tr>
<tr>
<td>Primarily hallucinogenic effects</td>
<td>Salvia, Amanita, methoxetamine, Bromo-dragonfly</td>
</tr>
<tr>
<td>Primarily depressant effects</td>
<td>GHB/GBL, nitrous oxide</td>
</tr>
<tr>
<td>Synthetic cannabinoids</td>
<td>Spice, Clockwork Orange, Black Mamba, Exodus Damnation</td>
</tr>
</tbody>
</table>

Source: NEPTUNE 2015, Drugscope 2015

NPSs are often manufactured in laboratories overseas and the number of substances available has grown rapidly since around 2008, with new ones produced quickly to replace those that are placed under legal control. The majority of products analysed are found to contain a mixture of substances, often including controlled drugs. They are often sold packaged and marketed as ‘plant food’, ‘bath salts’, ‘research chemicals’, ‘incense’ or ‘herbal highs’ and are typically labelled as ‘not for human consumption’. The main sources of NPSs in the UK to date have been head shops (high street outlets which often sell paraphernalia related to cannabis and other drugs), other non-specialist retailers, and the internet, although relatively small numbers of users source them online, particularly among young people. NPS users commonly use the internet for sharing information about new compounds and the effects of drugs.
Why are New Psychoactive Substances an important Public Health problem?
A number of characteristics of NPSs increase the likelihood of harms arising from their use including uncertainty about their contents, impurity, adulterants and contaminants and poor quality. There is little knowledge about their short- and long-term effects, which are made more unpredictable by often being used in combination with other substances. There is evidence that injecting some NPSs is becoming more common, particularly mephedrone. They are currently easily available and relatively cheap compared to other drugs or alcohol.

Physical problems related to overdose have included overstimulation, confusion, hallucinations, cardiac arrhythmias and loss of control of body temperature, and mental health problems have been linked with longer term use. Office for National Statistics data on drug poisoning deaths reported 60 deaths in 2013 where NPSs were mentioned, but this is a very small proportion of the total deaths due to drug poisoning (60/2955 in 2013). The figures for NPSs had increased sharply since 2011 though it is not clear how much of the increase was due unclear definitions. Table 2 shows the NPS associated deaths in England and Wales between 2009-2013. There was a clear increase in the number of these deaths linked with cathinones, including mephedrone.

Figure 2: Number of drug-related deaths where selected substances were mentioned on the death certificate, England and Wales, deaths registered between 2009–2013

<table>
<thead>
<tr>
<th></th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>NPS total (including cathinones/mephedrone)</td>
<td>26</td>
<td>22</td>
<td>29</td>
<td>52</td>
<td>60</td>
</tr>
<tr>
<td>Cathinones (including mephedrone)</td>
<td>0</td>
<td>6</td>
<td>6</td>
<td>18</td>
<td>26</td>
</tr>
<tr>
<td>Mephedrone</td>
<td>0</td>
<td>6</td>
<td>5</td>
<td>12</td>
<td>18</td>
</tr>
</tbody>
</table>

Source: ONS

There is no evidence that NPSs are currently significant drivers of social harms. Within prisons NPSs are a part of the pattern of substance misuse which also includes ‘traditional’ illegal drugs and prescription drugs. There has been a dramatic increase in prison seizures of Spice (synthetic cannabinoids) since 2010. Figure 3 shows the number of seizures of Spice between 2010-14. Although the presence of Spice in prisons is evident
there is no evidence on the extent of their use in this setting because they are not tested for as part of Mandatory Drug Tests.

**Figure 3: Number of seizures of Spice (synthetic cannabinoids) in prisons, England and Wales, 2010-14**

Source: Hansard 21 Oct 2014

**What is known about New Psychoactive Substance use in the UK and more widely?**

NPSs are predominantly used by those who also use other illicit drugs such as club drugs, either as a substitute or alongside other substances. Convenience, availability and lower prices are thought to be bigger drivers for NPS use than legal status alone, although legal status might influence new users. There is good evidence that some NPS users are prepared to take an ‘unknown white powder’ with no idea about its contents (Home Office 2014c).

A number of subgroups among whom NPS use is relatively high have been identified, including clubbers and other participants in the night-time economy, men who have sex with men, some groups of young adults, ‘psychonauts’ who experiment with psychoactive drugs, and vulnerable young people living in socially disadvantaged environments (Home Office 2014d).

NPSs are the primary drug of use among only a very small proportion of adults seeking treatment from substance misuse services, although around 5% cite use of any club drug. Among young people in treatment use of mephedrone or club drugs is more common than among adults, and the commonest age for NPS use was 15. Reported mephedrone use
increased up to 2012/13 in both adults and young people using services, but not significantly in 2013/14. Many NPS users do not recognise themselves as drug users and would not consider seeking help from services, and many who do come into contact with services who are using multiple substances would not consider they needed help with NPSs.

The Crime Survey for England and Wales (CSEW) found that by far the commonest ‘legal high’ used was nitrous oxide, taken by 7.6% of 16-24 year olds and 2.3% of all 16-59 year olds in 2013/14. Use of both salvia and nitrous oxide had increased since the previous year, while reported mephedrone use fell significantly between 2010/11 and 2012/13. The vast majority of NPS users also used other illicit drugs. The CSEW also found a long-term downward trend in overall rates of illegal drug use over the last decade, although rates in 2013/14 were higher than in 2012/13. In 2013/14, 8.8% of 16-59 year olds (and 18.9% of 16-24 year olds) had taken any illicit drug (excluding mephedrone) in the last year.

An online survey looking at use of ‘legal highs’ in the UK included responses from 468 people who had ever taken ‘legal highs’, half of whom had used them first between the ages of 18 and 21, and a third when they were younger than that. There was a small proportion of very frequent users and many reporting only occasional use. Use with other substances (including alcohol) was common. Many users reported unpleasant physical symptoms associated with ‘legal high’ use and the majority considered that there were likely to be associated health risks. Most said they would go to a friend for help if they had a health problem due to taking a 'legal high', and only 40-50% said they would seek help from NHS health services; a greater number said they would look on the internet for help.

Intentions to use ‘legal highs’ again were influenced more by perceptions of safety, cheapness and easy availability, and views of friends, than by scientific information or news reports about their effects. Among people who had never used ‘legal highs’, the majority said they never would.

Two international surveys gathering information about NPSs included respondents from the UK. Among respondents to the Global Drug Survey in November/December 2013 (who tended to be young adults, about 50% regular clubgoers), 12% of the UK sample (n=7,326) and 7% of the international sample reported using ‘legal highs, research chemicals or synthetic cannabis’. Of the total UK sample, 11% admitted to taking ‘mystery white powders’ with no idea what they contained, and this increased to a fifth among those aged 18-25. The
Eurobarometer survey of 15-24 year olds in the EU in June 2014 found that 10% of the UK sample had ever used NPSs, 2% in the last 20 days and 4% in the last 2-12 months. The proportion of the whole EU sample who had ever used NPSs increased from 5% in 2011 to 8% in 2014.

The European Early Warning System run by EMCDDA reported that over the past five years there has been an ‘unprecedented’ increase in the number, type and availability of NPSs in Europe. In 2014 it reported 101 newly identified NPSs, compared with 14 in 2008. The single largest group was synthetic cannabinoids.

**What is the local picture?**

The only data on substance misuse service users’ experience of using NPSs are those available from the National Drug Treatment Monitoring System (NDTMS). There were increases between 2012/13 and 2013/14 in the number of users of all types of NPSs accessing services nationally, but the number of NPS users in Suffolk services appear relatively low compared to the East of England and nationally. The largest group were mephedrone users who comprised about 1% of service users in Suffolk. There is also evidence that NPS users accessing the services in Suffolk tend to be older than in other areas.

Professionals in Suffolk substance misuse services did not consider NPSs to be a large problem locally, although a number commented on particular concerns in Lowestoft, with mephedrone reported to be in common use both with young people and adults. Research carried out by University Campus Suffolk (UCS) with young people in Lowestoft reported that drug use is very common in the area and that drugs are easy to get hold of (though NPSs were not referred to specifically). The young people perceived a strong association between drug use, homelessness, unemployment and crime.

Staff in the three Suffolk prisons reported that synthetic cannabinoids ('Spice') were by far the commonest NPSs used, that use has risen dramatically in recent years and that they had seen some severe and idiosyncratic reactions to Spice. In a survey the Rehabilitation for Addicted Prisoners Trust (RAPt) carried out with their service users, 60% said they had used Spice and 54% that they would be able to get hold of it if they wanted. Staff reported anecdotally a link between NPS availability and more violence and discipline problems in the prison.
Little information was available from other services contacted across Suffolk. Sexual health services reported very little awareness of ‘chemsex’ among MSM using their services, and thought it likely that anyone seeking chemsex would go outside Suffolk. Mental health services were not aware of seeing patients with mental health problems linked to NPSs, and information was not available from Accident and Emergency.

A head shop in Ipswich was closed down earlier in 2015 due to the efforts of local trading standards and police, who also reported that other retailers have been visited and agreed to stop supplying. Other head shops are known to operate in neighbouring counties thought to be sources of supply for people in Suffolk.

An online survey was developed to try and gather views from local young people. There were 99 responses from young people at Ipswich college, most of whom were aged 16-18, although it is not possible to say how representative they are of young people in Ipswich as a whole. Almost a quarter said they had ever taken a ‘legal high’, and 11% were frequent users. Over two-thirds said they would not try one if offered it by a friend but 45% said they knew where to get ‘legal highs’, the internet, head shops or friends being the commonest sources. The majority said they did not feel very well informed about ‘legal highs’ but most did not think that ‘legal highs’ are safer than illegal drugs. Many appeared to be unaware of local potential sources of information about ‘legal highs’, and the majority would look on the internet (including FRANK) or media for more information if they wanted it.
What is the evidence base for interventions? What is best practice?

There are no specific approaches to reducing demand for NPSs compared to other substances, so generic approaches to providing information, reducing risk and building resilience apply to NPSs as to other substances and risky behaviours. A range of resources and guidance is available for educators and practitioners to support work in these areas, and schools are seen as a particularly important setting. There is likely to be a training need for many of those working with young people and other potential users who currently feel insufficiently informed about NPSs, including those in substance misuse services. A local integrated strategy for drug prevention should include action to tackle the use of NPSs.

A variety of approaches has been required to date to tackle the supply of NPSs, including preventing the activities of local retailers such as head shops through the use of Product Safety Regulations. The Psychoactive Substances Bill published on 29th May 2015 will outlaw the distribution of all NPSs but local control measures and monitoring will still be needed. The PHE toolkit for substance misuse commissioners advises that there should be a partnership and local strategy to tackle NPS supply and use.

There are no specific pharmaceutical interventions for the management of NPS use, so drug treatment services can largely adapt current approaches to working with users of traditional drugs, focusing on psychosocial interventions following a stepped care model. The NEPTUNE project has recently produced guidance on the management of acute and chronic ill-effects and harm reduction for club drugs including a number of NPSs. A recent review by the Royal College of Psychiatrists argues for significant changes in the approach of services in the UK to deal with problems due to NPS use, including increasing accessibility of services for NPS users, training for staff, better links and clear pathways between non-specialist and substance misuse services, and better data recording.

Harm reduction approaches, although not a key part of current drugs policy, are also relevant to NPSs, particularly in relation to potential harms associated with injecting, reducing the risk of overdose and acute toxicity, and reducing risky sexual behaviour.

The above approaches are equally applicable to prisons and PHE, the National Offender Management Service and NHS England have identified the need to explore best practice in addressing the harms of NPSs within the prison setting as one of their current joint development priorities.
Working in partnership is critical for all these elements to be tackled successfully and many agencies need to be engaged in this work including various healthcare providers (both specialist substance misuse and non-specialist services), children’s and adults’ social care, teams working with Young Offenders and those who are not in education, employment or training, schools and colleges, youth services and various third sector organisations, the police, trading standards, and the criminal justice system including prisons and community rehabilitation.

What is in place in Suffolk at present?
A large number of services could potentially have an impact on reducing levels of NPS use, reducing the risk of associated harm, and supporting people to help them stop using NPSs. It was not possible to identify what is currently in place in schools across Suffolk with respect to drug education but it is planned to implement a project called Risk Avert with Year 7s in schools later in the year, aiming to tackle risk-taking behaviours. A number of voluntary sector services work with young people but none had identified particular concerns about NPSs. The Matthew project provide drug and alcohol education and outreach in Suffolk for young people aged under 25, and training around drugs and alcohol is provided to many different professional and other groups across Suffolk by specialist workers with extensive knowledge of NPSs.

Police and Trading Standards have been working to reduce NPS supply in Suffolk for around three to four years and action has been taken against several outlets which were known to be supplying NPSs. Prison services take a number of approaches to reducing supply into prisons including intelligence-based searches, and additional netting was installed at HMP Highpoint to try and reduce the possibility of drugs being thrown in over the fence.

Since April 2015 the main substance misuse services in Suffolk have been commissioned from Turning Point under a single specification for an integrated service which includes NPSs in the scope of services provided. No data on service provision or activity in Suffolk were available apart from that obtained from NDTMS. Services are open to self-referral or professional referral, and psychosocial interventions are provided for people with problems with NPSs as required, but staff recognised that service users might not realise that they provide help with NPSs alongside other drugs, and that staff might need more training in this
area. A Tier 2 service (formerly the Westminster Drugs Project) works mainly with people referred from Criminal Justice, aimed at crime reduction alongside promoting recovery. Services within prisons in Suffolk are provided by RAPt (the Rehabilitation for Addicted Prisoners Trust). They provide information and health promotion to inmates, and one-to-one and group work for those with problems with alcohol, drugs or both.

The Suffolk Recovery Forum is now the main partnership group for work on substance misuse in Suffolk. Three Recovery Networking Forums between them cover the whole of Suffolk, engage a large number of partner organisations and individuals, and feed into the Recovery Forum. However concerns about NPS have not really come on the agenda of the Forums to date as they have tended to deal with more ‘traditional’ substance misuse.

**What can be concluded about health needs?**

The main health needs associated with NPSs relate to:

- The provision of accurate, up-to-date information and advice about the harm of NPSs
- Generic approaches to support young people in building resilience and decision-making skills and reducing risky behaviours
- Ensuring services are accessible and seen as appropriate for users of NPSs
- Providing effective interventions to reduce dependence
- Ensuring services are targeted at particular risk groups including young people, prisoners, MSM, and those from socially deprived areas

It is difficult to say to what extent current services in Suffolk meet these needs. While there has been some work to inform and advise young people about NPSs, this has been focused on certain groups such as those at Ipswich college, and it was not possible to identify what approaches are taken to drugs education and developing resilience in schools across Suffolk. There appears to have been limited experience with NPS users in Suffolk substance misuse services to date, and uptake of services by NPS users in Suffolk appears to be lower than in other areas. It is not known to what extent this reflects differences in need, or whether services are not currently seen as accessible or appropriate by users of NPSs in Suffolk.
References


Public Health England (2015b) Young people’s Statistics from the National Drug Treatment Monitoring System (NDTMS) 2013-14
Royal College of Psychiatrists (2014). One new drug a week. Royal College of Psychiatrists Faculty of Addictions Psychiatry (FR/AP/02)
Chapter 7

Communities that live in Rural Deprivation
Summary

Rural deprivation introduction

- This needs assessment considers the meaning of rurality and deprivation from geographical, public health and sociological perspectives in order to support the current trend towards greater collaboration between health and social services.
- Suffolk is a relatively wealthy county, with areas of deprivation in some town centres and rural areas.
- The rural population is older than that in urban areas. This difference will increase because of the natural movement of the younger population towards urban centres for education and job opportunities.
- The needs assessment cannot cover all issues of rurality, deprivation, and all aspects of health, health determinants and health services. So the focus has been on the areas in which greatest achievement might be made in improving the health of the population.

Rural deprivation key points

- Suffolk is a largely rural county with small towns but many more remote areas.
- Suffolk is relatively wealthy but has some areas of deprivation in town centres.
- There are pockets of deprivation in rural areas; these may be less apparent owing to the average scores on which deprivation indices are based.
- Many indicators show that health is better in rural areas. Major conditions such as coronary heart disease, cancer and stroke all have lower incidences.
- In contrast, death rates from suicide and undetermined injury are higher, which may also indicate a poorer level of mental health.
- Service provision is more expensive to provide owing to delivery charges, costs to staff attending in remote areas and time taken in travelling.
- Many older people may be “asset rich, cash poor”. The purchase of food and fuel may be a problem.
- Staff and patients (travelling to work or to attend a clinical appointment), may find the time taken and the cost incurred much higher than in urban areas, owing to distances to travel, poor public transport and the cost of running a car.
- Domiciliary services such as social care may be more difficult to obtain owing to the distance to travel.
All these factors suggest that choice is reduced and costs may be higher both to the service provider and to the service user. Many services in rural areas such as postal services, doctors’ surgeries, public houses, libraries, village shops and dentists are gradually reducing in number. Services in rural areas will be increasingly difficult to provide owing to the ageing population, and younger people moving into urban areas for cheaper accommodation nearer to their place of work. This reduces the availability of the extended family to provide help when it is needed. Rural roads may be more dangerous than urban ones, and the rate of road traffic accidents and fatalities is much higher in the country. There is a strong network of voluntary services, but their use to supplement statutory services has been questioned.

Rural deprivation recommendations

1. Suffolk County Council should review the findings of the “Hidden Needs” report (Fenton 2011). Discussions should be held with the commissioners of that report and decisions taken on where targeted support will be made to prevent increasing isolation of rural communities.

2. Mental health services should provide more targeted and specific support to ameliorate rural isolation, amongst the indigenous population as well as migrant labour.

3. A survey should be carried out of people without cars who live in rural areas on how they access GP, dental, optician and hospital appointments. When appointments are offered to people living in rural areas, patient’s travel arrangements should be taken into account.

4. The studies available for this needs assessment have included a review of the voluntary sector and its input, some information on health services, and some information on health need, but these different analytical perspectives need to be brought together in order to reveal and allow analysis of the gaps. This is the joint responsibility of the CCGs and SCC Public Health.

5. SCC in conjunction with the district and borough councils should identify the most deprived rural wards and make firm plans on improving the life chances of the residents in those areas.

6. In taking decisions on budget allocation, SCC should consider the high value of the voluntary sector in reducing rural social isolation and support the sector to
What is rural deprivation and why is it important for Suffolk?

Introduction

The 2011 Census described 82.4% of the population of England as being urban and 17.6% of the population living in rural areas. Urban areas are defined as settlements of more than 10,000 people (DEFRA Rural Statistics 2015).

“Rural” is defined in a distribution developed by the Office for National Statistics (ONS) which assigned units at Output Area level to one of six types on the basis of their predominant settlement component (ONS 2013):

**Urban**
- Major conurbation
- Lesser conurbation
- City and town

**Rural**
- Town and fringe
- Village
- Dispersed (hamlets and isolated dwellings).

This classification has been applied to many indicators.

Nationally, the percentage of working age people in employment in 2013 was 71% in urban settlements and 76% in rural settlements. The rate is based on where people live and not where they work. People living in rural settlements may travel to work in larger urban settlements and vice versa for urban residents.

In 2013, the unemployment rate overall in rural settlements was 4.6%. Nationally there was an increase in unemployment between 2007 and 2011, when it started to decrease and in 2013 the rate for all England was 7.4%. The unemployment rate has tended to be highest in urban settlement types and lower in rural village and hamlets and rural sparse settings.

“Working age” is now defined as 16 to 64 years for males and females.

Deprivation is often found in small pockets within a geographic area which is described by a single measure (for example the Index of Multiple Deprivation). This may be misleading. It is
possible that in rural areas wealthier people may be either commuting for well-paid city employment, or may have retired or even moved to the rural areas to enjoy retirement. Other people living in the vicinity may be in a quite different income bracket but even measurements at lower super output area level will not account for those differences (Shucksmith 2003). Caution is needed against assumptions as the employment indicators are based on where individuals live rather than where they work, so those who do commute to well-paid city jobs will have their income recorded against the rural economy.

Many people do not now travel for work, or only do so for part of the time. DEFRA (2015) found that the highest rate of home workers was found in rural hamlets and dispersed areas, at 33%, compared with 12% in urban areas. Overall rural areas had a higher rate of home working compared with urban areas. According to the Office for National Statistics, home workers were more likely to be working in higher skilled roles and earn on average a higher hourly wage (ONS 2013).

The rural population is older than in urban areas and this effect is likely to increase as younger people find accommodation unaffordable and move away, leaving an increasing proportion of ageing population. More than 50% of those living in rural areas are aged above 45 years, compared with 40% in urban areas, and overall there are proportionately fewer younger people in sparse areas.

**Deprivation in rural areas**

There is much evidence of the difficulties of rural living particularly in an ageing population. Studies have identified families and older people whose situation is “asset rich, cash poor”, owning large houses but on a limited income (SCC 2014) (Shucksmith, 2003).

Other factors influencing the cost and satisfaction of rural living included

- having to travel to access goods and services with additional petrol costs or fares
- having less choice and competition which can result in the higher cost of goods and services
- a higher proportion of income spent on essential services
- inadequate technological infrastructure, and
- having proportionally more older people (particularly pensioners living on the state pension) than in urban areas (Richards, 2011)
A comprehensive discussion is given in Shucksmith (2003). Different concepts are outlined as an approach to studying social exclusion:

- poverty, an outcome, denoting an inability to share in the everyday lifestyles of the majority because of a lack of disposable income
- deprivation, lack of certain essentials such as food, housing, mobility or services
- disadvantage, essentially similar but considers all aspects of a person’s life and not only income or expenditure
- social exclusion, the breakdown of the systems in society that should guarantee the social integration of the individual or household.

Poverty is considered to be primarily *distributional*, but social exclusion focuses on *relational* issues. The term “rural deprivation” coined in the 1970s, was a counter to the threat of loss of funding in favour of urban authorities, leading to several attempts to measure and quantify rural deprivation.

Attempts to construct indices of deprivation which can be applied usefully to both rural and urban areas have been fraught with difficulty, and this has not yet been resolved.

**Rural deprivation and health**

The health of people in rural areas is on average better than that of urban areas (Defra 2014). Hypertension, all-cause premature mortality, total hospital stays and admissions due to coronary heart disease as outcome measures were strongly associated with older age and lower social class but there was no consistent pattern of better or poorer health in people living in rural areas compared with cities (Teckle et al 2012).

Infant mortality is lower in rural areas than in England as a whole. Life expectancy is highest in predominantly rural areas. Potential years of life lost from common causes of death such as cancers, coronary heart disease and stroke were lower in rural areas. This means that fewer people living in rural areas are dying prematurely of these diseases than those living in urban areas. This was not true of suicide and undetermined injuries which were higher in the rural than urban areas.

However the finding is corroborated by Teckle et al (2012) who found no consistent pattern of better or poorer health in people living in rural areas was found, compared to primary
cities when examining the association between rurality and health in Scotland.

These reports also recognise the “masking of deprivation” and ill-health and the diverse experience of rural communities, just as much as in urban communities. This raises the question of a different approach to measuring deprivation and need that is not dependent even on lower super output area geographies (Shucksmith, 2003). OCSI (2015)\textsuperscript{21} analysed the volume and pattern of the ‘rural share’ of deprivation, helping understand whether targeted area-based programmes or broader thematic interventions might be more appropriate. These would be more closely targeted on individuals rather than a wide population poverty prevention strategy.

This is an important public health issue for Suffolk, which, as shown in the next section, is a largely rural area. Rural deprivation may be experienced in households but not reflected in statistical analyses, demonstrated in national work by Shucksmith, (2003) and also specifically related to Suffolk by Fenton et al (2011) who noted that “hidden” deprived households in a mixed economy area are likely to be particularly vulnerable when resources are allocated to areas with the highest average levels of need.

This is important to public health analysis as “hidden” deprived households are likely to be vulnerable and may become further marginalised. Defra (2015) noted that the percentage of people living with relative and absolute low income\textsuperscript{22} is lower in rural areas than in urban areas, but nevertheless many thousands of individuals living in rural areas are in households below average income. There is a close relationship between lower income and poor health, thus rural deprivation is a public health priority.

\textsuperscript{21} OCSI’s programme of work on rural exclusion is helping local, regional and national partners make the case for increased regeneration funding to rural areas, and enabling mainstream services in rural areas to more effectively target services.

\textsuperscript{22} with an income below a percentage (60% in this case) of median income (the income earned by the household in the middle of the distribution in a given year) and absolute low income (below a threshold of median income, in this case 60% of median income) in a specific year adjusted for inflation, before or after housing costs.
What is the local picture?

Urban Rural Classification by age
The 2011 Census described 82.4% of the population of England as being urban and 17.6% of the population living in rural areas.

Table 1 shows the distribution of urban and rural population for Suffolk, the percentage rural population being significantly greater than that of England, based on mid-2012 population data. The proportion of the population in the older age groups is greater in the rural than the urban areas.

Table 1: Suffolk population, urban and rural, by age group 2011

<table>
<thead>
<tr>
<th>Total population</th>
<th>Urban 458,900 (62.7% of Suffolk) with age structure</th>
<th>Rural 273,500 (37.3% of Suffolk) with age structure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age groups:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-15</td>
<td>84,300 (18.4%)</td>
<td>49,100 (18.0%)</td>
</tr>
<tr>
<td>16-29</td>
<td>76,600 (16.7%)</td>
<td>40,200 (14.7%)</td>
</tr>
<tr>
<td>30-44</td>
<td>86,500 (18.9%)</td>
<td>47,400 (17.3%)</td>
</tr>
<tr>
<td>45-64</td>
<td>119,300 (26.0%)</td>
<td>75,900 (27.8%)</td>
</tr>
<tr>
<td>65 &amp; over</td>
<td>92,200 (20.1%)</td>
<td>60,800 (22.2%)</td>
</tr>
</tbody>
</table>

Source: Suffolk Diversity Profile 2012

This needs assessment is concerned with the population living in the rural areas of Suffolk. This excludes the towns of Lowestoft, Beccles, Bury St Edmunds, Woodbridge, Felixstowe, Ipswich, Greater Sudbury, Stowmarket, Haverhill, Newmarket and Mildenhall.

Figure 1 shows the rural urban distribution for Suffolk according to the ONS classification can be seen in Figure 1. Figure 2 shows the population density across the County. The main urban areas in Suffolk include the county town of Ipswich and the large towns of Bury St. Edmunds and Lowestoft. Elsewhere in Suffolk, population is located in smaller market towns and villages and in more isolated settlements in the countryside and along the coastline.
Figure 1: 2011 Census Output Areas: Rural Urban Classification for Suffolk

Urban and Rural Areas of Suffolk

As defined by the updated classification developed by DEFFA using Lower Super Output Areas

- Sparse—Town and Fringe
- Sparse—Village, Hamlet & Isolated Dwellings
- Less Sparse—Urban with Population > 10k
- Less Sparse—Town and Fringe
- Less Sparse—Village, Hamlet & Isolated Dwellings

Dark boundaries denote Middle Super Output Areas
Light boundaries denote Lower Super Output Areas

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Source: Diversity of Suffolk: Ethnicity and Nationality. Suffolk: Suffolk County Council. (SCC 2014a)
Figure 3 shows that, relative to England as a whole, Suffolk has only pockets of deprivation. A total of 10.6% (45/436) LSOAs in Suffolk fell into most deprived quartiles of LSOAs in England. These LSOAs were located mainly in the large towns: Ipswich, Lowestoft, Bury St. Edmunds, Haverhill, Sudbury, Newmarket, Felixstowe, Beccles, and in some parts of the rural area, mainly in eastern Suffolk.
Routine population datasets do not allow differentiation between rural and urban areas. We know that the rural population is proportionately older than the overall population of Suffolk, and older people are at risk of both economic and social deprivation (particularly in rural areas), especially if they live alone. Over 40% of people aged 75 and over live alone, and in most parts of Suffolk, at least one person in ten of retirement age is living in poverty and the rural population is fragmented throughout the County. The proportion of very elderly people in the population is expected to rise, presenting a challenge to both public and third-sector service providers (Fenton 2011).

Suffolk Action with Communities in Rural England (Suffolk ACRE) and Suffolk County Council commissioned Oxford Consultants for Social Inclusion (OCSI) to further develop the evidence base on rural deprivation across the County (Fenton et al 2011). This showed that 42% of the whole population of Suffolk live in rural areas, and that nearly the same proportion of some deprived groups live in rural areas. This was based on the 2001 census;
since then more towns have grown beyond the 10,000 size so they have been ‘moved’ from
the rural into the urban category.

The Suffolk countryside contains almost an even share of people with long-term illness, adults with no qualifications and low-income pensioners. OCSI’s research enabled deprivation to be examined at the smaller Output Area (OA) scale rather than the much larger Local Super Output Areas (LSOA). It identified 11 rural Suffolk OAs within the 10% most deprived OAs in the whole region. The number of people living in deprivation in the OAs constituted only 16% so the large majority of people living in situations of rural deprivation live in parts of the countryside where most of their neighbours were not in similar circumstances. Such close apparent economic inequality can have a particularly adverse effect on the health of those in deprived circumstances and indeed can decrease the overall level of health status in the area (Wilkinson and Pickett 2009).

In addition to reviewing need, community service provision was documented in the Suffolk Rural Services Review (Gibson 2012) undertaken by Suffolk ACRE. Every town and parish council in the County was invited to take part, with the exception of eight towns, which were excluded from the Rural Survey, as the population exceeded 10,000. The purpose of the survey was to establish the level of service provision available in rural parishes and towns in Suffolk.

Geographically, Suffolk contains a number of small towns which are situated significant distances away from the three main hubs of Ipswich, Bury St Edmunds and Lowestoft. Although services provide out-reach to smaller towns, issues such as limited transport links, slower broadband speeds alongside funding cuts to organisations that serve these towns, act as a barrier to equity of service provision.

A multi-agency conference was held in Leiston in June 2015 to focus on issues faced by residents and the services supporting them. The conference was well attended with a number of important issues discussed. The conference not only provided an opportunity for links to be made between agencies to facilitate an improved level of joint working, but allowed focused discussion about important issues for the town. Actions that resulted from the event include: seeking funding for a youth worker and summer activities for young people, additional support from the substance misuse treatment service and the
development of a directory of services. Additionally there was support for a Leiston Needs Assessment to be developed.

A further conference is organised to take place in November 2015 to track the progress of the recommendations and to give those who attended the event in June, an opportunity to update on developments.

What is the evidence base for interventions? What is best practice?

Access

Much of the literature analyses the difficulties of, rather than the solutions to provision of and access to health and social care in rural areas.

- There is considerable variability in service provision to people in rural areas but overall they are less likely to receive services comparable with their urban counterparts.
- Rural services cost more to deliver than those in urban areas and a higher burden in the time and cost of access falls upon rural service users.
- The needs of some rural dwellers, especially those from minority ethnic groups, are often neglected.
- Efforts to ensure equity in terms of the standards and levels of service provision through policy initiatives such as ‘rural standards’ and ‘rural proofing’, have had mixed success so far (Pugh et al 2007).

Others (Longley et al 2014) have reviewed service design to account for rurality:

- Ensuring that those elements of the patient pathway which can be delivered locally are so delivered
- Organising clinics and other services to recognise the difficulties of transport;
- Giving the patient a choice when deciding on the location of their specialised care
- Providing patients and their families with up-to-date and detailed information on issues such as public transport, suitable overnight accommodation for visitors
- Much greater use of telehealth.

Mental health is an issue which is perceived to be more difficult to manage in the rural setting. (Pugh et al 2007). Stigmatisation and isolation are widely reported. Whereas in some situations rural life may be perceived to be a more solitary existence than urban life,
daily life in small communities may be more socially exposed, leading to greater difficulties in dealing with personal issues such as mental health problems, or domestic violence. The lack of anonymity may lead to a culture of silence, making people unwilling to talk about or admit to personal problems.

A similar situation of stigmatisation and isolation in women wishing to escape domestic violence was also identified.

Pugh (2007) recognised that;

- people in rural areas are generally not well served by health and social services,
- the idealisation of country living may deny the presence of poverty, drug misuse, domestic violence and racism.

He noted that between different social groups, the overall picture is of under-provision compared to urban areas. Older people in rural areas were likely to be receiving lower levels of supportive services such as domiciliary care and meals on wheels than those living in urban areas, and the general take-up rates for welfare benefits seemed to be lower than in urban areas.

**Rural service provision**

A number of studies have identified parity of health status between the rural and urban communities. Hypertension, all-cause premature mortality, total hospital stays and admissions due to coronary heart disease as outcome measures were strongly associated with older age and lower social class but there was no consistent pattern of better or poorer health in people living in rural areas compared with cities (Teckle et al 2012). There is agreement that where there is a rural deficit, it lies in service provision and access rather than in health status.

Others have reviewed service design for better rural delivery:

- Ensuring that those elements of the patient pathway which can be delivered locally are so delivered
- Organising clinics and other services to recognise the difficulties of transport
- Giving the patient a choice when deciding on the location of their specialised care
- Providing patients and their families with up-to-date and detailed information on
issues such as public transport, suitable overnight accommodation for visitors

- Much greater use of telehealth (Longley et al 2014).

Dissatisfaction was recorded on the social care “15-minute slot model of service” which was particularly ill-suited to rural provision with its comparatively high transport and time costs (Glendinning et al 2006). The increasing interest in person-centred and outcomes-focused approaches offered more individually tailored and appropriate models of service, but it was too early to show purported benefits for rural dwellers.

- An idea pioneered in some areas has been to organise home care service providers into geographically zoned areas thus reducing user choice but enhancing access and reliability of service.

In a study seeking ways of improving access to hospital care, Gruen et al (2003) found that simple 'shifted outpatients' styles of specialist outreach to local facilities were shown to improve access, but there was no evidence of their impact on health outcomes. Outreach as part of more complex multifaceted interventions involving primary care collaborations, education and other services was associated with improved health outcomes, more efficient and guideline-consistent care, and less use of inpatient services.

**Costs and funding**

Equitable health resource allocation is considered as health and social services departments are required to work in partnership and to attain national quality standards. A case for a rural premium can be made on the basis of precedent as England is the only country in the UK that does not make a major adjustment for rurality in its NHS formula (Asthana et al 2003). A study by Yang et al (2014) reviewed whole system costs of falls in people over the age of 65 years found that on average, the cost of hospital, community and social care services for each person admitted for a fall were almost four times as much in the 12 months after admission, than the cost of the admission itself. The most dramatic increase was in community health care costs (160 per cent), compared to a 37 per cent increase in social care costs and a 35 per cent increase in acute hospital care costs.

- This finding is a recommendation for a planned care pathway to better-integrated responses to frail elderly patient’s needs.
Transport and access

Transport was a major problem. Poor transport networks meant that service users and carers living in rural areas who did not have a private car would have less opportunity access to services. Those with a private car would spend a much higher proportion of their income on transport. Even where public transport was available, the timings and frequency of service could militate against it use.

This problem has been characterised as “distance decay”, the phenomenon of service take-up diminishing, or being delayed, the further away that potential users live from the point of service.

This was corroborated in the Suffolk research by Suffolk ACRE (2012). People were asked whether they could reach their GP or their dentist by public transport, and comments received showed that in many cases it would be difficult if not impossible.

Ethnic minorities

A study of rural child care in Suffolk found that ethnic minorities were less likely to use child care services, partly because of the costs, but also because of their perception that these were aimed at a white clientele (ACRE 2002).

Another East of England study (Gilpin et al, 2006) showed the growing numbers of migrant workers from the newer member states of the European Union, 83% of them being between 18 and 34 years of age, and without dependants, for whom there was also some evidence that they were not making use of health services.

It was also possible that their low wages and often precarious housing situations made them more vulnerable to homelessness, problems of isolation and unhealthy behaviours.

Volunteering

There has been a turning to voluntarism and self-help in recent years. A voluntary medical transport scheme reviewed in the Midlands (Sherwood, Lewis 2000) found it played an important role in the welfare of rural residents, particularly elderly women and was effective but raised questions about the viability of the scheme and also about increasing calls on the voluntary sector as a means of delivering health care to rural people.
In 2011 Suffolk had 3,100 registered charities, many focused on the rural areas. One we heard about was the coffee caravan, equipped with coffee, tea and homemade cakes, with information about organisations and the services available to members of the public. Volunteering both for those providing services, and those for whom the service exists is an important intervention in health promotion by reducing isolation and giving a sense of self-worth.

**What is the pattern of services in Suffolk at present?**

Suffolk Rural Services Review 2012 gives a detailed picture of what services and community resources exist in rural communities across Suffolk. Four hundred and thirteen Parish and Town Councils (up to 10,000 population) were contacted and provided 345 responses, an 84% response rate. A number of the questions relating to health facilities giving widespread information on these.

The Executive Summary indicates (among many other indicators) that 30% of parishes offer IT and computing skills classes, 67% have no youth organisations and 63% have no banking facilities. In 69% of parishes there is no post office and 94% have no railway station. A broadband quality rating of average, poor or still unavailable was submitted by 83%, and 68% had no general store, 18% had no scheduled bus service, 78% did have a pub but 80% had no doctor’s surgery.

These results were compared with a previous study four years earlier and found that almost all services were less available that they had been. The sense of the study was that rural areas are increasingly isolated, in essential services supporting health, in communications, and transport, but also in structures supporting social life leading to the potential for increased isolation and loneliness.

Services directly relevant to healthcare are given in the tables below:
Table 2: Suffolk ACRE Survey, GP Surgery by Parish, 2012

<table>
<thead>
<tr>
<th>Doctor's surgery in parish</th>
<th>% response</th>
<th>No. parishes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Responding parishes which do not have a doctors’ surgery within them</td>
<td>80%</td>
<td>276</td>
</tr>
<tr>
<td>Responding parishes which do not have a permanent doctors’ surgery within them</td>
<td>14%</td>
<td>50</td>
</tr>
<tr>
<td>Responding parishes which do not have a visiting doctors’ surgery within them</td>
<td>2%</td>
<td>6</td>
</tr>
<tr>
<td>Respondents who chose not to answer</td>
<td>4%</td>
<td>13</td>
</tr>
</tbody>
</table>

Source: Suffolk ACRE Ltd

Table 3: Suffolk ACRE Survey, Dentist available by Parish, 2012

<table>
<thead>
<tr>
<th>Dental surgery in responding parish</th>
<th>% response</th>
<th>No. parishes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Responding parishes which do not have a dental surgery within them</td>
<td>90%</td>
<td>313</td>
</tr>
<tr>
<td>Responding parishes which have a private dental surgery within them</td>
<td>3%</td>
<td>12</td>
</tr>
<tr>
<td>Responding parishes which have an NHS dental surgery within them</td>
<td>1%</td>
<td>3</td>
</tr>
<tr>
<td>Responding parishes which have both an NHS and private dental surgery within them</td>
<td>3%</td>
<td>11</td>
</tr>
<tr>
<td>Respondents who chose not to Respond to this question)</td>
<td>2%</td>
<td>7</td>
</tr>
</tbody>
</table>

Source: Suffolk ACRE Ltd

For 117 (34%) patients the distance to travel to the dentist was more than five miles.
Table 4: Suffolk ACRE Survey, Other health service visiting or permanent by Parish, 2012

<table>
<thead>
<tr>
<th>Type of Health service</th>
<th>% with service visiting or permanent in the parish</th>
<th>No. Respondents with service visiting or permanent in the parish</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pharmacy</td>
<td>14%</td>
<td>49</td>
</tr>
<tr>
<td>Prescription collection point</td>
<td>19%</td>
<td>64</td>
</tr>
<tr>
<td>Chiropody</td>
<td>11%</td>
<td>39</td>
</tr>
<tr>
<td>Chiropractor</td>
<td>5%</td>
<td>17</td>
</tr>
<tr>
<td>Alternative therapies</td>
<td>7%</td>
<td>25</td>
</tr>
<tr>
<td>Other</td>
<td>6%</td>
<td>19</td>
</tr>
</tbody>
</table>

Source Suffolk ACRE Ltd

Suffolk has two district general hospitals, at Ipswich and at Bury St Edmunds. There are also smaller community hospitals with a limited range of services, and also small community outpatient" services. The population to the north of the County also access James Paget Hospital in Norfolk.

Transport and access are very important. Studies have shown that the further a patient is from services, the less likely he or she is to attend for treatment, even where the condition is serious. The ambulance service has targets for reaching patients, but these are averaged across the County, so some patients may have to wait longer than the average time, and targets may still be reached.

It is also known that road traffic accidents are much higher on country than urban roads, In 2012, the Department for Transport reported that most fatalities (almost 60 per cent) occur on rural roads, with 38 per cent occurring on rural A roads and a further 21 per cent on other rural roads. This is considerably higher than the 42 per cent of traffic which is found on these roads (DfT 2013).
Figure: 4 Map of Suffolk, main hospitals, community hospitals and outpatient services, each with a 10 mile radius.

Source: Hospitals by NHS Choices
*WHFHT Community OS West Suffolk NHS Foundation Trust Community Outpatient Service

At 10 miles the journey by car should take about 20 minutes. However more detailed work would be needed to analyse travel times by public transport. The 2001 census found that 55,000 households in Suffolk had no car, and that over a quarter of all households were in rural parts of Suffolk.

What additional information is needed?

- Coverage of the County by secondary and tertiary care services, and information on private and public transport to those services for accessibility, for opportunity for older people to visit family members, and for follow up visits.
- Availability of screening to remote communities.
- A very important aspect of rural life is transport, accessibility, and road traffic accidents in remote areas and this should be considered in any future work.
A review of the fast changing developments in telemedicine in the rural situation should be incorporated into any next stages.

An audit of how people visit the GP, dentist, optician, or pharmacy if there is no car.

What healthcare is in place for Eastern Europeans working long hours and living in rural areas close to their employment? Are employers placed under any duty of care for their employees?

What can be concluded?

- Suffolk is a largely rural County with small towns but many remote areas.
- Suffolk is relatively wealthy but has some areas of deprivation in town centres.
- There are pockets of deprivation in rural areas; these may be less apparent owing to the average scores on deprivation indices are based.
- Many indicators show that health is better in rural areas. Major conditions such as coronary heart disease, cancer and stroke all have lower incidences.
- In contrast, death rates from suicide and undetermined injury are higher, which may also indicate a poorer level of mental health.
- Service provision is more expensive to provide owing to delivery charges, costs to staff attending in remote areas, and time taken in travelling.
- Many older people may be “asset rich, cash poor”. The purchase of food and fuel may be a problem.
- Staff and patients (travelling to work or to attend a clinical appointment), may find the time taken and the cost incurred much higher than in urban areas, owing to distances to travel, poor public transport, and the cost of running a private car.
- Domiciliary services such as social care may be more difficult to obtain owing to the distance to travel.
- All these factors suggest that choice is reduced, and cost may be higher both to the service provider and to the service user.
- Many services in rural areas such as postal services, doctor’s surgeries, public houses, libraries, village shops and dentists are gradually reducing in number.
- Services in rural areas will be increasingly difficult to provide owing to the ageing population, and younger people moving into urban areas for cheaper accommodation nearer to their place of work. This reduces the availability of the extended family to provide help when it is needed.
Rural roads may be more dangerous that urban ones, and the rate of road traffic accidents and fatalities is much higher in the country.

There is a strong network of voluntary services, but their use to supplement statutory services has been questioned.
www.ncbi.nlm.nih.gov/pubmed/11027959  Last accessed 14/06/15


Suffolk ACRE Suffolk Rural Services Review 2012


Chapter 8
Transgender Community
Summary

Transgender introduction

- Gender dysphoria is the discomfort or distress arising when a person’s gender identity – their psychological sense of themselves as male or female – does not match the sex to which they were assigned at birth. People with gender dysphoria are sometimes referred to as trans-people, trans-gendered people or members of the trans-community.

- Trans is a term for people whose gender identity and/or gender expression diverges in some way from the sex they were assigned at birth. A trans-man is a person who was assigned female at birth but has a male gender identity and a trans-woman is a person who was assigned male at birth but has a female gender identity. Both trans-men and trans-women propose to transition, are in transition or have transitioned to live as the gender of their choice.

- A person’s gender identity is entirely distinct from their sexual orientation, for example whether they are bisexual or heterosexual. People with gender dysphoria are often attracted to people of the opposite gender to their own identity, but this is not always the case.

- Gender reassignment is the medical intervention to adjust the appearance so that it aligns with the gender identity. It is often associated with changes to the gender role and expression, as well as names and pronouns. These changes may alleviate much or all of the discomfort arising from the gender dysphoria.

Transgender key points

- The prevalence of gender dysphoria and those going through gender reassignment are uncertain. Estimates for Suffolk vary between eight and thirty trans-females and between two and twelve trans-males, to as many as seven hundred people. The evidence is weak and those presenting to services are likely to be lower than the true number due to historical stigma and prejudice.

- Gender dysphoria is characterised by mental distress. This is exacerbated by the impact of other people’s reactions to trans-gender people, the stress associated with managing the condition and the disruption of personal relationships to which it often gives rise.
• Trans-people have a high incidence of anxiety and depression. They are more likely to self-harm, and attempted and completed suicide is more common.

• Consumption of tobacco, alcohol and illicit drugs is higher among trans-people.

• We found only limited evidence about the effectiveness of treatment for gender dysphoria. Research to support the use of hormonal treatments and gender reassignment surgery is of low reliability. More research of a higher quality is required as lack of evidence does not mean lack of effectiveness.

• General practitioners refer trans patients for further assessment and treatment, and provide and monitor treatment thereafter. Suffolk GPs reportedly vary in their awareness of gender dysphoria and how to treat it. We were told that some will not prescribe hormones or arrange blood tests, and some are reluctant even to refer patients for specialist assessment.

• Secondary care services assess patients before referral to a gender identity clinic. Previously in Suffolk, a designated consultant psychiatrist with an interest in gender dysphoria saw patients referred by GPs and made onward referrals, but this arrangement has lapsed. Instead, referred patients are seen by a clinician from a community mental health team without specialist knowledge or expertise in the condition. We heard reports that some patients and parents of children with gender dysphoria did not feel that the mental health professionals who saw them had the appropriate knowledge and attitudes.

• Local services also treat mental health problems other than gender dysphoria. These problems are common, but we heard that services were hard for people with gender dysphoria to access.

• Tertiary services provide gender identity clinics, where people with gender dysphoria can receive more specialised assessment, hormonal treatment and gender reassignment surgery.

• The Suffolk Lesbian, Gay, Bisexual and Trans Network provides support to local trans-adults via the Gender Xplored network.

• Patients and parents of transgender children told us that healthcare professionals seemed reluctant to accept the validity of their gender dysphoria. They “struggled to be believed” as they described their transgender issues and repeatedly had to convince apparently sceptical clinicians that they were genuinely affected by the diagnosis.

• Specifically, service users mentioned the lack of a dedicated professional to assess patients locally for referral to a gender identity clinic. Allocating this task to a generic
mental health worker reduced the appropriateness and quality of the service that they experienced, and possibly the quality of onward referrals.

- Patients fear that revealing any signs of anxiety, depression or other psychological disturbance risks causing delay in the progress of treatment. They would prefer to use local mental health services for these issues, but find them hard to access.
- More than most other diagnoses, gender dysphoria has a severe impact on family members. We heard that no local support services were available for family members of people with gender dysphoria.
- Long waiting times for assessment cause considerable concern for trans people and their families. This can create particular problems for children who do not receive hormone blockers in a timely way.
- There is likely to be a growing demand for services that support children with gender dysphoria as the social stigma of being transgender diminishes.

Transgender recommendations

6. More awareness raising and specific training are required in primary care. The previous training was limited to only a fraction of Suffolk practices. There is a need to improve knowledge and attitudes about how to treat trans-people in primary care, and also about referral and support of those who seek treatment.

7. Providers of mental health services in Suffolk should designate a consultant psychiatrist or clinical psychologist to see patients referred with symptoms of gender dysphoria. This will improve the quality of the service.

8. These services should also provide better access to people being seen at a gender identity clinic who need support with other psychological problems such as anxiety and depression, or just emotional support in dealing with the difficulties of gender transition.

9. The specialist services need, at the least, to explain to patients and parents why the correctness of their diagnosis and their commitment to treatment require such frequent testing.

10. Support for trans-people and their families’ needs to be increased. The Gender Xplored support group should continue, but with more involvement by the County Council to ensure its long-term viability and effectiveness. At present it attracts only a small fraction of the Suffolk trans-community. More active marketing and publicity and wider availability of meetings might increase the use and impact of the group.
What are gender dysphoria and gender reassignment? Why is it important for Suffolk?
The nomenclature used in this field varies, but we define here the approach that we will use in this report.

Gender dysphoria is the discomfort or distress arising when a person’s gender identity – their psychological sense of themselves as male or female – does not match the sex to which they were assigned at birth. People with gender dysphoria are sometimes referred to as trans-people, trans-gendered people or members of the trans-community.

A person’s gender identity is entirely distinct from their sexual orientation, for example whether they are bisexual or heterosexual. People with gender dysphoria are often attracted to people of the opposite gender to their own identity, but this is not always the case.

Those people with intense feelings of gender dysphoria want to live and be accepted as a member of a sex other than that assigned at birth. This usually involves changes to social role and presentation. These trans-people aim to make their appearance as congruent as possible with their self-identified gender, typically through dress but also hormonal and surgical treatment; this is known as transitioning. Although most trans-people are clear as to their gender identity, others have a gender identity which is neither male nor female.

Trans-sexualism used to be a term that was regularly used by medical staff and is a recognised disorder in the International Classification of Diseases. However there is challenge about the condition being a mental illness and the trans-community reject the description, trans-sexualism and the mental health label. Trans-sexualism is a term frequently seen in medical literature and will only be referred to when quoting specific information from research papers. It is not a term which should be used when speaking to trans-people or their families as it may cause offence.

Gender dysphoria can cause anxiety, depression and other serious mental health problems. These arise more from the social reception of the condition rather than from the condition itself.

Discrimination against lesbian, gay and bisexual people in Britain has become much less common in recent years, supported by changes in legislation and public attitudes. There has
been less progress in ensuring that trans-people do not suffer unfairly as a result of their sexual and gender identity, and their needs now deserve more active attention.

The health needs of trans-gender people are important because:

- the condition can give rise to substantial distress and mental illness
- meeting these health needs requires primary care and specialist services
- there are indications that current services are not fully satisfactory.

People who intend to transition, are doing so or have already done so are protected from discrimination by the Equality Act 2010. The Act also protects those associated with them, such as family members, as well as others who are perceived to have characteristics protected by the Act. The Gender Recognition Act 2004 allows adults to acquire a gender recognition certificate that records a change of gender and makes it legally effective.

**What is the local picture?**

There are important difficulties in estimating the prevalence of gender dysphoria:

- The conditions are not precisely defined and the terms may be used differently by different people.
- The conditions are stigmatising, so affected people may not be visible to researchers or to wider society.
- The prevalence may vary between areas and over time. There are indications that it is rising.

A research review of ten prevalence studies in eight countries found rates for trans-females (trans-sexuals assigned to the male sex at birth) ranging from 2.2 to 8.4 per 100,000, and for trans-males (trans-sexuals assigned to the female sex at birth) from 0.5 to 3.3 per 100,000 (De Cuypere, 2006). These figures show a wide range of possible prevalences and must be treated with some caution, but suggest there may be between eight and thirty trans-females and between two and twelve trans-males in Suffolk.

Another analysis suggests much higher figures (Olyslager 2007). This paper was presented at a scientific meeting but never published in a peer-reviewed journal. The authors adjusted previous prevalence estimates to produce new figures, concluding that the true prevalence of trans-sexualism was between 50 and 100 per 100,000. On this basis, there may be between 370 and 735 people with gender dysphoria in Suffolk.
The Amsterdam Gender Dysphoria Clinic has collected data on the Dutch trans-sexual population for more than forty years. The Clinic’s estimate of the prevalence is at 1 in 10,000 assigned males and 1:30,000 assigned females (van Kesteren 1997). This suggests about thirty-five trans-females and about twelve trans-males in the County.

The disparities between these figures indicate the difficulty of reaching reliable estimates of the prevalence of gender dysphoria. This makes it hard to plan services, with two important implications:

- We cannot readily gauge the extent of unmet health need among trans-gender people in Suffolk. There are certain to be a number of trans-gender people who are at present isolated and not in receipt of services, but who might benefit from them if they were available or easier to access.
- If the range and availability of services improved, some of these under-served residents are likely to come forward seeking treatment and care. However, we know too little about the numbers of these people and their needs to reach exact conclusions about the volume of services needed.

What are the health problems for trans-gender people?

Mental health

As noted above, whether trans-sexualism is a disorder is controversial. However, gender dysphoria is undoubtedly associated with mental distress. This is exacerbated by the impact of other people’s reactions to trans-gender people, the stress associated with managing the condition and the disruption of personal relationships to which it often gives rise.

Research from the United States illustrates the nature and extent of discrimination against trans-people (Grant 2011). A survey of 6450 trans-people reported that

- 57% had experienced family rejection
- 53% had been verbally harassed or disrespected in a public place such as a hotel, restaurant or bus
- 40% had been harassed when presenting identification
- 26% had lost a job because of being transgender
- 19% had been refused a home or apartment because of being transgender
- Respondents were four times more likely to live on an annual income of less than $10,000 than the average American
• Respondents were twice as likely to be unemployed than the average American.

Figure 1 illustrates how gender dysphoria can lead to a series of socially mediated disadvantages which concatenate to undermine mental health. Trans-people can have anxiety, depression and other serious mental health problems. These arise more from the social reception of the condition than from the condition itself.

Figure 1: The relationship between gender dysphoria and mental health

Source: PHAST

For these reasons, trans-gender people have a high incidence of mental illness. A survey of trans-people recruited 889 respondents (McNeil 2012). It found that 88% of respondents reported previous or current depression, 80% reported stress and 75% reported anxiety. Fifty-three per cent of respondents had self-harmed at some point, with 11% currently self-harming. Self-harm reduced following transition for the majority of those who had a history of self-harm. Sixty-three per cent felt that they harmed themselves more before they transitioned, with only 3% harming themselves more after transition. Nearly 60% of the participants felt that there were reasons they self-harmed which related to them being trans, while 70% felt there were non-trans related reasons for their self-injury. The reasons for self-harm which directly related to being trans included:

- Gender dysphoria
- Social and economic disadvantage
- Stigma
- Discrimination
- Disrupted personal relationships
- Reduced emotional resilience
- Anxiety and depression
• Gender dysphoria
• Delays in getting gender reassignment treatment
• Stumbling blocks in treatment, and negative attitudes
• Not being able to access treatment or being denied treatment
• Not being taken seriously by medical professionals
• Treatment complications
• Struggling with coming to terms with identity or suppressing gender issues
• Not understanding identity or unwilling to admit to difference
• Not being accepted or experiencing negativity from others
• Not having identity or gender recognised.

The study reported that 24% of trans-people had used drugs within the previous year, the most common being cannabis, poppers and ecstasy. A separate study in Northern Ireland reported that ten per cent of trans-people had signs of severe drug abuse using the Drug Abuse Screening Test (Rooney 2012).

Suicide
Trans-people are more likely to attempt suicide than members of the general population. Suicide attempt rates between 19% and 25% have been reported in transgender people seeking surgical gender reassignment (Dixen et al 1984). More recent data from surveys of transgender people have reported that up to a third of respondents have made at least one suicide attempt (Clements-Nolle 2001, Clements-Nolle 2006, Grossman 2008, Kenagy 2005, Whittle 2007, Xavier 2007). Suicide attempts appear to occur more frequently among transgender adolescents and young adults than among older age groups (Xavier 2007). These studies report that suicide attempts are associated with higher rates of depression, anxiety and substance abuse (Clements-Nolle 2001, Xavier 2007). Transgender young people have reported parental rejection to be a particular source of stress (Grossman 2008). Reported rates of suicide attempts are much higher in trans-people. One reported that 41% of trans-people had attempted suicide at some point in their lives, compared with only 1.6% of the general population (Braveman 2006).

Eighty-four per cent of respondents to the McNeil survey had thought about ending their lives at some point, including 63% in the last year, and 27% in the last week (McNeil 2012). The prevalence of suicide attempts among those who had thought about ending their lives at
some point was 48%. Thirty-five per cent of respondents had attempted suicide at least once and 25% more than once. Suicidal thoughts and attempts reduced post-transition.

Physical health

We found no UK evidence about the physical health of trans-gender people. However, there is evidence from the United States which is likely to be relevant to British trans-people (Grant 2011). The 6450 respondents to the survey reported over four times the national average of HIV infection. Rates were particularly high in trans-women, the unemployed and those who have been sex workers.

We found no specific information about the use of tobacco, alcohol and illicit drugs among British trans-people. Members of the lesbian, gay and bisexual communities are reported to smoke and drink alcohol more heavily than the general population (Lee 2009, King 2003, King 2008). However, it is not clear whether these findings are applicable to trans-people. In the United States, 35% of the respondents misused drugs or alcohol specifically to cope with the mistreatment they faced due to their gender identity or expression. The prevalence of smoking in American trans-people was 50% higher than in the general population (Grant 2011).

What is the evidence base for interventions? What is best practice?

We found only limited evidence about the effectiveness of treatment for gender dysphoria. A systematic review from 1998 found one controlled study comprising 40 participants, and 11 non-controlled studies comprising 519 participants (Best 1998). The controlled study reported that, after two years, trans-people who had undergone gender reassignment surgery were significantly more active in visits to family and friends, eating out, sport in company and sexual interest. They had significantly reduced scores on the psychoneurotic index, which measures free-floating anxiety, phobic anxiety, obsessionality, somatic anxiety, depression and hysteria, although the clinical significance of this result was not reported. Positive outcomes in the non-controlled studies were reported in cosmetic appearance, sexual functioning, self-esteem, body image, socio-economic adjustment, family life, social relationships, psychological status and satisfaction. However, little could be reliably concluded from these studies because they all had serious methodological limitations.

Postoperative complications include haemorrhage, urethral stenosis, urinary incontinence, rectal fistula, vaginal stenosis and erectile tissue around the urethral meatus. The incidence of these events varied between the studies and there were high rates of loss to follow-up.
New problems may emerge following reassignment surgery, such as painful loss of jobs, families, partners, children and friends. Some people are forced to move away from their familiar environment and, despite being confident in their gender role, may have difficulty with social adaption and acceptance by others. The extent of these problems has not been recorded in the published studies.

These findings were corroborated by a systematic review from 2002 (Day 2002). This review concluded that there is not enough evidence to support the efficacy of gender reassignment surgery for specific subgroups of persons selected for surgical intervention. Subgroups of trans-sexual people who will most likely benefit from surgery could not be identified from the evidence reviewed. The quality of the evidence was poor: there was only a small number of studies, and they had unreliable study designs and important methodological limitations. The authors concluded that gender reassignment surgery may benefit some carefully assessed and selected trans-people who have satisfied recognised diagnostic and eligibility criteria, and have received recognised standards of care for surgery. More research is required to improve the evidence base identifying the subgroups of trans-people most likely to benefit from gender reassignment surgery.

A more recent review of hormonal therapy and sex reassignment also reached cautious conclusions (Hassan Murad 2010). Twenty-eight studies were included in the review, with 1833 participants. It was unclear whether three or four studies included a control group; the other studies did not. None of the studies were randomised. The overall quality of the evidence was very low. Following gender reassignment, most participants reported statistically significant improvements in gender dysphoria, psychological symptoms, quality of life and sexual function.

What is the pattern of services in Suffolk at present?

Primary care

General practitioners (GPs) have two roles with respect to patients with gender dysphoria:

- **Referring patients:** The GP will consider whether there are any co-existing conditions, mental or physical health issues, or risk and vulnerability factors which need to be taken into account. In Suffolk, GPs refer people with gender dysphoria to a local mental health professional, who in turn refers them to a gender identity clinic.
This may be valuable in diagnosing the condition more thoroughly and assessing whether there are other mental health issues. It is not specifically recommended or deemed necessary in national guidance.

- **Providing and monitoring treatment:** After assessment at the gender identity clinic, the GP is responsible for the initiation and ongoing prescribing of endocrine therapy and organising blood and other diagnostic tests as recommended by the specialist gender identity clinician. In the longer term, the GP is responsible for the life-long maintenance of their patients’ wellbeing. The GP is also responsible for making appropriate changes to patient record systems to reflect the patient’s desired future gender role and to ensure that such changes facilitate screening.

Suffolk GPs reportedly vary in their awareness of gender dysphoria and how to treat it. We were told that some will not prescribe hormones or arrange blood tests, and some are reluctant even to refer patients for specialist assessment.

In 2013, a group of clinicians with a specialist interest in gender dysphoria prepared a guide to gender dysphoria services for primary care staff (Anon 2013). Their key recommendations were to:

- Refer early and swiftly to a reputable gender service
- Support the treatment recommended by the gender service
- Get pronouns right; if in doubt, ask discreetly
- Be particularly mindful of medical confidentiality
- Avoid misattributing commonplace health problems to gender.

The authors point out that “Of all the things that could offend a trans-person or lead them to feel misunderstood, excluded and distrustful, mistakes involving forms of gender-related speech are perhaps the most upsetting. Potentially they are also easiest to pay attention to getting right.”

**Screening**

The screening services offered to a trans-person who has had gender reassignment surgery depend on the risk of disease, which is related to the new anatomy and any additional risk from hormonal treatment. This should be agreed after surgical treatment is complete and GPs should ensure that correct arrangements are then put in place. They must ensure that patients’ gender histories are not disclosed to third parties.
Secondary services

Secondary care services have two functions with respect to people with gender dysphoria:

- Assessment before referral to a gender identity clinic
  
  The *UK Intercollegiate Good Practice Guidelines for the Assessment and Treatment of Adults with Gender Dysphoria* were published in 2013 (Royal College of Psychiatrists 2013). The document describes in detail how people with gender dysphoria should be managed by specialist services. It notes that “Gender dysphoria may be confirmed in different ways, for instance by engaging in a period of therapy with a counsellor, psychotherapist, psychologist or a psychiatrist. This can take place in either primary or secondary care settings.”

  Previously in Suffolk, a designated specialist psychiatric nurse with an interest in gender dysphoria saw patients referred by GPs and made onward referrals, but since his retirement and subsequent service changes, this arrangement has lapsed. Instead, referred patients are seen by a clinician from a community mental health team without specialist knowledge or expertise in the condition. We heard reports that some patients and parents of children with gender dysphoria did not feel that the mental health professionals who saw them had the appropriate knowledge and attitudes.

- Treatment of mental health problems other than gender dysphoria
  
  People with gender dysphoria may experience concurrent mental health problems, either coincidentally or as a result of the underlying condition; these include anxiety, depression and self-harm. Gender identity clinics are highly specialised and generally do not provide treatment for these diagnoses. It is therefore for local mental health services to do this, though we heard that they were hard for people with gender dysphoria to access, partly because of the overlap with the more specialised condition.

  NHS England says “Some, but not all, patients may require formal psychiatric intervention to assist with psychiatric comorbidities and in such cases shared care may be appropriate” (NHS England 2013). The document notes that “If significant medical or mental health concerns are present, they must be reasonably well-controlled”. Some people seeking gender reassignment believe that revealing
psychological distress, anxiety or depression will cause delay or prevent them having hormone treatment or surgery, and therefore do not disclose this to staff at the gender identity clinic. They would therefore be assisted by better access to local mainstream mental health services for mental health problems not requiring specialised skills.

**Tertiary services**

Tertiary gender identity services are commissioned by NHS England, based on an interim gender dysphoria protocol and service guideline 2013/14 (NHS England 2013). Figure 2 is illustrates the model of care that NHS England commissions.
Adult patients from Suffolk are referred to the gender identity clinic at the Charing Cross Hospital in West London. Patients under 18 are referred to the Tavistock and Portman Clinic, London for assessment and then to University College London Hospital for possible hormone blocking treatment. The hormone blockers are used to stop the onset of puberty or
diminish its progress, giving time; for further assessment and reflection before a decision is made about gender alignment.

NHS England requires the clinics from which it commissions gender identity services to:

- have an effective multi-disciplinary team that meets regularly, either in person or through electronic communication
- deliver patient care that is based upon individual care plans that are agreed and reviewed by the provider’s multi-disciplinary team
- offer the complete range of multi-disciplinary services described in the commissioning document
- meet team member training and quality standards that will be determined from time to time by NHS England.

Tertiary treatment in a gender identity clinic includes:

- hormonal treatment to render the patient’s appearance more congruent with their intended gender
- a period of living in the gender role that is congruent with the individual’s gender identity, referred to as real-life experience, before the provision of genital reassignment surgery. It typically lasts one to two years. At the beginning of this, the clinic and the patient should discuss the practicalities and requirements of the experience and patient and family support, as well as the possible treatments available. The period can be extended. Patients who elect not to have surgery can continue on hormone therapy.
- Gender reassignment surgeries to provide sexual anatomy as close as possible to that of the intended gender. For a trans-man this may include bilateral mastectomy with male chest reconstruction, phalloplasty (creation of phallus), metoidioplasty (creation of micropenis), urethroplasty (creation of urethra), scrotoplasty (creation of scrotum) and placement of testicular prosthesis, implantation of penile prosthesis, vaginectomy (removal of vagina), salpingo-oophrectomy (removal of ovaries and fallopian tubes) and hysterectomy. Trans-women may have a penectomy (removal of penis), orchidectomy (removal of testes), vaginoplasty (construction of neovagina), labioplasty (construction of labia) and clitoroplasty (creation of clitoris).
Hospital activity analysis

We analysed hospital episode data about Suffolk residents admitted to hospital with a main diagnosis of trans-sexualism (an historical medical term still used by many practitioners) or gender identity disorder.

In the thirty-five months\(^{23}\) to February 2015, eleven Suffolk residents were admitted to hospital at least once with one of these diagnoses. There were six admissions in 2012/13, eight in 2013/14 and five or fewer\(^{24}\) in the first eleven months of 2014/15. Sixty-one per cent of the admissions were to Cambridge University Hospitals NHS Foundation Trust, and the rest were to one of Imperial College Healthcare, University College London Hospitals, St George’s Healthcare, Norfolk and Suffolk or Papworth Hospital NHS Foundation Trusts. Imperial College Healthcare is the organisation responsible for gender-identity and gender-reassignment services at the Charing Cross Hospital in London. The small numbers mean that no more detailed analysis can be published, to protect confidentiality, including what treatment was provided during the admission.

Awareness raising and professional education

In June 2014, a workshop was held with for thirty people from three groups of Suffolk GPs. The aim was to gather information about the GPs’ information needs in providing care to trans-gender people and improve their understanding of gender dysphoria and the transition process. It focussed on trans-people who wanted gender reassignment surgery and the GP as gatekeeper in this process. It emphasised a holistic approach to treating and supporting a person living with gender dysphoria and that the GP was best placed to co-ordinate the diverse aspects of care needed, as well as influencing the development of a safe and supportive culture across the practice.

Support groups

The Suffolk Lesbian, Gay, Bisexual and Trans Network (www.suffolklgbtnetwork.org.uk) is a registered charity and support organisation that aims to promote equality and diversity in Suffolk, and combat sexual orientation and gender identity discrimination and prejudice. The network provides help, support, advice and events, and hosts equality and diversity training.

\(^{23}\) Data for March 2015 was not yet available. Data for 2014/15 is provisional.
\(^{24}\) To protect patient confidentiality, values of five or less are not published.
for businesses and organisations. It receives funding from Suffolk County Council for specific projects.

The network includes four groups that meet monthly, respectively for gay and bisexual men, for lesbian and bisexual women, for 18 to 30 year olds and for trans-people. The group for adult trans-people is called Gender Xplored; five to ten people attend its monthly meetings. We heard concerns that the Network needed strengthening organisationally and financially in order to be fully effective. Specifically, there is no funding for a facilitator for Gender Xplored.

What problems are reported by trans-people and parents in Suffolk?

- Patients and parents of trans-children told us that healthcare professionals seemed reluctant to accept the validity of their gender dysphoria. They “struggled to be believed” as they described their trans-gender and repeatedly had to convince apparently sceptical clinicians that they were genuinely affected by the diagnosis. They felt that professionals were holding out the diagnosis as a prize to be earned. Few other NHS patients face this, and it made the distress of the condition all the more painful.

- Specifically, service users mentioned the lack of a dedicated professional to assess patients locally for referral to a gender identity clinic. Allocating this task to a generic mental health worker reduced the appropriateness and quality of the service that they experienced.

- There are often delays between referral and assessment – we heard that these may be as long as eighteen months. There are further delays before gender reassignment is offered. These delays stand between patients and their goal of having a body congruent with the gender with which they identify, and also exacerbates the dysphoria that they experience. These delays can be of particular concern to trans-children and their parents as a delay in receiving hormone blocker treatment can make gender dysphoria more distressing for children than it could be due to body changes brought on by puberty.

- Older children being treated by gender dysphoria services can find poor transition arrangements between child and adult services increases the length of time it takes for them to get the right support.

- Patients fear that revealing any signs of anxiety, depression or other psychological disturbance risks causing delay in the progress of treatment, as it might be seen as evidence that they were not adjusting well to living openly as a member of the gender
to which they are transitioning. They would prefer to use local mental health services for these issues, on grounds of convenience and separation from the gender identity clinic, but find them hard to access.

- Travelling to London to attend the gender identity clinic is not easy for some patients. In addition to the costs of travel, often in the peak period, some people find it difficult to be on a crowded train, especially trans-women who may have facial hair growth in preparation for electrolysis.
- More than most other diagnoses, gender dysphoria has a severe impact on family members. They may feel that a change of gender is such a large step that it constitutes the loss of the relative that they loved. We heard that no local support services were available for family members of people with gender dysphoria.

**What additional information is needed?**

- The epidemiology of gender dysphoria is not well understood. We need to know more about who has the condition.
- Research into the effectiveness of treatments for gender dysphoria is of low reliability. We need more evaluations of the clinical and cost effectiveness of hormonal treatment and gender reassignment surgery.
- We found no investigations of patient satisfaction with gender identity services. This group of patients may be disempowered by the consequences of their gender dysphoria and are dependent on the decision of their clinicians for access to the treatments they are seeking. This makes it harder for them to influence their care and more importantly to find ways to promote this in a way that protects their anonymity.

**What can be concluded?**

1. Primary care services are not always responsive to people with gender dysphoria. When they first present, they are sometimes not given appropriate support and referral, and there are problems with primary care staff using the correct name, gender and title.
2. There is no single point of referral locally for people seeking access to tertiary services such as gender dysphoria clinics in London. There used to be a consultant psychiatrist who saw and assessed patients and made onward referrals, but now GPs refer to generic professionals without specialist knowledge or interest. This is a less satisfactory approach because it does not provide concentrated expertise in a single clinician who has an interest in gender dysphoria.
3. There is little local support for trans-people. They see a need for local peer support and also for access to local mental health services for the anxiety, depression and other common mental health problems that follow from their position. These are apparently difficult to access.

4. Trans people and their parents often experience specialist services as sceptical. They feel that they need to repeatedly "prove" that they have the diagnosis in a way no other type of NHS patient does. It is necessary to ensure that the diagnosis is correct, but the rationale for repeatedly testing the patient's dysphoria and commitment to change is not clear, at least to the patients themselves.

5. The financial and personal cost of travelling to London is burdensome for some people.

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NHS Choices patient information about gender dysphoria http://www.nhs.uk/Conditions/Gender-dysphoria/Pages/Treatment.aspx
Chapter 9
Sickle Cell Community
Summary

Sickle Cell disease introduction

- Sickle cell disease is the commonest genetic disorder in the UK. People affected cannot make enough normal haemoglobin (the protein that carries oxygen in the red blood cells), instead, an abnormal haemoglobin is produced, which changes its structure when oxygen levels are low.
- Sickle cell disease occurs when a person inherits two abnormal copies of the haemoglobin gene, one from each parent. A person with a single abnormal gene does not experience symptoms and is said to be a carrier with sickle-cell trait. The disease is more common in people descended from inhabitants of sub-Saharan Africa, Asia, the Middle East and the Eastern Mediterranean.

Sickle Cell disease key points

- Sickle cell disease is a serious and potentially life-threatening health problem.
- There are only limited means of preventing sickle cell disease. However, mothers are tested routinely during antenatal care for their sickle status. Infants are also screened for the condition.
- There is no widely available cure for sickle cell disease. However, there are several treatments which relieve symptoms and prevent or treat complications.
- There are fifteen people with sickle cell disease known to the NHS in Suffolk. There may be up to twelve further people with the diagnosis not known to the NHS.
- Sickle cell disease is stigmatised within some ethnic communities. One example is recent Portuguese migrants to Suffolk, who are affected by sickle cell disease but have only limited contact with services.
- There has been an apparent lack of awareness of the diagnosis in the local NHS.
- There are clear standards for NHS sickle cell services in England.
- Local screening services perform well.
- We found little information about primary care services.
- Hospital services for people with sickle cell disease are improving in Suffolk. However, there are apparent weaknesses in the clinical service for patients presenting to the emergency department.
• The numbers of children and adults in Suffolk admitted to hospital with sickle cell disease has been falling for the past three years.

**Sickle Cell recommendations**

1. Awareness of sickle cell disease in ethnic communities and in primary care needs improvement:

2. Suffolk’s clinical commissioning groups should address the issues in primary care, by leading and educating primary care staff to consider the diagnosis more often and perform the appropriate investigations.

3. The County Council should continue to support and foster the Thalassaemia and Sickle Cell Support Group. The Group should concentrate at first on promoting awareness of the disease, countering stigma and overcoming the apparent under-diagnosis of sickle cell disease.

4. Hospitals in Suffolk should continue their present efforts to improve sickle cell services. This should include consideration of a single tertiary hospital as a service partner, a clearer clinical pathway, better staff training and awareness, and clinical audit, including use of the National Haemoglobinopathy Register. They should signpost people to the Thalassaemia and Sickle Cell Support Group. The hospitals’ specialist clinicians should play a more active part in promoting awareness and understanding in the local community.

5. As the number of patients increases, it will become more appropriate for tertiary services to be provided locally, with specialist teams traveling to district hospitals rather than vice versa. This is more convenient for patients and families, and less expensive.

**What is sickle cell disease and why is it important for Suffolk?**

Sickle cell disease is the most common serious genetic disorder in the United Kingdom. It is an important serious and potentially life-threatening health problem, affecting an estimated 13,500 people, with an estimated 240,000 carriers (NHS Sickle Cell and Thalassaemia Screening Programme, 2015). People affected cannot make enough normal haemoglobin, the protein that carries oxygen in the red blood cells. Instead, an abnormal haemoglobin is produced, which changes its structure when oxygen levels are low. As a result, the red blood cells become distorted into a crescentic or sickle shape, are less malleable and have shorter life-spans (Figure 1).
Sickle cell disease occurs when a person inherits two abnormal copies of the haemoglobin gene, one from each parent. A person with a single abnormal gene almost never experiences symptoms and is said to be a carrier with sickle-cell trait. Carriers of sickle cell disease have some resistance to malaria. For this reason, the disease is found in people descended from inhabitants of areas where malaria is common, such as sub-Saharan Africa. Sickle cell disease is however by no means confined to the Black population. It also occurs in people with Asian, Middle Eastern and Mediterranean ancestry. For example, in 2013/14, the condition was diagnosed in fifteen Asian infants and five White British infants (NHS Screening Programmes, 2014).

There are about 13,500 affected people in the United Kingdom. Sixty per cent of people in England with sickle cell disease live in London, and most of the others live in large conurbations, especially in Birmingham. In low-prevalence areas such as Suffolk, the needs of people with sickle cell disease may be inadvertently neglected because they are more easily overlooked.

Thalassaemia is a separate inherited disorder of haemoglobin structure which falls outside the scope of this needs assessment. Rarely, people are affected by both thalassaemia and sickle cell disease.
Figure 1: Blood flow in people with normal red cells and with sickle cell disease

A Normal red blood cells

- Normal red blood cell (RBC)
- RBCs flow freely within blood vessel

B Abnormal, sickled, red blood cells (sickle cells)

- Sickle cells blocking blood flow
- Sticky sickle cells

Cross-section of RBC
- Normal hemoglobin

Cross-section of sickle cell
- Abnormal hemoglobin form strands that cause sickle shape
Complications

- Anaemia is caused by the red cells' short lifespan.
- Sickle-cell crises are sudden deteriorations in the health of a person with sickle cell disease. They occur when the blood supply to an organ is suddenly reduced by sickling. Crises are painful and often lead to organ damage.
- Severe bacterial infections arise because the disease leads to loss of spleen tissue and this reduces the body’s ability to clear bacteria from the bloodstream.
- Stroke is more common in people with sickle cell disease. Narrowing and blockage of blood vessels can prevent oxygen from reaching the brain. Cerebral haemorrhage can also occur. Strokes in people with sickle cell disease can occur at any age, are commoner in children and can be disabling or even fatal.
- Gallstones may result from the excessive rates of breakdown of sickled red blood cells.
- Avascular necrosis of the hip and other major joints may occur as a result of an inadequate blood supply.
- Priapism (prolonged and painful erections) occurs because of sickling of cells in the penis.

Prevention

There are only limited means of preventing sickle cell disease. Mothers are tested routinely during antenatal care for their sickle status. When a woman tests positive, the father is also tested. Couples at high risk of an affected baby are then offered pre-natal diagnosis. This provides early information to the parents, who may then choose to terminate the pregnancy. Couples can also be offered pre-implantation genetic diagnosis. Infants are screened for the condition so that appropriate treatment can be started promptly, and carriers identified.

Treatment

There is no widely available cure for sickle cell disease. However, there are several treatments which relieve symptoms and prevent or treat complications. The goals of treating sickle cell disease are to relieve pain, to prevent infections, organ damage, and strokes, and to control complications if they occur.
Infants who have been diagnosed with sickle cell disease through screening are treated with antibiotics to prevent infections, and are immunised against infection. Their parents are educated about the disease and how to manage it.

Many people with sickle cell disease take hydroxyurea, a drug which leads to the production of another type of haemoglobin. This helps prevent red blood cells from sickling and improves anaemia. People taking hydroxyurea therefore need fewer blood transfusions and have fewer hospital visits.

Blood transfusions are used to treat worsening anaemia and other sickle cell complications. They may also have a role in preventing complications such as stroke, spleen problems or acute chest syndrome. However, having routine blood transfusions can cause side effects, such as allergic reactions and an overload of iron in the body.

Adults who have sickle cell anaemia should be immunised against influenza every year, and also against pneumonia.

Sickle cell crises are treated with oxygen, blood transfusions, antibiotics, pain relief and rehydration.

**What is the local picture?**

**Results of screening**

Data on NHS screening services for sickle cell disease are published for each region (NHS Screening Programmes, 2014). Suffolk is part of the East of England region. In 2013/14, 81,303 blood samples from expectant women were processed in the region. There were 1120 (1.4%) positive tests, indicating that the woman was a carrier. Sixty-five high-risk couples were identified, in which both parents were sickle cell carriers. These results were similar to other parts of England with a comparable ethnic composition but lower than in London, where 5.2% of antenatal blood samples tested positive for sickle cell disease.

We obtained screening coverage results for Suffolk. Table 1 shows the proportion of pregnant women eligible for antenatal sickle and thalassaemia screening for whom a conclusive screening result is available. It shows good results, with improvement over the time period analysed.
Table 1: Antenatal sickle cell and thalassaemia screening coverage, by Trust, 2012 to 2015

<table>
<thead>
<tr>
<th></th>
<th>2012/13 (%)</th>
<th>2013/14 (%)</th>
<th>2014/15 (%)</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Q1</td>
<td>Q2</td>
<td>Q3</td>
</tr>
<tr>
<td>Ipswich</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>During this period, Ipswich Hospital did not collect data.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>West Suffolk</td>
<td>97.7</td>
<td>98.7</td>
<td>98.1</td>
</tr>
</tbody>
</table>

** = There is a discrepancy recognised between the numerator and denominator, leading to a result exceeding 100%. The most likely explanation is that the initial sample cannot be analysed for technical reasons and a repeat sample is provided. This inflates the numerator but not the denominator.

Source: Public Health England

Table 2 shows the proportion of babies registered at birth, eligible for newborn blood spot screening and with a conclusive result recorded. It also shows high coverage, improving over time.

Table 2: Neonatal sickle cell and thalassaemia screening coverage, Suffolk PCT 2012 to 2014 and by Trust 2014 and 2015

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td></td>
<td>Q1</td>
<td>Q2</td>
<td>Q3</td>
</tr>
<tr>
<td>Suffolk PCT</td>
<td>96.6</td>
<td>97.3</td>
<td>96.4</td>
</tr>
<tr>
<td>Ipswich</td>
<td>98.1</td>
<td>98.5</td>
<td>98.4</td>
</tr>
<tr>
<td>West Suffolk</td>
<td>96.0</td>
<td>97.0</td>
<td>99.0</td>
</tr>
</tbody>
</table>

Source: Public Health England

Figures are not published on the results of screening for sub-regional populations. According to the 2011 Census, there were 117,400 people registered as Black in the East of England, of whom 6900 live in Suffolk (Office of National Statistics, 2014). Let us assume that the proportion of the Black population who have sickle cell trait, become pregnant and use antenatal services is equal across the region. If we then use Black ethnicity as an indicator
of the overall population prevalence of sickle cell disease, we can expect about 65\textsuperscript{25} Suffolk women to have a positive result each year, and four\textsuperscript{26} high-risk couples to be identified. This is a crude approach, because the risk of sickle cell disease is not equal in all categories of Black people, nor is the disease confined to people of this ethnic group.

**Prevalence of sickle cell carriers and sickle cell disease**

The prevalence of sickle cell disease varies widely, depending on the proportion of people from specific ethnic groups and the prevalence in each of those groups.

There is no reliable means of obtaining accurate figures on the prevalence of sickle cell disease in Suffolk:

- We cannot rely on the numbers of people known to the NHS. Since the introduction of universal screening between September 2003 and July 2006, children born in the UK will almost certainly be diagnosed in infancy and can be enumerated. However, people born in the UK before then or born overseas may not have been diagnosed, or may not be in contact with services.
- We cannot readily apply information on the prevalence of sickle cell disease in specific ethnic groups to generate an overall prevalence estimate. Data on the ethnic composition of the County’s population and on the prevalence of sickle cell disease in specific ethnic groups are not sufficiently precise to enable us to calculate this reliably.

One approach is to base an estimate on the number of infants with the condition born in Suffolk and/or treated there. This number is the product of the ethnic composition of the population and the risk in each ethnic group, and so circumvents the problems with the approaches described above. However, it is still not straightforward to extrapolate from this to the number of people living in Suffolk with sickle cell disease. The total depends on the numbers of affected people born in, entering and leaving the County, and the longevity of people with sickle cell disease.

In 2014/15, two infants born in Suffolk screened positive for sickle cell disease. Both were born at the Ipswich Hospital. Importantly, of the fifteen people known to the hospital service in Suffolk with sickle cell disease, nine are under the age of sixteen years and at least two of

\textsuperscript{25} \frac{6854}{117442} \times 1120 = 65.4.

\textsuperscript{26} \frac{6854}{117442} \times 65 = 3.79.
the others are young adults who were diagnosed and treated as children. People with sickle cell disease often now live to around fifty years of age (NHS Choices, 2015).

The skewing of the age profile of diagnosed people towards a younger age suggests that there are adults with the condition as yet undiagnosed. Nine people with the diagnosis aged less than 16 years suggests perhaps another eighteen people above that age, of which only six are known to the NHS. However, this estimate should be treated with caution:

- Another explanation for the skewed distribution is that adults with sickle cell disease choose to live in higher prevalence areas, for cultural reasons or because health services are perceived to be of higher quality there.
- Some haematologists believe that it is unlikely that there are many people with untreated sickle cell disease. They argue that the disease is usually too symptomatic for this to be plausible. However, they suggest that there may be patients who attend hospital as emergencies for the treatment of sickle cell crises but are not seen regularly as outpatients.
- However, the local support group say that they are aware of twelve to fifteen adults in Suffolk who are not in contact with services.

Local support groups

There is a new support group for people in Suffolk with haemoglobinopathies, which received a grant from the County Council. Thalassemia Sickle Cell Support Suffolk first met in September 2014 with five members.

Members of the support group made these observations:

- Sickle cell disease is stigmatised within some ethnic communities. It is sometimes termed “bad blood”. Affected people and their families may ignore or suppress the existence of the diagnosis – even to the extent of denying it to a doctor – and not seek care because of fear of other people’s reactions.
- There are recent Portuguese migrants to Suffolk who are affected by sickle cell disease but are not seeking treatment.
- There has been an apparent lack of awareness of the diagnosis in the local NHS, particularly in primary care and the emergency department at Ipswich Hospital. Some people have received inappropriate care as a result.
In April 2015, members attended a meeting with executive directors of the Ipswich Hospital NHS Trust. The Trust agreed to add stickers to the notes of people with sickle cell disease to ensure that staff were aware of the diagnosis, to design a care pathway for the condition and to implement training to improve staff awareness, especially in the emergency department.

**What is the evidence base for interventions? What is best practice?**

**Services for children**

*Sickle cell disease in childhood: standards and guidelines for clinical care* was published by the NHS in 2010 (NHS Screening Programmes, 2010). It sets out how specialist haemoglobinopathy teams should provide hospital services for sickle cell disease at:

- hospitals in urban areas with a large local population of children with sickle cell disease
- large district general or teaching hospitals in low prevalence areas with few local patients, but where geography dictates that they will need to provide most services for sickle cell patients. These hospitals act as a centre of expertise for patients in the surrounding areas.

The document sets standards for what should be available from a specialist haemoglobinopathy team. No hospitals in Suffolk fall into these categories.

All other district hospitals, such as those in Suffolk, should provide a local haemoglobinopathy service. This should:

- Have a named paediatrician to link to the specialist haemoglobinopathy team and neonatal screening laboratory
- Arrange initial contact with family and provide a paediatric clinic for routine outpatient management
- Promote and support management at home by parent, GP and community sickle cell and thalassaemia centre (if available)
- Manage acute pain and acute anaemia, and provide initial care for other complications before transfer to the specialist haemoglobinopathy team according to shared guidelines and protocols
- Liaise with the specialist haemoglobinopathy team for annual review
- Follow up children who fail to attend, reporting to specialist haemoglobinopathy team on annual activity as part of a network review meeting
• Liaise with local authorities, e.g. education\textsuperscript{27} and social services
• Manage transition to the adult service
• Provide accurate, comprehensive and timely data to the NHS Sickle Cell and Thalassaemia Screening Programme to enable outcomes of newborn screening to be evaluated
• Complete and update entries into National Haemoglobinopathy Registry when consent has been given.

The document makes these recommendations about the organisation of care for children with sickle cell disease:

• There should be a network of care based on local community care, including GPs, the local sickle cell and thalassaemia centre, health visitors, school nurses, the local hospital and specialised centre with links to paediatric intensive care where relevant. Parents should be put in touch with local and national voluntary organisations and local sickle cell and thalassaemia centres. There should be a named paediatrician responsible for follow-up in the local hospital.
• There should be a named paediatrician and/or paediatric haematologist in the specialist haemoglobinopathy team.
• General practitioners and community nurses should be regularly informed about patients’ progress.
• Parents should be encouraged to acquire knowledge about their child’s condition and should be informed about initiatives such as the Expert Patient Programme.
• There should be community paediatric services to coordinate the community needs of the child and to liaise with child and adolescent mental health services, local authority services and the voluntary sector as needed.
• Local authority services including education and social services should be aware of the specific needs of children with sickle cell disease and their families.
• Child and adolescent mental health services should be aware of the specific emotional and learning needs of children with sickle cell disease and their families.

These recommendations were based on clinical consensus in “the absence of directly applicable studies of good quality.” The document also makes specific recommendations about clinical practice.

\textsuperscript{27} A Guide to School Policy on sickle cell disease is available at www.sicklecellanaemia.org/OER/article.php?id=36
Services for adults

*Standards for the Clinical Care of Adults with Sickle Cell Disease in the UK* was published by the Sickle Cell Society in 2008 (Sickle Cell Society, 2008). However, it appears to have official status, being published on the website of the NHS Sickle Cell and Thalassaemia Screening Programme and endorsed by the then Prime Minister and the Department of Health’s then Head of Blood Policy. The document identifies the following areas as most critical:

- acute pain
- acute complications
- detecting and managing chronic complications
- networks for care
- education and training
- adequate resources

The document then sets out standards for the care of adults with sickle cell disease under the following headings:

- organisation of care and commissioning sickle cell disease service
- managing acute complications
- managing chronic complications
- pregnancy, contraception and fertility
- blood transfusion
- surgery and specific therapies

These approaches are the basis for NHS England’s service specification for specialised services for haemoglobinopathy care.

The Royal College of Nursing (Royal College of Nursing, 2011) and the National Institute for Health and Care Excellence (National Institute for Health and Care Excellence, 2012) have published guidance on sickle cell disease.

**What is the pattern of services in Suffolk at present?**

Services for people with sickle cell disease are commissioned as follows:
Prevention

NHS screening services for sickle cell disease are commissioned by NHS England and described above.

Coverage of antenatal sickle cell screening and of newborn bloodspot screening form part of the public health outcomes framework, but neither data item is included in the most recent report on Suffolk, which covers 2013/14 (Public Health England, 2015). However, results at regional level are available (NHS Screening Programmes, 2014):

- Coverage at regional level is excellent, with 97.8% of eligible women tested.
- Fifty-eight per cent of samples are tested by ten weeks' gestation. This is similar to other regions and above the acceptable threshold of 50%, but well below the screening programme's achievable level of 75%.
- The proportion of eligible babies tested is 97.6%. This is similar to other regions and above the acceptable threshold of 95%, but below the achievable target of 100%.
- Two per cent of tests are avoidable repeats. This is low in comparison to other regions, on the acceptable threshold but above the achievable target of 0.5%.
- Results are available in timely fashion, with 99.7% communicated within six weeks, above the achievable target of 98% and one of the best results in England.

Primary care

This is also commissioned by NHS England, though some clinical commissioning groups are taking more responsibility for primary care services.

Primary care services include the provision of day-to-day support to people with sickle-cell disease, routine prescribing and the management of other health problems.

No data are available on the performance of primary care services for people with sickle cell disease. However, there are anecdotal reports that many general practitioners and other primary care staff lack experience in recognising and responding appropriately to the condition. While this is explained by the low prevalence of the condition in Suffolk, it has implications for the quality of care. For example, some of the Suffolk residents with undiagnosed sickle cell disease may present to primary care with symptoms attributable to the condition but without the diagnosis being considered. This may be more likely in people not obviously of Afro-Caribbean heritage. Greater awareness of the condition, and specifically of its occurrence in the non-Black population, would be valuable.
Secondary care

Services at district hospitals in Suffolk are commissioned by local clinical commissioning groups. They include emergency services and other care agreed with the specialist team on a shared care basis. Some patients may however make their way to their tertiary centre when they need emergency treatment.

In Suffolk, nine children and six adults are known to have sickle cell disease. Some of the children were born in Suffolk and diagnosed by neonatal screening, some were born and diagnosed elsewhere in the UK and moved to Suffolk and some were born and diagnosed overseas.

Children and adults can be seen at the Ipswich, West Suffolk and James Paget Hospitals with a shared care arrangement with either Addenbrooke’s Hospital in Cambridge or London hospitals including Central Middlesex Hospital in Acton, North Middlesex Hospital in Enfield and Kings College hospital. From July 2015, children treated in Ipswich will attend a specific haemoglobinopathy clinic at least twice a year.

No clinical audit information is available on the performance of these services.

Tertiary care

Specialist haemoglobinopathy services are commissioned by NHS England. The most important element of this is a multidisciplinary annual review. This may however be delegated or shared with a local hospital. There is a detailed service specification which describes how this service should operate (NHS England, 2013).

There are specialist haemoglobinopathy teams at Addenbrooke’s Hospital in Cambridge and at several hospitals in London.

Hospital activity analysis

We analysed hospital episode data about Suffolk residents admitted to hospital with main diagnosis of sickle cell disease.

Table 3 shows the number of Suffolk residents admitted to hospital at least once with a diagnosis of sickle cell disease. It shows a steep fall in admissions over the three years. This
may indicate a declining prevalence of sickle cell disease, improving care with fewer complications giving rise to admission, or a higher threshold for admission. The first of these explanations seems unlikely. Eighty percent of these admissions are for sickle cell crises.

Table 3: Patients admitted to hospital at least once with a diagnosis of sickle cell disease, Suffolk, 2012-13 to 2014-15, by age at admission

<table>
<thead>
<tr>
<th>Year</th>
<th>Unique patients admitted to hospital per year</th>
<th>Aged under 18 years</th>
<th>Aged 18 years or over</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012-13</td>
<td>62</td>
<td>20</td>
<td>42</td>
</tr>
<tr>
<td>2013-14</td>
<td>37</td>
<td>8</td>
<td>29</td>
</tr>
<tr>
<td>2014-15</td>
<td>30</td>
<td>*</td>
<td>*</td>
</tr>
<tr>
<td>Total</td>
<td>129</td>
<td>*</td>
<td>*</td>
</tr>
</tbody>
</table>

Source: Hospital activity analysis

* Due to small numbers, these values have been suppressed.

2014/15 data are provisional and only include April 2014 to February 2015 inclusive.

This is corroborated by the data on admission numbers (Table 4). The fall in admissions affected children only and was continuous over all three years. For children, about two-thirds of the admissions were to Ipswich Hospital, with nearly all the rest being to Addenbrooke’s Hospital in Cambridge. For adults, about half are to each hospital.

Table 4: Admissions to hospital with a diagnosis of sickle cell disease, Suffolk, 2012-13 to 2014-15, by age at admission

<table>
<thead>
<tr>
<th>Year</th>
<th>Admissions per year</th>
<th>Aged under 18 years</th>
<th>Aged 18 years or over</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010/11</td>
<td>140</td>
<td>66</td>
<td>74</td>
</tr>
<tr>
<td>2011/12</td>
<td>123</td>
<td>50</td>
<td>73</td>
</tr>
<tr>
<td>2012/13</td>
<td>104</td>
<td>29</td>
<td>75</td>
</tr>
<tr>
<td>Total</td>
<td>367</td>
<td>145</td>
<td>222</td>
</tr>
</tbody>
</table>

Source: Hospital activity analysis

2014/15 data are provisional and only include April 2014 to February 2015 inclusive.
What additional information is needed?
- More complete information on the prevalence of sickle cell disease in Suffolk
- A clinical audit of paediatric and adult services at Ipswich Hospital, to check the extent to which they meet published standards.

What can be concluded?
The single most important finding from this needs assessment is the apparent under-diagnosis of sickle cell disease in Suffolk. Because of the previous absence of universal screening coupled with inward migration of affected people, there are probably about ten people with the condition in the County who are not known to the NHS. Some will be undiagnosed and others will be deterred by stigma from seeking help.

Some of these residents will have symptoms from their disease which treatment would reduce or abolish. All are at risk of complications which timely treatment could prevent. Antenatal and neonatal screening appears to function well in Suffolk. Although the performance of the screening programmes leaves some room for improvement, for example in the timeliness of testing, the programmes are successful.

We found little information about primary care services. The low prevalence of sickle cell disease in Suffolk means that members of primary health care teams have little experience of the condition. However, the likely presence of people with undiagnosed sickle cell disease in the County suggests that greater awareness would be valuable. It would make it more likely that people with symptoms possibly attributable to the diagnosis would be tested for it. It might also help reduce the stigma associated with the condition in some communities, by making it easier for affected people and their families to alert health care professionals about the possibility of the disease.

Hospital services for people with sickle cell disease are improving in Suffolk. Partly this is a result of rising numbers of diagnosed people, itself a consequence of the universal screening programmes and the increasing ethnic diversity of the County. There are however ways in which the service could be further enhanced:
- There are links to four tertiary centres. It might be more straightforward for patients and enhance professional working to have a partnership with a single centre.
• There are apparent weaknesses in the clinical service for patients presenting to the emergency department. The Trust concerned has committed itself to resolving this, but this will need detailed attention.

• The hospital is required to “promote and support management at home by parent, GP and community sickle cell and thalassaemia centre (if available)” (NHS Screening Programmes, 2010). At present, there is only limited engagement of hospital services with the wider community. In view of the stigma attached to the condition, the lack of public and professional awareness and the nascent state of the local support group, there is an opportunity for the hospital’s clinical staff to make an important contribution to improving awareness and understanding of sickle cell disease. This may assist in reaching the people as yet undiagnosed.

• No clinical audit is apparent.

The support group for people with sickle cell disease is at an early stage of development. It has an important potential contribution to raising awareness and combatting stigma, but will need continued investment of effort and resources to achieve its goals.

References
Chapter 10

Glossary, acronyms and appendices
Glossary

**Acute chest syndrome**: A complication of sickle cell disease in which there is widespread sickling of blood cells in the chest.

**Asylum seeker**: A new arrival from another country with no right to be in the UK, but will avoid arrest if he promptly submits himself to the authorities on arrival.

**Concealed Homelessness**: People sleeping in; hostels or shelters, in campsites or other sites used for recreational purposes or organised protest, squatters or travellers.

**Coverage**: The proportion of people for whom an intended screening programme is successfully delivered.

**Dispersal**: The policy to move new asylum seekers to different parts of the UK. Previously all asylum seekers were based in London but this became untenable. Asylum seekers are warned that they may not be placed in London or in South East England.

**Gender identity clinic**: A specialist NHS service providing assessment for trans people who are seeking hormone treatment and/or surgical gender reassignment procedures. They are usually run by consultant psychiatrists who may or may not have other types of NHS staff working with them.

**Gender reassignment surgery**: Surgery to align anatomy as closely as possible to the gender identity intended.

**Immigration control**: Describes the conditions under which people must live whilst going through the asylum process. During that time their accommodation and subsistence needs are provided for by the Home Office so they may not apply for additional benefits, that is, they are prohibited from accessing public funds.

**National Asylum Support Service**: The Home Office service that will provide support where an asylum seeker can show that he has no means.

**Non-statutory Homelessness**: Homeless people to whom no duty is owed because they are not deemed eligible for assistance. It includes those who become intentionally homeless.
and not falling within a specified priority need group. It includes the "single homeless", many of whom are young people of both sexes and, in the larger cities, of different ethnic groups, as well as some older white men.

**Real life experience:** The process of a person changing their name and living full-time in accordance with their felt gender identity as part of a treatment pathway required by gender identity clinics prior to approval for surgical gender reassignment procedures.

**Refugee:** The status accorded when a positive decision has been given to an asylum seeker.

**Positive decision:** A decision by the Home Office granting an asylum seeker refugee status for five years prior to applying for indefinite leave to remain in the UK if he wishes.

**Rough Sleepers:** Rough sleepers are defined for the purposes of rough sleeping counts and estimates as:

- people sleeping, about to bed down (sitting on/in or standing next to their bedding) or actually bedded down in the open air (such as on the streets, in tents, doorways, parks, bus shelters or encampments)
- people in buildings or other places not designed for habitation (such as stairwells, barns, sheds, car parks, cars, derelict boats, stations, or ‘bashes’).

**Sickle cell disease:** An inherited disorder in which the body produces an abnormal form of haemoglobin, the molecule that carries oxygen in the blood. As a result, the red blood cells become distorted into a crescentic or sickle shape, are less malleable and have shorter life-spans, leading to serious complications for affected people.

**Sickle cell carriers:** Have a single abnormal sickle cell gene. They have no symptoms of the disease, but are at risk of having a child with the disease if their partner is also a carrier.

**Sickle-cell crises:** Sudden deteriorations in the health of a person with sickle cell disease. They occur when the blood supply to an organ is suddenly reduced by sickling. Crises are painful and often lead to organ damage.
**Sofa Surfers:** Homeless people who sleep on the floors or sofas of friends, family or acquaintances.

**Statutory Homelessness:** Those households which meet specific criteria of priority need set out in legislation, and to whom a homelessness duty has been accepted by a local authority.

Such households are rarely homeless in the literal sense of being without a roof over their heads, but are more likely to be threatened with the loss of, or are unable to continue with, their current accommodation. The ‘priority need groups’ include households with:

- dependent children or a pregnant woman
- people who are vulnerable in some way e.g. because of mental illness or physical disability.
- aged 16 or 17
- aged 18 to 20 who were previously in care
- vulnerable as a result of time spent in care, in custody, or in HM Forces
- vulnerable as a result of having to flee their home because of violence or the threat of violence

These people represent a small proportion of those who are homeless.

**Thalassaemia** is a separate inherited disorder of haemoglobin structure which falls outside the scope of this needs assessment.

**Trans:** A term for people whose gender identity and/or gender expression diverges in some way from the sex they were assigned at birth, including those who identify as trans-sexual people, those who identify as non-binary gender people, and cross-dressing people.

**Trans-man:** a person who was assigned female at birth but has a male gender identity and therefore proposes to transition, is transitioning or has transitioned to live as a man.

**Trans-woman:** a person who was assigned male at birth but has a female gender identity and therefore proposes to transition, is transitioning or has transitioned to live as a woman.
<table>
<thead>
<tr>
<th>Acronym</th>
<th>Definition</th>
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<tbody>
<tr>
<td>A&amp;E</td>
<td>Accident and Emergency</td>
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<tr>
<td>ACMD</td>
<td>Advisory Council on Misuse of Drugs</td>
</tr>
<tr>
<td>ADEPIS</td>
<td>Alcohol and Drug Education and Prevention Information Service</td>
</tr>
<tr>
<td>CCG</td>
<td>Clinical Commissioning Group</td>
</tr>
<tr>
<td>CSEW</td>
<td>Crime Survey for England and Wales</td>
</tr>
<tr>
<td>DH</td>
<td>Department of Health</td>
</tr>
<tr>
<td>EMCDDA</td>
<td>European Monitoring Centre for Drugs and Drug Addiction</td>
</tr>
<tr>
<td>FEWS</td>
<td>Forensic Early Warning System</td>
</tr>
<tr>
<td>FGC</td>
<td>Female Genital Cutting</td>
</tr>
<tr>
<td>FGM</td>
<td>Female Genital Mutilation</td>
</tr>
<tr>
<td>GUM</td>
<td>Genito-urinary Medicine</td>
</tr>
<tr>
<td>HEE</td>
<td>Health Education England</td>
</tr>
<tr>
<td>HSCIC</td>
<td>Health and Social Care Information Centre</td>
</tr>
<tr>
<td>LASB</td>
<td>Local Adults Safeguarding Board</td>
</tr>
<tr>
<td>LSCB</td>
<td>Local Safeguarding Children Board</td>
</tr>
<tr>
<td>LSOA</td>
<td>Lower Super Output Area</td>
</tr>
<tr>
<td>MASH</td>
<td>Multiagency Safeguarding Hub</td>
</tr>
<tr>
<td>MDT</td>
<td>Mandatory Drug Testing (in prisons)</td>
</tr>
<tr>
<td>MSM</td>
<td>Men who have sex with men</td>
</tr>
<tr>
<td>NDTMS</td>
<td>National Drug Treatment Monitoring System</td>
</tr>
<tr>
<td>NEET</td>
<td>Not in Education, Employment or Training</td>
</tr>
<tr>
<td>NHSE</td>
<td>NHS England</td>
</tr>
<tr>
<td>NOMS</td>
<td>National Offender Management Service</td>
</tr>
<tr>
<td>NPS</td>
<td>New/ Novel Psychoactive Substance</td>
</tr>
<tr>
<td>ONS</td>
<td>Office for National Statistics</td>
</tr>
<tr>
<td>PHE</td>
<td>Public Health England</td>
</tr>
<tr>
<td>PSHE</td>
<td>Personal, Social and Health Education</td>
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<tr>
<td>RAPt</td>
<td>Rehabilitation for Addicted Prisoners Trust</td>
</tr>
<tr>
<td>RCM</td>
<td>Royal College of Midwives</td>
</tr>
<tr>
<td>SARC</td>
<td>Sexual Assault Referral Centre</td>
</tr>
<tr>
<td>SCC</td>
<td>Suffolk County Council</td>
</tr>
<tr>
<td>SRS</td>
<td>Suffolk Refugee Support</td>
</tr>
<tr>
<td>TCDO</td>
<td>Temporary Class Drug Order</td>
</tr>
<tr>
<td>UCS</td>
<td>University Campus Suffolk</td>
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<tr>
<td>YOS</td>
<td>Youth Offending Service</td>
</tr>
</tbody>
</table>
Appendices

Appendix A: Asylum Seekers and Refugees

Surveys of service user opinion

These views were collected at two meetings. The first was a group for international women held weekly by Suffolk Refugee Support. The women take time for coffee and to socialise and then do an activity together. It is an important meeting place for women many of whom are entirely alone, and at different stages of the asylum seeking process.

**Client 1.** From Nigeria, an asylum seeker awaiting a decision. She has been in the UK for four years, the only one in her family, and she has a daughter of 1.5 years.

She likes her GP surgery. She has been at another one in the town centre but she had to change accommodation and the new one is better, much quieter and not so busy. She has come from London where she was had an apartment for mother and baby.

The health system was different in Nigeria. You had to pay for everything so you would just go and buy the medicine you wanted.

She understands how to keep herself well, but she is quiet and a bit withdrawn. She has depression, which she had before the baby was born. She has medication which she has taken for a long time. For eighteen months she has received counselling at The Health Outreach Project and this really helps.

We talked about the weather and how she found England. She would not go back – she does not want her daughter to be cut. She said you cannot live in Nigeria if this is not done; she could not go to school, as the child’s mum she could not get a job. She would be outcast.

**Client 2.** Travelled from Eritrea to Ethiopia. Had been in Sudan previously. She was hounded out because she was a Pentecostal. She has been in the UK for four years, and she had a positive decision so now she is a refugee and can remain for five years. Now she is anxious about whether she can get independent leave to remain. She is the only one in her family in
the UK and she has a three year old child. She says the women’s group and her church are her family. She also gets counselling at The Health Outreach Project.

She is registered with a GP and has a hospital appointment for a bladder infection. The child’s immunisations and vaccinations are up to date, and she attends for cervical screening.

Money is difficult for her. As a refugee she does not receive the small amount she had as an asylum seeker. She has a zero hour’s contract which does not pay much. She works night shifts when she can leave the child with friends, but she wants a job with a proper contract. It is difficult as sometimes they call her into work, and the travelling is not cheap but when she gets there they may say they don’t need her.

Clients 3, 4, 5. Three women interviewed together. All from Iraqi Kurdistan but unknown to each other prior to living in the UK.

<table>
<thead>
<tr>
<th></th>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Been in England</td>
<td>6 years</td>
<td>1 year</td>
<td>7 years</td>
</tr>
<tr>
<td>Income</td>
<td>Husband taxi driver</td>
<td>Benefits. Her husband has NRPF but wife gets support as an asylum seeker.</td>
<td>Husband works in a garage</td>
</tr>
<tr>
<td>Registered with GP</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Husband helped her at first with language. Now he wants her to manage. She will take her son to an appointment</td>
<td>Trying for a baby and depressed. Went for fertility treatment and they tried to use Language Line but it did not have her language – Bandini, a local dialect in Kurdistan.</td>
<td>Went to A &amp; E for a heart problem. Her friend interpreted. She can do English but not when it’s her and she’s worried.</td>
<td></td>
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<tr>
<td>Dentist</td>
<td>yes</td>
<td>yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Cervical</td>
<td>yes</td>
<td></td>
<td>Yes</td>
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</table>
This lady was a bit older than the others and more able to express her thoughts. She was very concerned about the political situation in Iraq. First thing every morning she tuned in on the radio to hear what was happening in Kirkuk where her family were. She would cry at night because she did not know what was happening. Soon they were going out to visit. It was all consuming for her.

Client 6. From Sri Lanka. Her husband was wrongly accused of being a member of the Tamil Tigers and had to flee Sri Lanka or be killed. He came to England and after 5 years, with indefinite leave to remain he was able to bring his wife and children to join him. The children are bilingual but the father will never be able to return to Sri Lanka. He had been a pharmacist in their country but now works in an off licence. The children are now 11 years and 15 years, and the mum would love to get a job but she cannot. In Sri Lanka she had a professional role but here cannot find any sort of job.

The children are up to date with immunisations and vaccinations (BCG). They do not use the health service much. She had a breathing problem in 2013 and had an emergency appointment at the GP and was sent to hospital.

She does not like the system in the NHS. In Sri Lanka everything had to be paid for but you could buy what you wanted, there was no restriction for example on antibiotics. She would like to be able to get them when she wanted them.
Focus Group report from Asylum Seekers and Refugees Ipswich 13/05/15

In total there were 16 respondents.

1. What is your country of origin?

   Nigeria, Eritrea, Kurdish (Iraq x3), Sri Lanka (x2), Iran (x7), Congo, Ruanda.
   There were 13 women and three men.

2. How long have you been in the UK?

   Length of time in Britain ranged from 10 months to 13 years.

3. Do you consider yourself to be healthy?

Most respondents considered themselves to be healthy. One older man said he had diabetes, a hernia and heart trouble. One woman mentioned infertility, another lack of treatment for painful periods and one was pregnant. As the conversation developed more conditions and visits to hospital were discussed. One woman was concerned that she had pain and had returned to the doctor 2 – 3 times but still has the pain.

Access and use of health services

4. What do you do if you feel ill?

   Most said they would go to A and E, although they knew about calling 111. They were critical of the time to wait at the doctor’s surgery. Experience is that they pay in their own country and they get service when they ask for it. They did not like waiting and queuing.

5. GP registration, use of GP service

   All respondents were registered with a GP. One woman had been required to move house and found her new GP surgery much less supportive than the previous one which had provided a very good service to asylum seekers. A man reported that if patients booked a double appointment with the GP, the surgery knew that translation was needed.

6. Hospital attendance

   Antenatal care had been used by some of the women.

7. Health Outreach Project
This was a first point of call for most Asylum seekers. Here they had been introduced to a GP, provided with application forms for free prescriptions, advice on using 111 (with request for an interpreter), all of the male asylum seekers and refugees had used Health Outreach Project. Also advice had been received on accessing an optician and a dentist. Screening had been offered for HIV and TB and this was appreciated.

8. What else do you need?

One woman would have liked information on how to cook British ingredients which they had not seen before. She described cooking broccoli until it was soft rather than to retain the vitamins. Vegetables in her country required long cooking and she had not seen broccoli before.

9. Prevention – ways you keep yourself healthy

Participants were a bit vague here. They knew they did not like winter and cold houses and some talked about being unable to afford enough heat. They knew about healthy food and exercise. All the women participated in cervical screening.

10. Any other factors affecting health or access to care

Halal shops centre Ipswich - good
Unaccompanied minors – have issues with budgeting and cooking skills
If they are under 16 they are fostered; if 16 – 17 independent living.
Appendix B: Countries defined as Eastern European by international Organisations

<table>
<thead>
<tr>
<th>United Nations Statistical Division</th>
<th>United Nations Regional Group Membership</th>
<th>Thesaurus of the European Union</th>
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<tbody>
<tr>
<td>Albania</td>
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<td>Bosnia and Herzegovina</td>
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<td>Estonia</td>
<td>Former Yugoslav Republic of Macedonia</td>
<td>Former Yugoslav Republic of Macedonia</td>
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<td>Poland</td>
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<td>Montenegro</td>
<td>Republic of Moldova</td>
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<td>Poland</td>
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<td>Republic of Moldova</td>
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Appendix C  Diagrammatic representations of Types of FGM

Unaffected female anatomy

Type 1 FGM
Removal of all or part of the clitoris and/or the prepuce

Type 2 FGM
Removal of part or all of the clitoris and the labia minora, with or without excision of the labia majora

Type 3 FGM
Cutting and bringing together the labia minora and/or labia majora to create a narrow orifice, with or without removal of the clitoris.
**Type 4 FGM**

Different practices of varying severity, including pricking, piercing or incising of the clitoris and/or labia, stretching/pulling of the clitoris and/or labia, cauterisation of the clitoris and surrounding tissue, scraping or introduction of corrosive substances or herbs into the vagina, and scraping of tissue surrounding the vaginal orifice.

Appendix D: Interviews with Gypsies and Travellers and with Roma women

**West Meadows Traveller site. Accompanied by a support worker from NSGRTS**

1. **Female aged 19**
   - Not originally Gypsy but has a partner who is. She is 21 years, with a child of 15 months and a second due in 3 months. She is permanent at West Meadows and will not travel.
   - Registered with GP at Chesterfield surgery.
   - All immunisations and vaccinations complete
   - No need of GP or hospital – generally well, only for pregnancies.
   - Is visited by the Family Nurse Partnership fortnightly which gives extra support to teenage mothers.
   - The community midwife also visits and sees her in the trailer.
   - She does not see a dentist, nor does her child.
   - She smokes and has thought about giving up but finds she needs a cigarette to calm her down.
   - Her health concern is the rats on the site. The children cannot go out to play.
     There is a huge amount of rubbish and the site is subject to fly-tipping. It has been cleared but it reappears, so there is no possibility of getting the rats cleared.

2. **Female aged is 21, part Irish traveller and part English Gypsy, but considers herself Irish traveller.**
   - She has moved round, about every two years. But sees herself as being settled at West Meadows. She has a child of three and is pregnant with twins. She has never visited a dentist nor has her child. The HV visits the child and the midwife also visits at home.
3. Female a Romany Gypsy  age 37

- Has 7 boys
- Registered with the GP at Chesterfield
- Is a summer traveller.
- She goes round visiting sites where her boys might live when they take a wife.
- Her 11 year old is still at school – unusual for children at the site. She says they are home tutored. The boys take an apprenticeship with their older brothers, in tree work etc.
- The girls do not go to school – they are home schooled in washing, cooking, care of the van etc. – training for Gypsy womanhood.
- Men do not seek medical help until it is very urgent.
- Women will be accompanied to hospital by other women.
- They do have dental care.

4. Husband, wife and adult daughter (who has a 4 year old girl)

- It is ten years since this couple travelled. They now have some stability and comfort but feel it has come at a very high price. They are grandparents and share the trailer with their daughter and her family with two children.
- The man has arthritis and depression and anxiety and is forgetful. His wife cares for him. He is concerned not to let the community know about his mental state. He has received advice and care through the wellbeing service and NSFT.
- The granddaughter has a serious kidney complaint which is worsening. They have been advised that she should be living in a house for management of the frequent infections and warmth. They have to leave the van for frequent visits to the toilet in a separate building and this includes night visits and in winter. The child tries not to go which also worsens the condition. Many representations to the housing department on the part of medical professionals has brought no result and the appeals have been continuing for a long time. This was referred to the MVA to see if they could help.
- The opinion was expressed that no help was forthcoming as the child is in the Gypsy community. This was a strongly held belief.
Roma women. Accompanied by an interpreter who works with The Health Outreach. Interviews at Health Outreach Project 20/05/15

The Clinic
This was a clinic run at the Health Outreach, St Helen’s Street (MVA), for Roma women. The clinic was extremely busy, with 15 – 20 clients and many children waiting when I arrived. The clinic was staffed by a social worker and an education engagement officer, but clinical staff were also available in the building if there were physical or mental health queries. Probably the main attraction of the clinic was the Roma interpreter who has lived in the UK for many years.

Social care
A number of the queries concerned obtaining school places for children. The interpreter stated that Roma women continue to have children “until their bodies pack up”, and a number of the queries I witnessed concerned families with between 6 and 12 children. Through the interpreter one woman with 12 children described her very small accommodation. Another who had seven of her own children, was seeking school places for an additional four boys whom she had adopted as a result of family tragedy. It was explained that she needed to provide passports, and proof of adoption and of the presence of the children in the UK. In seeking school places families naturally wanted the children together. Places in two different schools had been offered to one mother, the schools in different directions from her home. Opposite her home was another school but that had no places at all. She was advised to accept the place for the older child, then wait for a place to become available in the same school for the younger child. She was concerned about being in trouble for not sending the younger one to school but was assured that as long as the school engagement officer was dealing with it, there would be no problem.

The women were generally illiterate so they received letters at home and had to attend the clinic to find out what they were about. The interpreter was teaching them to recognise logos, for the Borough Council, the NHS, and the Department of Work and Pensions so they would know where the letter had come from.

One woman was proud of her children’s grasp of English and she had been helped to get into an English for Speakers of Other Languages (ESOL) class. She brought a Council Tax...
bill in arrears of some thousands of pounds. She was advised how to pace the payments to avoid further measures against her. Another had a claim for payment of health charges which required information relating to her husband’s self-employed scrap metal business. The interpreter herself was able to deal with most of these queries as she was experienced by her attendance at the clinic.

**Accessing health services**

There was evidence of poor understanding of how to deal with services. A woman arrived when the waiting area was very full but she just wanted her blood pressure to be checked. She was not willing to wait. The interpreter spent quite a few minutes explaining to her the need to take her turn, but the conversation was prolonged as the woman argued. The interpreter afterwards explained that it is the same in Romania; people do not want to wait to be seen.

Another woman had attended as requested, for a cervical smear at the GP surgery. She arrived and sat in the waiting room but she had not booked in and so was not called and missed the appointment. Again, although she had got herself that far, she did not understand that she needed to let the receptionist know that she was there. For another woman who appeared quite unwell, an appointment was made the following day for her to attend her GP.

Most are now registered with the GP and can use language line at appointments (a double appointment is needed when booking). But getting registered is difficult as they have no English, and a member of the MVA staff must accompany them to the surgery to make the registration. After that language line is available. GPs often ask other organisations to provide the interpreter or ask the patient to bring someone with them. If this is their children it is inappropriate and would be quite unacceptable to the women.

The obverse problems occur once the Roma people start to trust and then may become dependent on services put in place to help them to become independent.

It was acknowledged that there is a higher prevalence of hepatitis B and tuberculosis. The view of the Interpreter – culture of the Roma.
Following the clinic which ran over time by about two hours, the interpreter explained the situation for these families. They derived originally from India but had experienced discrimination in the Eastern European countries from which they now came. As Roma gypsies they had always travelled. There was no contraception and having children was the sole aim of the women. They had come with many years of neglect of their health. Minor problems would be managed within the community; big fears included cancer. The women are very private in health matters; if they are ill they would go to the doctor but not tell their husband or children. In the UK they accept vaccination for babies and children but would not have done in Romania. Illness was generally dealt with only when it was a last minute emergency. In Romania they would buy antibiotics over the counter and self-medicate, or share round a medication which had helped one person and so was recommended for all. They would not follow through in taking medication if they felt better. Even in the UK some do not attend for antenatal care. An example was given of a pregnant woman working in agriculture for 12 hours a day and would have been unable to attend any sort of medical appointment.

About 90% of the women were illiterate. Before they came to the UK, boys would achieve maybe 3 – 4 years education; girls would not go to school but be trained in doing what their mothers did in running the house and family.
Appendix E: Surveys of service user opinion and additional information about homelessness

A number of groups relating to homelessness were visited to obtain a spread of views of local people. These comprised:

- Visitors to the soup kitchen in Ipswich town which hosts The Health Outreach team every Wednesday and Sunday evening,
- Attendees at the Chapman Centre, a voluntary sector walk in day advice and support centre providing showers, meals, support, advice and hosting The Health Outreach team for a daily surgery,
- Christchurch House hostel for young people aged 16 – 25
- The Winter Planning meeting organised by Ipswich Locality Homelessness Partnership (ILHP) and attended by a number of providers of services to homeless people.

Soup Kitchen

There was an air of disturbance as one of the regular attenders had died the previous night. This obviously created a sense of upset and was what most people wanted to talk about. Some were expressing anger. Although it was a very cold evening there was a large number, maybe 40 people.

- A young woman in a hostel spoke of her anger that she would be required to undertake a detox programme or “be thrown out”. It was one of the conditions of her place in the hostel.
- Another young woman age 24 had had a large number of children, all in care, and The Health Outreach had arranged for her to have a long acting contraceptive, a great saving to service budgets and to the young woman.
- Two men just wanted conversations. Each lived in a one bedroom flat. There is an association between loss of relationships and homelessness, and either might be the causal factor. Each came to the soup kitchen, on a very cold, dark night, as it was lonely at home. Although there is distrust among those who are most vulnerable (apparently if two friends go for an emergency bed at the hostel for a night, and only one can get a place, both will sleep on the street as they feel safer than alone in the hostel), there is also a need for companionship.
Chapman Centre
Here five people joined the conversation.

- V living in a bedsit for the last 15 months following 28 days at Cavendish Lodge
- W from the street moved to Cavendish Lodge for 28 days and then to a room provided by a Housing Association
- X had lived on the streets then to a shared accommodation bedsit and a council house in January 2015
- Y had been in bed and breakfast accommodation for six months and then had obtained a council flat where she has been for 2 years.
- Z was homeless following eviction from private rented accommodation. He was at Cavendish lodge for a short time and then was offered a room in sheltered accommodation where he is very happy.

Most were pleased with the outcome of their search for a home especially the female, Y who had a bed and breakfast arrangement for six months and now has a home. One man was depressed by his bedsit, a one room flat. Because he was now “adequately housed” there was no prospect of improvement and that was hard for him. He found it lonely.

Impact of rough sleeping on health
Those with experience of sleeping rough knew the great importance of keeping warm and dry. They could get showers and wash clothes at the Chapman Centre and so keep clean but it was a struggle to survive and depression and feeling “down” was often mentioned. Personal danger and survival was also a very real issue – “if I go to sleep in the tent, will someone come and kick it over? Will it still be there in the morning?” Care of self and belongings was the most important concern, and to this fear and anxiety was attributed being underweight and stress. Companionship – having a mate – was key, a relationship of trust. If one of the two emergency direct access beds at the Cavendish Lodge was offered, but there was no space for a mate, the two would rather sleep on the street for safety.

Use of drugs and alcohol was common.

Healthcare services
One mentioned a problem with discharge from hospital which following a 999 call and visit to A & E, left him to return to his life on the streets within a few hours. Discharge from hospital was discussed in other meetings as well. Some of the homeless people use the Chapman Centre address to receive mail, or as a home address for registration with a GP. On
discharge from hospital, some have been taken by ambulance to the Chapman Centre and left there although there are no beds and indeed the service closes at 2pm although it runs specific sessions on two days from 3pm – 5pm.

They had experienced discrimination, from doctors surgeries which would not offer registration if the address was the Chapman Centre. There were a few practices that would accept those without a permanent home and they were very good but very busy. It was not always possible to get an immediately necessary appointment. Also there were experiences of rejection by paramedics if they were called – referring to the homeless person as “just a junkie”.

Most healthcare was provided by The Health Outreach and there was a community dental nurse. The Health Outreach was very much appreciated although there was some confusion about the source of the clinical staffing provided at the Chapman Centre. Clients did not always realise this was provided by The Health Outreach. This is where they would come for a head wound, a foot problem (cases of trench foot have been known), more serious conditions (heart or leg) or other conditions. Many times they would not report until the condition had become serious.

**Christchurch House Hostel for 16 – 24 years olds**

Approximately 8 young people were in evidence at the 29 bed hostel for 16 – 24 year old people.

Four young people, two men and two young women, all in their very early twenties were interviewed separately.

All were registered with a local GP, although one was where he used to live, not near the hostel. None was worried about physical health but most admitted to a poor level of mental health from having emotional problems from anxiety and depression to personality disorder and psychosis. They had not experienced any discrimination in primary care though they had not always found the service they wanted. For example, a young man had missed his GP appointment and needed another as he was keen to see a consultant psychiatrist. He felt he should be getting more help. A young woman who had an ectopic pregnancy had discharged herself from the hospital when she overheard staff talking about her in a derogatory manner.
None had visited the dentist though one young man wanted to get his teeth “sorted out”. The men were at either end of the scale in length of stay, one having been there for three weeks, one for three years. One woman had been there for one year and the other for 2 ½ months. Reasons for admission to the hostel (sometimes more than one reason per client) were loss of job leading to inability to pay rent (2) or children taken into care so loss of council accommodation (1) and two were from a progression of other hostels (or women’s refuge) and rough sleeping.

They were comfortable with their current accommodation though all wanted to move on. The hostel does have a system of progression to independence but a young woman who was very anxious to get her own place was not moving to the more independent wing of the hostel as that was classed as a Band C (more independent) from which it is harder to get a place from the council. But from a Band A – her current place – she was more likely to get housed independently. It was very difficult to obtain small units of social accommodation. The spare room subsidy made these the most sought after units.

The young people did express concerns about their current accommodation. The young man who had been there longest found it difficult when friends moved on, or if he had stuff taken from his room; the young woman keen to get her own place found it hard that she could never be alone, also that the kitchen was locked at 10.30pm, coupled with the fact that it was shared and never clean enough for her. She found these limitations quite frustrating. However the other young woman was concerned about her mental health if she moved on to living alone having been in the hostel. She is a smoker and would not think of giving it up. 

Information from hostel staff and other voluntary providers

The manager knew those who were rough sleeping at that time: 4 – 6 in the town centre and sometimes someone in a tent.

There were two emergency beds at Cavendish Lodge and eight 28 day Hostel beds. People were in and out of prison on short sentences. Currently there was a couple in a tent by the swimming pool and one who is in door way of Methodist church in Blackhorse Lane Normally about 12 “do the rounds”, people who were roofless. They tend to sofa surf then into temporary accommodation then back to prison and back again.
Discharge from hospital was raised in different forums. The drop in centre said they received a call each week from Ipswich asking if the hospital could send someone home to them. But about once in six weeks the hospital would simply put a patient in an ambulance and send him to the Chapman Centre. It was agreed that a better discharge arrangement was needed. It is possible that it happens as GPs register patients with the Chapman Centre as their home address so they can receive mail there and also to get onto the GP list.

The Lighthouse
Lighthouse Women’s Refuge Ipswich is one of three refuges in Ipswich Bury St Edmunds and Lowestoft. The Lighthouse has 15 bedrooms of which 11 are family rooms and four for single women. Average length of stay is 3 – 9 months, but if they are waiting for rehousing it will often be longer. If they are moving to another refuge or have family or friends elsewhere they might need to wait for housing. The women move frequently for fear of being located. They provided for 67 women in 2014/15.

They provide accommodation and are also a women’s centre to support women experiencing domestic violence, offering the Freedom programme, building emotional resilience. There is an outreach service which is county wide Anglia Care Trust. The proportion of women is one third is local, two thirds from outside Suffolk. When they first arrive they go through a needs assessment and part of it would ask if they have medication, and whether they have it with them. If they are on long term medication whether they need to see a GP quickly.

The Lighthouse Works with two local surgeries. They have been in the area for 15 years and have good relationships with health services. If a woman came and needed to register quickly, they would help her register with one of the surgeries.

Generally it is safe for a woman to leave the house to see the GP as much as they are safe in the house. Some women may feel very anxious about going out.

If a woman required an inpatient stay and there are children it is difficult. If she is not local and does not have family locally then they have to get social services to arrange childcare. Social Services were supportive and if the children had been receiving support elsewhere then notes were sent on quite quickly.
Their common health problems are mainly mental health issues, depression and anxiety and stress related illness.

As everybody is living in quite close quarters they always catch any infection that is contagious. They have family rooms where they live quite closely and use common bathrooms and kitchens. Often the women have different attitudes to cleanliness and hygiene and attitudes to child care.

The Health Outreach used to provide a visit to do flu vaccinations, talk about nits and how to protect against contagious diseases. The women used to find it quite useful. But residents usually have many issues to deal with and are in a state of crisis when they first arrive so that attending courses or clinics can be difficult. Uptake varies greatly depending on the dynamics of the house at the time. We were told that attendance could be quite low, possibly The Health Outreach taking the view that it was not a good use of time and resource.
Figure B1: Map of geographic service focus of The Health Outreach

Source: [www.openstreetmap.org.uk](http://www.openstreetmap.org.uk) and The Health Outreach Project. Each yellow spot indicates a frequent venue.

The following is information obtained through analysis of the Suffolk Co-ordination Service application forms from clients (See “What is the local picture?”). It indicates some additional factors about those facing, or experiencing homelessness. Figure B2 illustrates responses on whether applicants had a medical condition. To this question, nearly 500 (14%) did not respond, and 100 (3%) replied “Don’t know”. Of the remainder, 1,780 (50%) did not claim a medical condition, and 1,176 (33%) did.
Table A1 shows the main medical problems that were reported. Of 3,557 applications in a period of fourteen months, 2279 gave no reply or declined to answer. Of the 1,278 who responded, the conditions above were the most frequently mentioned.
Table A1 Main medical problems cited by applicants to SCS, April 2014 – May 2015

<table>
<thead>
<tr>
<th>Problem</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>285</td>
</tr>
<tr>
<td>Anxiety</td>
<td>144</td>
</tr>
<tr>
<td>Asthma</td>
<td>111</td>
</tr>
<tr>
<td>ADHD</td>
<td>77</td>
</tr>
<tr>
<td>Back problem</td>
<td>57</td>
</tr>
<tr>
<td>Mental health</td>
<td>57</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>42</td>
</tr>
<tr>
<td>Heart problem</td>
<td>40</td>
</tr>
<tr>
<td>Arthritis</td>
<td>27</td>
</tr>
<tr>
<td>Leg problems</td>
<td>25</td>
</tr>
<tr>
<td>Hep C</td>
<td>22</td>
</tr>
<tr>
<td>Hearing problem</td>
<td>20</td>
</tr>
<tr>
<td>Diabetes</td>
<td>19</td>
</tr>
<tr>
<td>Asperger</td>
<td>18</td>
</tr>
<tr>
<td>Bowel problem</td>
<td>16</td>
</tr>
<tr>
<td>High blood pressure</td>
<td>16</td>
</tr>
<tr>
<td>Autism</td>
<td>14</td>
</tr>
<tr>
<td>Liver problem</td>
<td>14</td>
</tr>
<tr>
<td>Eczema</td>
<td>11</td>
</tr>
<tr>
<td>Stroke</td>
<td>9</td>
</tr>
<tr>
<td>Psychosis</td>
<td>9</td>
</tr>
<tr>
<td>Seizures</td>
<td>9</td>
</tr>
<tr>
<td>Hepatitis</td>
<td>8</td>
</tr>
<tr>
<td>Bi-polar</td>
<td>6</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>6</td>
</tr>
<tr>
<td>Cancer</td>
<td>5</td>
</tr>
<tr>
<td>Alcoholic</td>
<td>4</td>
</tr>
</tbody>
</table>

Source: SCS

Figure B4 considers some factors which may offer the opportunity of prevention against homelessness if clients in these groups can be identified with a significant risk earlier in the process.

Figure B4: Characteristics of people found to be statutorily homeless, SCS, April 2014 – May 2015

- Have you ever stayed in Emergency Accommodation in Suffolk?
- Do you have a criminal record?
- Do you have a learning disability?

Source: SCS
Appendix F: Suffolk online survey on ‘legal highs’ – questionnaire and detailed findings, NPS Legal background, NPS Development and Distribution, NPS Health Harms

‘Legal High’ Questionnaire
The Matthew Project and Public Health at Suffolk council would like to find out what young people think about ‘New/Novel Psychoactive substances’. You may have heard these referred to as ‘Legal Highs’.

To help us get a better understanding of the impact ‘Legal Highs’ might be having in Suffolk, we would like you to complete our online survey. Your answers will be anonymous, which means nobody will know what you have said.

The survey should take no more than 15 minutes to fill in. Please be as honest as you can, without talking to your friends.

Please follow the link to the survey, which needs to be completed by the 22nd May:
https://www.surveymonkey.com/r/X3DV93D

Services for young people wanting help and support for drug (inc Legal Highs) and alcohol issues

The Matthew Project
Drug and Alcohol Service for children, young people and their families across Norfolk; for those using substances themselves or affected by someone else's substance misuse. The Matthew Project also provides drug and alcohol education, outreach and specialist services throughout Norfolk and Suffolk for young people under 25.

For more information about The Matthew Project visit www.matthewproject.org
Turning Point

Drug and Alcohol service for children, young people and their families and adults across Suffolk.
For more information visit: www.turning-point.co.uk
24/7 Single Point of Contact: 0300 1230872

1. Please tell us your gender
   - Male
   - Female

2. Please tell us your age
   - 15 and under
   - 16-18
   - 19-20
   - 21-24
   - 25 and over

3. Have you or your friends taken ‘Legal Highs’?
   - Yes - You
   - Yes - Friend
   - No
   - If yes, can you tell us which legal highs have been used by you or your friends? Please list all in the box below

4. If you have used 'Legal Highs', how often do you use them?
   - Tried them once
   - Once a month
   - 2-3 times a month
   - Once a week
2. 2-3 times a week
3. Everyday
4. I haven't tried them

5. Would you know where to get ‘Legal Highs’?
   - Yes
   - No
   - (Optional) If Yes, where would you get them if you wanted to?

6. If one of your friends offered you a ‘Legal High’, how likely would you be to try it?
   - Very unlikely
   - Fairly unlikely
   - Neither likely nor unlikely
   - Fairly likely
   - Very likely

7. How well informed are you about ‘Legal Highs’?
   - Not at all
   - A little
   - Fairly well
   - Very well

8. If you wanted to find out more about 'Legal Highs', where would you go for information?
   - Friend
   - Sibling(s)
   - Parent/Guardian
   - Teacher
   - FRANK
9. Please look at the following statement and say how much you agree or disagree with it: ‘Legal Highs are safer than Illegal drugs’. Please choose one.

- Disagree strongly
- Disagree a little
- Neither agree nor disagree
- Agree a little
- Agree strongly

10. We are also interested in getting together a small group who would be able to discuss some questions about ‘Legal Highs/ NPS’ with us. If you would be interested in taking part in this, please provide your name and email address below. We will only use this to contact you about the group and will not pass on your contact details to anyone else.
Detailed findings of Suffolk online survey on legal highs

The survey was made available on the intranet at Ipswich college in the 2 weeks ending 22 May 2015.

There were a total of 99 respondents, 71 male (M) and 28 female (F). The questions, and the number of respondents to each (n) are shown on the charts.

The survey was also offered to a number of other settings including Lowestoft college, West Suffolk college, UCS, the YOS, the Prince’s Trusts, and youth services Just 42, Level-2 and CYDS. However as there were a total of less than 10 responses across all the other settings these findings have not been presented.
Which ‘legal highs’ have been taken by you or your friends? (n=27)

<table>
<thead>
<tr>
<th></th>
<th>Hawaiian Baby Woodrose</th>
<th>Recovery</th>
<th>Fly Agaric</th>
<th>Magic Beans</th>
<th>Black Mamba</th>
<th>Orange Clockwork</th>
<th>Pink Champagne</th>
<th>Pandoras Box</th>
<th>Groov-e</th>
<th>Exodus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Glue</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Snowblind</td>
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<td></td>
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<tr>
<td>Bamboozie</td>
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<td></td>
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<tr>
<td>Salvia</td>
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<td></td>
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<tr>
<td>Nos</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Yopo</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Mimosa Hostilis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If you have used 'legal highs', how often do you use them? (n=95)

<table>
<thead>
<tr>
<th></th>
<th>F</th>
<th>M</th>
</tr>
</thead>
<tbody>
<tr>
<td>I haven't tried them</td>
<td>72%</td>
<td></td>
</tr>
<tr>
<td>Tried them once</td>
<td>11%</td>
<td></td>
</tr>
<tr>
<td>Once a month</td>
<td>5%</td>
<td></td>
</tr>
<tr>
<td>2-3 times a month</td>
<td>1%</td>
<td></td>
</tr>
<tr>
<td>Once a week</td>
<td>0%</td>
<td></td>
</tr>
<tr>
<td>2-3 times a week</td>
<td>1%</td>
<td></td>
</tr>
<tr>
<td>Every day</td>
<td>11%</td>
<td></td>
</tr>
</tbody>
</table>

Would you know where to get 'legal highs'? (n=27)

<table>
<thead>
<tr>
<th></th>
<th>F</th>
<th>M</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>45%</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>55%</td>
<td></td>
</tr>
</tbody>
</table>
Where would you get ‘legal highs’ if you wanted to? (n=19)

<table>
<thead>
<tr>
<th>Location</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Online</td>
<td>21%</td>
</tr>
<tr>
<td>Internet</td>
<td>16%</td>
</tr>
<tr>
<td>Friends</td>
<td>11%</td>
</tr>
<tr>
<td>People</td>
<td>11%</td>
</tr>
<tr>
<td>Head shops</td>
<td>9%</td>
</tr>
<tr>
<td>Purple shop</td>
<td>7%</td>
</tr>
<tr>
<td>Dad</td>
<td>5%</td>
</tr>
<tr>
<td>Smoking shops</td>
<td>2%</td>
</tr>
</tbody>
</table>

If one of your friends offered you a ‘legal high’, how likely would you be to try it?

- Very unlikely (58%)
- Fairly unlikely (11%)
- Neither likely nor unlikely (14%)
- Fairly likely (5%)
- Very likely (12%)

How well informed are you about ‘legal highs’? (n=97)

- Not at all (22%)
- A little (36%)
- Fairly well (24%)
- Very well (18%)
NPS Legal background

The Misuse of Drugs Act 1971 identifies three classes of controlled drugs, and some newer substances that have achieved widespread use such as mephedrone, GHB/GBL, and ketamine, are now controlled under the Act. Despite this, mephedrone and GHB/GBL are still widely considered to be NPSs, and are included as such in this report.

In 2011 the Government added a provision for Temporary Class Drug Orders (TCDOs) under the Misuse of Drugs Act 1971, under which the importation, exportation, production and supply (but not possession alone) of specified drugs can be prohibited (Home Office, 2011). A large number of NPSs have been covered by TCDOs (eg. synthetic cannabinoids,
many ketamine analogues, methylphenidate and related substances). However it has been found hard to keep pace with the constantly changing range of NPSs available through such controls which are based on specific chemical structures.

Different countries have taken different approaches to controlling NPSs. In addition to extending existing drugs legislation, the UK and some other countries have used consumer safety or medicines legislation that requires the correct labelling of substances with respect to their contents and expected use, to prevent the sale of NPSs which may be packaged with various labels such as ‘plant food’ or ‘bath salts’. Some countries such as Ireland, Romania and Portugal have introduced new laws to manage unauthorised distribution of all psychoactive substances. This effectively bans all NPSs without the requirement to identify individual substances or modes of action separately (EMCDDA, 2015a). New Zealand has aimed to reduce risk through an Act in 2013 which placed regulations on the manufacture and sale of NPSs, requiring producers to demonstrate that they are of ‘low risk’ to consumers before they are allowed to be sold, and that they are correctly labelled with active ingredients and health warnings. The impact of these different approaches has not been systematically evaluated. There is some evidence that NPS use has fallen in Ireland following the ban, although it still remains higher than other EU countries (see ‘What is known about NPS use in the UK and more widely?’) (European Commission, 2014).

The UK Government has been considering alternative approaches, based on the recommendations of the Expert Panel, and its Psychoactive Substances Bill was published on 29th May 2015. This will make it illegal to produce, distribute, sell or supply psychoactive substances in Britain. It does not make possession alone a criminal offence (Home Office, 2015a).

The definition of psychoactive substances used in the Bill covers ‘any substance intended for human consumption that is capable of producing a psychoactive effect’. As this includes substances such as tobacco, alcohol and caffeine, the Bill also includes exemptions for legitimate substances. It remains to be seen how this legislation will work in practice. Some commentators consider that it will push trade underground, and will have no effect on improving the safety of substances manufactured.
Development of New Psychoactive Substances

Various reports suggest that NPSs started appearing around the mid-2000s, and the number of substances available has grown rapidly since around 2008. Most of these NPSs are thought to be manufactured in China or India, or in clandestine laboratories in Europe. New substances are produced very quickly to replace those that are placed under legal control, and manufacturers may try to circumvent the law by developing compounds slightly different from those banned.

Some products contain a mixture of substances and analyses have shown that they may include illegal substances; for example, in 2013–14 19.2% of NPS samples collected by the Home Office’s Forensic Early Warning System (FEWS) contained controlled drugs. Approximately 91% of the samples analysed that contained NPSs were identified as mixtures of either 2 or 3 different active components. Products with the same brand name were also found to contain mixtures of different components (Home Office, 2014b; NEPTUNE, 2015).

The number of NPSs identified globally more than doubled between 2009-2013 (UNODC, 2014) and the most recent European data found that over 450 NPSs are currently being monitored by the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) and 101 new NPSs were identified in 2014, most commonly cannabinoids and cathinones (mephedrone-like substances) (EMCDDA, 2015b). There are now many more NPSs than there are drugs controlled internationally by UN Conventions (234 substances).

Distribution and use of New Psychoactive Substances

The main sources of NPSs in the UK currently are ‘head shops’, other non-specialist retailers, and the internet. Head shops are high street outlets which often sell paraphernalia related to the growing, production or consumption of cannabis and other drugs, alongside NPSs or ‘legal highs’. There is also evidence that non-specialist retailers such as corner shops and petrol stations may be selling NPSs.

On the internet, openly accessible websites are likely to be selling non-controlled NPSs, while sites on the ‘darkweb’ (which are not openly available and can only be accessed with anonymising software) may be selling illicit NPSs, although evidence suggests that their main focus is traditional illicit drugs (Home Office, 2014c). The extent to which NPSs are purchased in bulk over the internet for onward distribution is not known.
The 2014 European Eurobarometer survey asked about NPS use in a sample of over 13,000 15-24 year olds in EU member states (European Commission, 2014). They found that 10% of the UK sample (n=501) had ever used NPSs, and of those who had used them in the last 12 months (n=27) 58% had got them from a friend, 39% from dealers, 18% from a shop and only 6% from the internet. Although this was a small sample, this is in line with other evidence quoted in the Home Office evidence review that relatively small numbers of users source NPSs online, particularly among young people (Home Office, 2014c). The Global Drug Survey found that 22% of respondents from the UK reported ever buying any drugs on the internet, but this included many other drugs besides NPSs. However, the proportion using the internet was the highest of any country, and compared to an average of 11% for the whole sample which included European countries, Australia, New Zealand and USA (Global Drug Survey, 2014a).

NPS users commonly use the internet for sharing information about newer compounds and feeding back information about the effects of drugs, with many sites, blogs and discussion fora where such information is shared.

NPSs are often sold packaged and marketed as ‘plant food’, ‘bath salts’, ‘research chemicals’, ‘incense’ or ‘herbal highs’ and are typically labelled as ‘not for human consumption’ in an attempt to get round legal restrictions on products for human use. Lack of information about the contents is clearly not a deterrent for a significant number of users who are known to take substances when they have no idea what they consist of; for example, the Global Drug Survey found that 15% of all respondents and a fifth of those aged between 18 and 25 years had in the past 12 months used an ‘unknown white powder’ (Global Drug Survey, 2014a).

A number of different types of NPSs have been identified. The EMCDDA divides the market into the following categories (EMCDDA, 2015c):

**Legal highs** marketed in bright and attractive packaging. Sold openly in head/smart shops and online. Aimed at recreational users.

**Research chemicals** sold under the guise of being used for scientific research. Aimed at ‘psychonauts’ who explore the effects of psychoactive substances. Sold openly online.

**Food supplements** sold under the guise of being food or dietary supplements. Aimed at people wanting to enhance their body and mind. Sold openly in fitness shops and online.
**Designer drugs** passed off as drugs such as MDMA and heroin. Produced in clandestine labs by organised crime. Sold on illicit drug market by drug dealers.

**Medicines** that are diverted from patients or illegally imported into Europe. Sold on illicit drug market by drug dealers.

**NPS Health harms**

The relatively short time that NPSs have been available means that most evidence relates to short-term harms, with little information about longer-term effects. Even the short-term evidence is limited as little is known about toxicity for which medical advice is not sought or which does not lead to death. Within adult drug treatment services, those seeking treatment for NPS use comprise only a small proportion of the total treatment population, and the outcomes of treatment are generally positive (Home Office, 2014c).

While it is assumed that most of the NPSs being offered for sale have harms similar to the controlled drugs they have been manufactured to mimic, it is recognised that further research is needed to establish the full harms associated with these new drugs (Home Office, 2014b). The Scottish Drugs Forum identified the following as typical physical problems related to overdose of NPSs, based on information from drug services (Scottish Drugs Forum, 2013a):

- Overstimulation
- Confusion – paranoia, anxiety (sometimes provoked by physical symptoms)
- Hallucination - possibly visual and/or auditory
- Cardiac arrhythmia
- Loss of control of body temperature

They also identified longer term health problems related to use of NPSs (Scottish Drugs Forums, 2013b):

- Increase in mental health issues including psychosis, paranoia, anxiety, ‘psychiatric complications’
- Depression
- Physical and psychological dependency happening quite rapidly after a relatively short intense period of use.

Other research has identified a range of unpleasant physical effects reported as a consequence of using NPS, including nausea, heart palpitations, headaches, anxiety, feeling
paranoid, hallucinations and agitation (eg. see Figure 10). Presentations can be idiosyncratic and atypical and professionals need to be aware of the possibility of NPS use in young people presenting with bizarre or unexpected behaviour (Winstock et al, 2012).

Through their surveys of injecting drug users, Public Health England (PHE) have identified concerns about increases in injecting of mephedrone and about risky injecting behaviour among this group. They identify injecting of mephedrone as a recent practice among people who have previously injected other drugs, and among people who have switched from snorting mephedrone (Public Health England, 2014a). They found that in 2013, 8% (164 out of 2,077) of injecting drug users surveyed reported that they had injected mephedrone at some point during the preceding year. Among those who had injected mephedrone, 32% reported having injected drugs with a needle or syringe that had previously been used by someone else, compared to 16% of those injecting other drugs.