Edinburgh Health and Social Care Partnership

Joint Strategic Needs Assessment

Health and Care Needs of People from Minority Ethnic Communities

Final Report April 2018

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EXECUTIVE SUMMARY

This report provides an overview of the health and wellbeing of people from ethnic minority communities in Edinburgh, which has been developed to inform strategic planning and commissioning by the Edinburgh Integrated Joint Board.

There is a complex association between ethnicity and health, with socioeconomic factors recognised as having an important role. There are differences between ethnic groups in the types of diseases and health problems suffered and in the use of services such as Accident and Emergency and these have implications for the full spectrum of support, from prevention through to treatment.

An understanding of what contributes to poor health and wellbeing and the barriers and challenges to seeking and obtaining support (many being interrelated) helps to inform actions needed. This report includes an overview of the main contributors, from the perspective of people in minority groups and people involved in supporting them. These include:

- The impact of discrimination and racism
- Language barriers and literacy issues - affecting access and engagement
- Poverty and low socio-economic status
- Social isolation
- Culture and religion-specific issues which impact on health-seeking behaviours
- Stigma e.g. of mental health issues
- Impact of trauma and crisis in home country e.g. asylum seeks
- Interaction with the health care system – expectations versus reality.

Actions needed to address these include:

- Staff training including cultural sensitivity
- Recognition of the role of the Third Sector
- Effective community engagement
- Developing effective approaches to prevention including overcoming isolation.

Actions are needed beyond Partnership level to address the wider determinants of health including employment, immigration procedures, racism and overcrowding.

It is important to note that, while the work to produce this report has been generally well-received and participants keen to have the findings taken forward to make improvements for the lives of minority ethnic groups in relation to heath and care needs, to address a frustration expressed with the continued need to ask these questions of BME people it is important to ensure findings are used effectively.

This report will be considered by the reference boards which are overseeing the development of the Edinburgh Health and Social Care Partnership's outline strategic commissioning plans.

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1. INTRODUCTION

Joint Strategic Needs Assessment (JSNA)

The purpose of the JSNA process is to agree a comprehensive local picture of health and wellbeing needs, using intelligence and analysis to determine:

- Current and future needs
- What's working, what's not, and what could work better?
- What are the major health inequalities and what can be done about them?
- Unmet needs, including those of seldom-heard populations and vulnerable groups.

The JSNA is used to:

- Negotiate and agree overarching priorities on health and wellbeing
- Influence commissioning and decision making

The JSNA is a key part of the strategic planning process for health and social care partnerships.

The Health and Care Needs of Edinburgh's Minority Ethnic Communities

An initial, comprehensive JSNA for Edinburgh was published in 2015. Work is ongoing to continue to develop our understanding of needs in Edinburgh and how these change over time.

This report on the health and care needs of people from minority ethnic groups in Edinburgh is part of that. It has been produced by a working group of staff from the City of Edinburgh Council, EVOC and NHS Lothian's Public Health services, using a range of data, published reports and through engagement with, and feedback from, people from minority ethnic groups and the projects and services who provide health and social care support. Details of the engagement process led by EVOC, and the participants are given in Appendix 1.

The focus of the report is on the areas where problems exist because of someone's ethnicity or where ethnicity exacerbates the problems experienced by elements of the general population. It covers the following themes:

- The size and composition of Edinburgh's minority ethnic group population profile and what is known about variations in levels of particular diseases between different ethnic groups
- Factors – including social, economic and cultural - which contribute to health and wellbeing
- The barriers people describe in seeking and receiving support
- Recommendations to address these barriers
- An overview of current provision and perceptions of its effectiveness and any gaps

It is important to note that, while the work to produce this report has been generally well-received and participants keen to have the findings taken forward to make improvements for the lives of minority

ethnic groups in relation to heath and care needs, to address a frustration expressed with the continued need to ask these questions of BME people it is important to ensure findings are used effectively.

2. PROFILE OF ETHNICITY IN EDINBURGH

Ethnicity is defined as the group to which you belong, or are perceived to belong, because of your culture (language, diet, religion), ancestry, and physical features. Ethnicity can affect health and use of healthcare services for a variety of reasons. In general people from other countries who have settled in Edinburgh tend to have better health than the Scottish population – a manifestation of the 'healthy migrant effect' whereby people settling in Edinburgh tend to initially have better health than the local population but over successive generations become more similar to them.

Evidence shows that the relationship between ethnicity and health is complex. Patterns in Scotland differ from other parts of the UK and beyond due to the different socioeconomic profiles of many ethnic minority groups compared with those in other countries. Proportionately, much higher numbers of some of the key ethnic minority groups (e.g. Chinese, Indian, Pakistani) live in much less socioeconomically disadvantaged circumstances in Scotland compared with the rest of Britain[1].

The size of the ethnic minority population in Edinburgh increased between the 2001 and 2011 Censuses[2], as shown in table 1 below. While there are many uncertainties in relation to the future (Brexit, for example), recently published projections of the non-White population in Scotland indicate an increase from 4% to 7% by 2031.[1]

[1] The changing ethnic profiles of Glasgow and Scotland, and the implications for population health, Walsh, D, 2017 http://www.gcph.co.uk/publications/731_the_changing_ethnic_profiles_of_glasgow_and_scotland

[2] NB, although now six years old, the census remains the main source of data on the ethnicity of the population.

Table 1. Main Ethnic Groups 2001 – 2011, City of Edinburgh, NRS Scotland

	2011	% of Total	2001	% of Total	% Change
White					
Scottish	334,987	70.2 %	354,053	78.9 %	- 8.7 %
Other British	56,132	11.7 %	51,407	11.4 %	- 0.4 %
Irish	8,603	1.8 %	6,470	1.4 %	+ 0.4 %
Other White	37,445	7.9 %	18,439	4.1 %	+ 3.8 %
Total White	**437,167**	**91.7 %**	**430,369**	**95.9 %**	**- 4.2 %**
Non- white					
Asian	26,264	5.5 %	11,600	2.5 %	+ 3.0 %
African	4,474	0.9 %	1,285	0.2 %	+ 0.7 %
Caribbean / Black	1,031	0.2 %	292(*)	< 0.1 %	+ 0.1 %
Mixed / Multiple	4,087	0.8 %	2,776(**)	0.6 %	+ 0.2 %
Other non-White	3,603	0.8 %	2,302	0.5 %	+ 0.3 %
Total Non White	**39,459**	**8.2 %**	**18,255**	**4.0 %**	+ 4.2 %
TOTAL	**476,626**	**100.0 %**	**448,624**	**100.0 %**	

Table 2 shows that Edinburgh has a high ethnic minority population by Scottish standards with around 13% of the population coming from identified minorities as classified by the 2011 census, and so the increase for Edinburgh by 2031 may be proportionately higher.

Table 2: Edinburgh and comparators – ethnicity as a percentage of the population, Census 2011

Census 2011	White -- Scottish	White – other British	White – Irish	White -- Polish	White -- other	Asian, Asian Scottish, Asian British	Other ethnic groups
Edinburgh	70.3%	11.8%	1.8%	2.7%	5.1%	5.5%	2.8%
Glasgow	78.6%	4.1%	1.9%	1.4%	2.4%	8.1%	3.5%
Lothian	77.8%	9.6%	1.3%	2.1%	3.5%	3.7%	2.0%
Scotland	84.0%	7.9%	1.0%	1.2%	1.9%	2.7%	1.4%

Table 2 uses the census classification that groups Asian nationalities (Indian, Bangladeshi, Pakistani and Chinese) together. Table 3 shows these ethnic groups separately and confirms that Polish people are

the largest group in Edinburgh followed by Chinese people. It has to be remembered that these figures are not static and since 2011 there will have been changes with increasing numbers of people settling in Edinburgh from other counties.

Table 3: Detailed Edinburgh ethnicity, Census 2011

Ethnicity 2011 Census classification	Total population in Edinburgh
White Polish	12,820
Chinese	8,076
Indian	6,470
Pakistani	5,858
African	4,474
Bangladeshi	1,277

Table 4 shows the language needed for formal interpreted consultations within the NHS for languages with more than 100 consultations in quarter 1 of 2016-17. In line with Table 2, Polish is the most common language by far – almost four times that of the second, Arabic.

Table 4: Interpreted consultations NHS Lothian Quarter 1 2016-17

Polish	2,822
Arabic	715
Cantonese	491
Mandarin	470
Romanian	288
Turkish	274
Bengali	255

Spanish	245
Urdu	199
Italian	177
Portuguese	125
Bulgarian	112
Hungarian	106

In 2016 Arabic interpretation requests increased due to the arrival of Syrian refugees in Edinburgh – both on the Syrian Vulnerable Person Resettlement (VPR) Scheme and by irregular means. Refugees and asylum seekers potentially have particular health and social care needs such as post traumatic distress, malnutrition or untreated chronic medical conditions where good surveillance and primary care are important.

As well as around 100 Syrian people on the VPR programme there is another group of Syrians of a similar size in contact with Council and NHS services because of problems they are facing – usually regarding health and housing. There is also a group of unknown size of undocumented or poorly documented people who are not in contact with services who are likely be at particular risk of poor outcomes.

NOTE ON TERMINOLOGY

This report uses umbrella terms such as African, Asian and Eastern European. It is important to note that such terms can depict people from this as homogeneous, masking the wide range of countries, languages and cultures which they encompass. Care needs to be taken to avoid stereotyping and undermining the specific challenges faced by smaller groups or the individuals within them.

3. DISEASE-SPECIFIC HEALTH OF PEOPLE FROM BME COMMUNITIES IN EDINBURGH

As stated earlier, many people settling in Edinburgh from other countries are healthier than the indigenous population of Scotland – the phenomenon known as the 'healthy migrant effect'. With different health status comes different utilisation of health services.

The Scottish Health and Ethnicity Linkage Study[3] (SHELS) found many health variations between ethnic groups in Scotland. Examples include:

- Men and women from nearly all ethnic minority groups (both non-White and other White people) are less likely to develop cancer than the White Scottish population
- Chinese people living in Scotland seem to have better health than White Scottish people with lower risk of hospital admission or death in many health outcomes (heart disease, cancer, any psychiatric disorder, alcohol related diseases, asthma and chronic obstructive pulmonary disease)
- Risk of appendicitis was comparatively low in most non-White groups, while Crohn's disease was mostly higher in South Asians
- The risk for all-respiratory diseases was found to be relatively low in Other White British and Chinese men and high in Pakistani men and women
- The risks of common gastrointestinal (GI) diseases like peptic ulcer disease and pancreatitis were comparatively low in most White ethnic groups
- Pakistani men living in Scotland have a significantly higher risk of heart attack and of admission to hospital with asthma compared to White Scottish men
- White Scottish mums are less likely to breast feed their babies than mothers from all the other populations in Scotland
- All non-White ethnic minority groups gave birth to babies who weighed less than babies born to White Scottish mums
- There are unequal patterns of psychiatric hospitalisations by ethnic group in Scotland. South Asian and Chinese groups in particular access mental health services late or not at all. African men and

[3] http://www.ed.ac.uk/usher/scottish-health-ethnicity-linkage

women had the highest rates for psychotic disorders and relatively high rates for compulsory treatment

- There are substantial ethnic differences in breast screening attendance with South Asian women having lower rates of attendance
- There are particularly high rates of lower respiratory tract infection hospitalisations in Pakistani men and women.

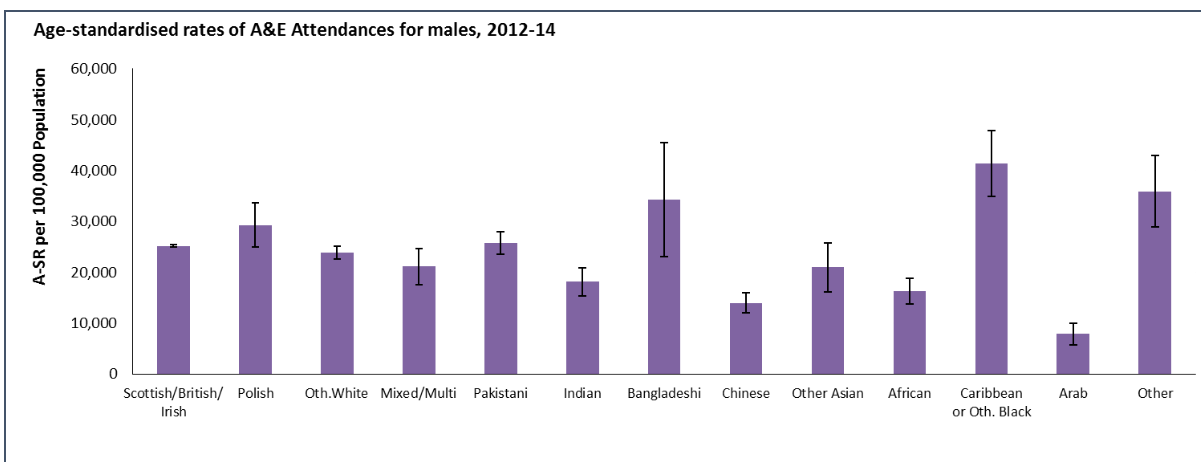
Separate evidence obtained through the engagement process indicates:

- That suicide rates among the Polish community in Scotland are higher than the Scottish average
- An increasing prevalence of mental health issues was noted by almost all organisations contacted
- Members of the African community are disproportionately affected by HIV and FGM (Female Genital Mutilation) as well as sickle cell anaemia
- Amongst the Roma community, diet, health and oral health is extremely poor from a very young age. Related health issues including diabetes, morbid obesity, and heart disease are prevalent.

Culture and behaviour can be different in different ethnic groups and smoking is one example of this where Polish and Bangladeshi men have much higher smoking rates than Scottish men. This supports the need to address inequalities by targeting preventive measures along ethnic lines.

Within Lothian, the NHS is collecting data about ethnicity to begin to study uptake of local services. Figure 4 illustrates Accident and Emergency use. Preliminary analysis shows a mixed picture with men of Caribbean or Black ethnicity showing increased use while Chinese and African males use the service less than would be expected in terms of population composition.

Figure 1. Preliminary results NHS Lothian – A&E



DISCUSSION

- The patterns of health variations, and behaviours in health-related behaviours such as screening, indicate the need for different responses, including at preventative level
- The changing population of Edinburgh in terms of the size of ethnic groups needs continued monitoring and regular review of access to services, health status and needs of minority groups.

4. CONTRIBUTORS TO HEALTH AND WELLBEING AND BARRIERS

The previous section summarised some of the known variations in the health needs of the ethnic populations in Scotland.

This section summarises what is known about the factors influencing health and wellbeing, the challenges and barriers people experience in seeking health care or support, and how these might be addressed. The evidence used is as follows:

- A desk top exercise, reviewing a range of existing research projects
- An engagement event hosted by EVOC in October 2016 for Third Sector organisations to come and speak about their experience of supporting people from minority ethnic communities and the barriers these people face when trying to access health and social care services
- Evidence and views provided during the engagement process based on the phase 1 draft of this report.

Although these sources span a number of years, the findings are consistent and are summarised below. Further details of the evidence are provided in the reference section.

WHAT CONTRIBUTES TO GOOD HEALTH?

Across all ethnic groups good health is reliant upon:

- Healthy Diet
- Physical activity
- Social inclusion
- Good mental health
- Economic stability
- Access to health services
- Decent housing

CONTRIBUTORS TO POOR HEALTH

The impact of the factors described below will vary within minority ethnic groups as well as between groups.

Psychological difficulties of living away from one's home country and of feeling discriminated against on a daily basis.

The impact of **racism and hate crime** which contribute to social exclusion and negatively affect mental and physical health.

Social isolation: *"For every migrant like me the worst scenario is social isolation which hinders everything"*[4] . Language barriers: can lead to social isolation with some participants struggling to communicate and integrate in their local community as well as at work. A lack of the availability of English language classes appears to contribute to this problem with many being unable to attend due to childcare issues.

Poverty and low socio-economic status: a healthy 'lifestyle' is often not a priority for people when they are struggling with living in poor housing, a lack of employment or low paid jobs, or immigration issues. These issues can be a product of racism and discrimination, and affect each minority ethnic group differently. For example, whilst Africans have some of the highest qualifications of any ethnic group in Scotland, they are the least likely to be employed in management or professional roles, and the most likely to be employed in service positions. They are also significantly more likely than other ethnic group to live in deprived areas, with overcrowded housing conditions.

The impact of unemployment was mentioned amongst participants as causing financial strain. Qualifications are often not recognised in the UK and language can prove to be a barrier in gaining employment.

The expense of eating healthily and the lack of local fresh fruit and vegetables from peoples' countries of origin.

The ability to maintain physical health was reported to be affected by the cost of physical activities, the timings of these activities and the lack of childcare available. Participants also identified the lack of culturally appropriate single sex activities (e.g. women only). Where single sex activities were provided, they were often at inconvenient times or did not meet requirements for modesty.

The challenges of parenting and families include a lack of child care support when parents are working long hours or for single parents. These can be exacerbated when there are no extended family members around for support.

Where parents' awareness of healthy behaviours is low, and there is a general lack of knowledge amongst other community members who could intervene, children experience negative health behaviours from an early age. This is a particular problem for communities who have recently migrated due to problems in their country of origin. Easy access to services for trauma and play therapy, can be limited.

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[4] Pilton Community Health Project and the Black Community Development Project (February 2009)

For children whose English is better than that of their parents, there can be a lot of pressure on them to take on inappropriate roles such as interpreting or attending meetings that should not concern children of their age, leading to high levels of stress and anxiety.

ISSUES FOR SPECIFIC EQUALITIES GROUPS

Older people: growing old in a second homeland can be extremely isolating. First generation migrants are less likely to have picked up English if they were older when they arrived. Where people have lived here for a long time, there is an expectation that they will have better language skills, but this is not always the case. In many communities, poor literacy is also more likely to occur among the older population. Problems that can affect the ability of older people from all ethnic groups to find out about available services, such as the digital divide, are therefore exacerbated. Older BME people are also more likely to be socially isolated even after the family has been here for a number of generations, as their grandchildren often do not learn the language of their grandparents.

The increasing prevalence of dementia is also affecting minority ethnic communities. Of particular note, is the loss of additional languages which is associated with dementia in its later stages.

Women: in some communities, women may be more isolated, or have fewer opportunities to engage due to the demands of childcare etc. This exclusion is associated with poorer mental health. Across ethnic groups, women are also more likely to be on the receiving end of relationship violence, and the associated health and social difficulties. For some African communities, there are also gender specific issues related to female genital mutilation.

People who experience discrimination for other reasons (e.g. disabilities, sexual orientation, gender identity) are more at risk of isolation and psychological damage. Participants in a study on LGBT migrants felt that there was less discrimination in Scotland in general, however, there are some examples of individuals continuing to hide their sexual/gender identities from people within their own community.

Carers from minority ethnic communities face similar issues of health and wellbeing as carers of all ethnic groups. However, they are at a greater risk of being isolated if they or the person they care for have additional language or cultural barriers affecting them, and there are also fewer services targeted towards them.

BARRIERS TO PEOPLE ENGAGING WITH SERVICES

Health and social care is not always a priority in people's lives; for people struggling financially and working long hours, just getting by day-to-day is often all they can manage. This can lead to stress, anxiety and isolation which then exacerbates physical and mental health issues which people may not seek help or support for.

Difficulties with the English language was cited by respondents as the biggest barrier to engaging with services. All other barriers are exacerbated where communication is a problem.

Lack of literacy means that some people are not able to read leaflets or information that has been translated into their first language.

Problems surrounding translated information:

- Some groups speak languages that are left out of translated materials, e.g. the Nepalese community, the Sikh community.
- Often translated information assumes a 'higher-level' of general language than is understood by most people (e.g. a university dialect). Transliteration is sometimes needed as well as translation.
- Low literacy levels can mean that even translated written materials are inappropriate.
- Mediums other than printed leaflets are less likely to have been translated (e.g. TV flashboards at GP surgeries or hospitals).

Uncertainty about how to access information about services and how to use them.

Lack of awareness of rights surrounding health and social care: where there are language difficulties, and in the most isolated communities, it is: 1) harder to ask about these rights, and 2) less likely that others around you will be able to tell you about them. This means that people are more likely to reach crisis point before receiving medical attention.

Nature of the information:

- In many communities, much information is transmitted by word of mouth, which means that if people have limited information about, or poor experience of using a service, this is what is shared and understood by the community as a whole.
- Information intended to attract everyone to a service can be seen as being specifically for white Scottish/British people, and as 'not being for us' by BME community members. This may even result in people returning to their country of origin to receive health care, particularly amongst those from other European countries, despite being entitled to free health care in Scotland in many cases.

Lack of confidence to access services alone.

Lack of ability to access services alone e.g. where an interpreter is needed, or for example, amongst South Asian women, where cultural, religious or lifestyle-related issues prevent them from going out alone, either directly, or because they make women more likely to have poor language skills, lower confidence, etc.

Fear of being dismissed by health professionals due to lack of English language skills or discrimination based on physical appearance. In many cases, this fear is backed up by previous experiences where

either the individuals themselves have felt dismissed for these reasons, or they have spoken to others who have had this experience.

Community-specific cultural and religious issues: in some communities, the religious or spiritual leader is the first port of call for any problems, and seeing the GP can be seen as a betrayal by other community members.

Cultural differences in health seeking behaviours: for example, many African communities do not traditionally access preventative health services; one of the challenges for service providers will be to help this community understand both the value of preventative health and how to access support.

Communities are often small and therefore the fear of others finding out about some medical issues also stops some people from engaging.

A general lack of awareness or understanding about mental health issues particularly, which means that people struggle to identify what they need help with or don't realise there is support available.

Stigma surrounding mental health: in some communities, there are high levels of stigmatisation associated with mental health issues which may result in the individual being excluded from the community. This means that until a problem reaches crisis point:

- The problem is less likely to be identified, as there is a lack of awareness about mental health symptoms or treatment options
- Individuals are unlikely to seek help for themselves
- People are unwilling to suggest to others that they seek help. In some cases, people do not seek help until after they have been socially excluded
- Some feel they find it difficult to access counselling, because they would want the counsellor to understand their cultural context.

Suspicion of the government and the confidentiality of any related services: in newly migrated communities, there is a fear of any service which asks for too much personal information - particularly ethnicity or visa status - for fear of deportation or residency issues. For example, young mothers have been known to go to full-term without seeing a doctor, and are likely to sleep on the streets with a new-born baby rather than going to services where they fear the child would be taken away. This level of mistrust and concern may well increase in the present political climate of the UK leaving the European Union.

BARRIERS PEOPLE MEET WHEN THEY DO ENGAGE WITH SERVICES

Case Study

A 28 year old Male (Kamara not real name) from West Africa who lived in London for over 10 years relocated to Edinburgh in 2016 to live and work as well as joining his friends.

During Kamara's stay in Edinburgh, he realised it was very difficult to find employment and he had no house to stay in but rather depended on relatives and friends giving him food and temporary accommodation until he could get his own rented house. Kamara came across a Waverley Care community volunteer who tried to help him overcome some of the difficult situations he was going through at that time. Unfortunately, Kamara became ill and the volunteer contacted Waverley Care's African Health Project worker to meet up with Kamara to assess his needs. Kamara was advised to visit and register with a GP. His first experience trying to register with a GP was not good and he was not used to being interviewed or interrogated in front of other patients just because he was different from other patients. Kamara told us how he felt being discriminated against, judged and wasn't given the opportunity to explain his situation. He was refused registration with a GP and he later resorted to taking traditional herbs offered to him by other people who were sympathetic to his poor health.

The Waverley Care African Health Project Worker engaged with Kamara to help with GP registration but the process was complicated as receptionists at GP surgeries seem not to understand the issues that affect Africans living in Scotland. Kamara is still unwell living in Edinburgh but continues to look for work as well as taking traditional herbs to help relieve his ongoing abdominal pains. Kamara has also found an African church that he goes to for prayer and worship. Waverley Cares African Health Workers regularly visit Kamara to reassure him that he is valued and will continue to offer Kamara any support that is available. *"I don't know why I am suffering like this. I have lost my sense of humanity and I don't know when my situation is going to change, I just want to feel safe and live just like other normal people do."*

Unfamiliar health care system can be a barrier to some people from other countries; even where people understand how the Scottish system works and speak English fluently, they may still choose to visit the doctor for a check-up in their country of origin when possible, simply because it is familiar.

Some differences in how the system is run in the UK can cause confusion or dissatisfaction, e.g. the length of a GP appointment, wanting to see a consultant directly but needing to be referred by the GP, or needing to ask in advance to see a female doctor.

Cultural expectations and differences in how much support is expected, or how much an individual is expected to solve problems themselves, or rely on their family to support them. These differ across minority ethnic groups. In some communities, this can mean that people do not always get the support they need; e.g. amongst the Chinese community, elderly people do not see it as appropriate to rely on their children for help, and express feelings of guilt about asking for help from them.

Booking appointments: speaking a second language can be harder over the phone, especially if answerphone messages are not clear. When calling to make appointments, GP surgeries often take a very long time to pick up. This is more likely to discourage those for whom the process is already stressful, and many choose to rely on Third Sector service appointments instead. For example, many Chinese elderly rely on Third Sector services to help translate letters and book appointments for them. This means that calling in the morning to arrange emergency GP appointments is a challenge, and people often miss out on appointments if they must first contact the Third Sector services and ask them to call. Open surgery is a better system for people with English language difficulties.

Transport to medical appointments: this is particularly difficult for older people or individuals with physical mobility challenges, as booking transport at short notice can be a problem. For those with the challenges of English as a foreign language, they may rely on Third Sector services to book their transport for them.

Primary Care frontline (reception) staff: some were reported to be insensitive and to make it difficult for people to get the help they need, telling women they'll have to wait longer to see a female GP, for example.

There were also many issues reported around the inconsistencies in the documentation asked for when registering at different GP surgeries. This has been noticeable where people have moved from one GP surgery to another, and found that they were asked for more information than when they registered at the first surgery. Often it is felt that more is asked of BME citizens based on their physical appearance. Where it was felt that the experience was discriminatory, there are reports of people deciding not to register at all.

Lack of understanding about the potential lower levels of literacy when filling in forms: this makes people feel uncomfortable and they will often leave.

Double appointments:

- Lack of knowledge that double appointments are available where more time is needed
- Double appointments for those with interpreter are not always happening in practice - hospitals are worse than GPs for cutting double appointments short.

Primary care medical practitioners:

- Because of the barriers they face, people sometimes choose to go abroad for diagnosis or treatment. When people choose to go abroad for treatment they can struggle to get the follow up they need in Edinburgh. For example, GPs can appear to be dismissive of a diagnosis made in a person's home country which can cause delays in getting treatment
- The lack of time that GPs have with a patient combined with language or cultural barriers mean that wider issues are often missed – a patient might come in with physical symptoms, for example, when the issue is actually to do with their mental health
- Some GPs lack awareness of different perspectives and responses to illness, or cultural or religious needs, such as dietary restrictions and the impact of racism on psychological health and opportunities, when giving diagnoses and treatment options
- Medical practitioners may also misinterpret cultural differences in behaviour and cultural differences in expression of symptoms
- Poor interpretation or lack of understanding from GPs can lead to people losing benefits because their health issues have been inaccurately recorded
- Doctors may assume a level of health literacy that people often don't have – giving a diagnosis without a full explanation of what it is and assuming that it will be understood (for example, autism), giving medicine or testing kits without enough explanation, lack of explanation about the benefits of breast screening, cervical smear etc.
- Often leaflets are given as supplementary information, if there is poor literacy this compounds the problem
- Many felt that an individual often needs to use certain 'buzzwords' for symptoms, to be properly heard by the GP. These are less likely to be used by those with more limited English, and they thus can feel that their feelings have been dismissed.
- A focus on immigration status has also been noted among some medical practitioners. In these cases, it is felt that the medical practitioners see this as more important to the health care system than their health. This creates mistrust for the system as a whole.
- In some cases, people have reported being made to feel like they were being given the prescription for free medication 'as a favour', due to assumptions about their residence status.
- In some cultures, men may find it intimidating or culturally uncomfortable to have a female medical practitioner. In some cases, there can also be lack of respect from men for the diagnosis of a female doctor.
- The lack of female doctors was also highlighted as an issue for some women

Interpreters and interpretation services:

- Can be difficult to access and the service is not available in every language

- Many people are ashamed of having to use an interpreter, especially if they are highly qualified in their own language. They report feeling ashamed of relying on others, and some also feel guilty about taking a double appointment and the expense of an interpreter when the system is strained.
- Their role is not always understood by the person - interpretation is not the same as advocacy, and they have a strict ethical code which prevents them from helping the client in any other way. Where this is not understood they can be perceived as cold and uncaring, which adds to the lack of trust.
- Allowing family members to interpret is useful in terms of flexibility and cost for the services, but is not always best for the person, as people can conceal information from their family members in order to protect them from what might be worrying information
- They are felt to vary in the quality of their interpretation, and are not felt to have specific medical knowledge or accreditation, and therefore may not be well-trusted. They often leave out key information when translating what a patient has said.
- There is sometimes an issue where the interpreters translate the word of the professional, but not into language that is understandable to the client, i.e. sometimes transliteration is needed, and this service is not always asked for or known about.
- For very small communities, there are fears around confidentiality when an interpreter is from the same community.
- Lack of consistency - getting a different interpreter each time makes it harder to build any kind of relationship
- Hospital staff do not always understand that Interpretation and Translation Services (ITS) is booked through the hospital and not privately. There are many cases where appointments are delayed and then have to be cancelled because the interpreter was not booked in for the correct time.

BARRIERS FOR SPECIFIC GROUPS AMONG THE ETHNIC MINORITY COMMUNITY

Men: are in general less likely to seek help than women. The barriers that men experience in seeking help varies between ethnic groups and may be expressed in a range of ways. Among Asian and Eastern European communities, for example, some men can be very private about problems which leads to them self-medicating, relying heavily on alcohol etc. which then impacts on other parts of their health and ultimately increases demand for crisis services down the line. This can lead to high suicide rates, and often they pass this attitude on to their partners and families which stops them accessing services.

Women – in some cultures, women can be extremely isolated when their principal role is to stay at home. Women often do not have the opportunity to see the doctor without their spouse. In these cases, they may not disclose all their health needs to the doctor, and their statements can be influenced by the presence of their spouse, particularly where there is an imbalance of control in the

relationship. Cultural and religious issues can also lead to lower levels of literacy amongst women than men in some communities, which can contribute to a lack of knowledge of available services

Students: many students encounter problems with their student visa relating to their 'right to remain' and the implications that this may have on their access to NHS care. This can cause a lot of confusion and is not a well understood problem by health and care staff.

Sufferers of domestic abuse can encounter problems accessing health care when they try to leave their partners, particularly if the partner withholds their visa or passport, or if they entered on their partner's skilled migrant visa. They can feel that they do not fit into the current system, and can be treated insensitively.

Older people: hospital discharge plans are often inappropriate. There is an inaccurate assumption that people have a lot of family around that will look after them, which may not be the case. In addition, the assumption that available care services are just for white people is higher amongst the elderly of many black and minority ethnic groups.

Children have all of the same barriers with stigma, language and cultural differences, but also with less understanding about their physical or mental health and symptoms, and less ability to articulate how they feel. They may also be carers and used as intermediaries/translators with the English speaking world by their families.

People with disabilities have to have multiple appointments per year to have their disability status reassessed for their benefits and blue badge allowance. This can be very demoralising, if they find the experience is made more difficult by language barriers, or staff prejudices.

People with sensory impairments, e.g. sign language users. It is challenging for sign language users to access health and care service regardless of ethnicity, as understanding of deafness is generally limited in the health service. For those who do not come from English-speaking communities, there is a double barrier. Often access to two interpreters may be necessary, which increases appointment time and reduces the feeling that they are receiving all the information. In other cases, cultural or familial approaches to deafness may mean that individuals never have access to learning sign language.

5. RECOMMENDATIONS

The recommendations included in this section were made in the published reports described earlier in this report, or through the feedback and responses to the engagement on the draft report.

Terminology: advertising services as BME - black *and* minority ethnic communities can itself be a problem, as it can appear to be exclusively for people from *black minority ethnic* communities, thus excluding white and Asian minority ethnic people. Using simply *minority ethnic* is more inclusive.

COMMUNICATION, INFORMATION AND AWARENESS-RAISING AND ADVOCACY

- Many organisations and their service users said they find it hard to find the appropriate information on English-language websites, and to navigate through the appropriate departments. It was suggested that there should be one website for all migrants in all languages that provides essential information needed when entering Scotland. Relying on the internet is not appropriate for all older people, however.
- Use a variety of ways to provide information on services taking account of the diverse audience and taking care to make sure that terms such as "independent living" and "community care" are explained in ways that are meaningful to people
- Information should be made available in short and topic-specific video or audio-clips, or podcasts, in all possible languages, to account for difficulties resulting from poor literacy. They should also be available to be downloaded to a phone, so they can be easily distributed by community organisations to people who do not have frequent access to a computer or the internet.
- Provide tools in a range of languages to explain to people how the NHS works and the main differences in provision from other countries; what services are available for different minority ethnic groups, as well as for all individuals, how to access preventative support, etc.
- Any tools produced to improve health literacy need to be supported by interactive events
- Education workshops should be held in the participants' first language- especially for older people
- Extra publicity and staff awareness raising may be needed in times of political turmoil and change (e.g. Brexit) when prejudices in the media portrayal of certain groups can seep into services (into staff behaviour, as well as the general public in the waiting areas).
- Greater awareness and recognition is needed within the minority ethnic communities of the problems that can be faced with the system, for example, that long waiting lists are the norm, to address perceptions that the Scottish health care system is being discriminatory.

- Encouraging the use of advocacy services - link workers generally and link workers from minority ethnic communities can provide advocacy/brokering services for people, supporting them to attend appointments

- In examples of good experiences, a number of people mentioned that their GP was very understanding about using creative solutions to the problem of language barriers, such as using a tablet with translation software.

INTERPRETING SERVICES

- Have dedicated medical interpreters, or an accreditation that can be given a visible and consistent symbol for this ability
- Services need to be cheaper and more accessible
- Give people clearer explanations of the different roles of interpreters and advocacy. Perhaps interpreters/advocates themselves need to be involved in making sure that expectations are clear. Education workshops should also include this topic.
- Given the problems surrounding confidentiality when interpreters come from small communities, any redesign of interpretation services needs to include a way of giving a stronger appearance of professionalism, to instil a greater sense of trust.

STAFF TRAINING

- Sensitivity training should be compulsory for all staff, and should include elements of cultural competency, as well as increased sensitivity in general. Training should include an understanding of the potential for lower levels of health literacy amongst minority ethnic communities, and differing perceptions of diagnoses which may mean that longer explanations of what a diagnosis will mean for the patient, treatment options, and how to take medication may be needed in some cases, and patients may need more ongoing support to manage long-term conditions.
- Staff need to feel comfortable in asking questions about ethnic identity and culture rather than making assumptions and using umbrella categories such as 'Asian - unknown' which makes it hard to analyse the health needs of specific communities.
- Recognising that cultural competency training can be too generalised and that differences in individual and family behaviours can be more important than behaviours related to culture, the aim should be good person-centred working, where staff are respectful to the attitudes and behaviours of the individual, whatever their background or ethnicity, where conversations say "I am listening to you, I want to understand, you can help me to do this".

- More broadly, in the long-term, new standards should be set within the education policy: cultural awareness should be taught from an early age (in schools), and it should be a compulsory part of any health or public sector courses from access onwards.

PRIMARY CARE RECEPTION STAFF

- All reception staff need to be clear on what documents are needed for registration with a GP practice, and the same should be asked of all patients. Strict guidelines should be made available for staff and patients so there is no confusion, discrimination, or perception of discrimination based on ethnicity.
- More training around cultural and other communication needs (e.g. hearing impairments) so that staff can provide the information that people need to make effective use of primary care services, including how to access female GPs, the availability of double appointments, etc.

SOCIAL CARE

- The assessment process should take account of the potential influence of a person's culture and faith significant on their spiritual, personal care and medical needs, and those carrying out the assessment process should be confident in recognising and addressing these topics effectively.
- **Social care staff may need to have a better understanding of the Self-Directed Support options, and how they** can affect minority ethnic people, particularly those whose first language is not English[5].

MEDICAL APPOINTMENTS

- It may be necessary to insist that women have some part of their medical appointments alone, to ensure that they have the chance to disclose all their concerns without being influenced by having a spouse in the room. However, this is a sensitive topic to deal with, and it was not suggested how best to do so.

ROLE OF THE THIRD SECTOR

The key role played by the Third Sector in the whole system of care and support should be recognised. It provides connection and signposting between services and directing people to the information they need. A better awareness by statutory sector staff of, and respect for, services available from the Third Sector would give more chances for this information to be passed on.

COMMUNITY SUPPORT

[5] MECOPP (2016), *Lost in Translation: Making Self-directed Support work for BME Communities,* Edinburgh, pp. 9.

- Mainstream versus community-specific provision was a matter of debate during the engagement phase with recognition that both forms have a place:
    - People from many communities would not feel comfortable in mainstream services, and community specific engagement is needed to address the barriers to health and care services documented in the draft report (which, as noted earlier, was used as the basis for engagement)
    - The level of community-specific support desired is also related to whether an individual is from the first generation of a migrant community in Edinburgh, or a later generation, highlighting the need for both.
- Effective community engagement is seen as crucial and the Third Sector can offer an effective role in this by identifying key members of the community who are trusted and respected, and bringing people together for discussions about community specific support. Key community members are also important for transmitting information, particularly as word of mouth is the most common way of finding out information for many small minority ethnic groups.
- Link workers are seen as very important in community engagement, but it is important to have the right member of staff with the best level of awareness and sensitivity.
- There is a need to continue support or funding of support for settled communities with continuing needs as well as supporting recently migrated communities.
- Existing minority ethnic organisations function as a vital bridge for very marginalised people until they can be enabled to move on to mainstream organisations, and for those who need a greater degree of trust and credibility, which organisations with a long history of working with minority ethnic groups can achieve.
- There should be recognition of the value that support staff, who are drawn from local faith and ethnic communities, can bring through their lived experience of migration, displacement, racism and difficulties they or their parents faced as newcomers. If these organisations were to cease to exist, it will be exceptionally hard to replace their expertise.
- Solutions for community-specific engagement can be quite inventive. For example, barber shops and hair salons function as informal meeting places for the African community[6], where issues are often openly discussed, and would be a good place for signposting people to available services

[6] Baker, G. (2016), *Mwamba Project Evaluation,* Edinburgh: Waverley Care and Relationships Scotland.

PREVENTION AND EARLY INTERVENTION

- Many health issues which affect minority ethnic groups disproportionately relate to discrimination and to adverse social and economic circumstances. Improving overall equality will therefore help combat the associated health inequalities.
- Many third sector organisations felt that their service users responded better to health care-related messages from medical professionals and so workshops about healthy behaviours, diseases, and how the system works delivered to minority ethnic communities through Third Sector services should be led by the NHS. These workshops:
    - would provide the opportunity to do blood pressure/cholesterol tests, or to arrange for a breast/bowel/general health screening, etc., to help pick up early signs of disease.
    - should use appropriate engagement methods that include one to one support, confidence building and use of simple language, and provide childcare and transport as necessary and be carried out regularly as service users change.
- Increase opportunities for culturally appropriate single sex physical activity sessions at convenient times
- Diet: increase the availability of specialist (e.g. halal) foods and fruit and vegetables from countries of origin in local retailers and ensure that appropriate meat is available in schools; and provide more information about healthy diets to the BME community

WIDER DETERMINANTS OF HEALTH

- Processes to recognise qualifications from other countries should be cheaper and more streamlined
- Support to find work and to remove barriers to work (e.g. prejudice, language)
- Promotion of equalities laws to employers
- Better and more affordable English as a Second Language (ESL) classes at a range of levels
- A local campaign for clearer, quicker and more humane immigration procedure to remove uncertainties surrounding immigration
- A wide and open campaign against racism and discrimination to seek to prevent members of BME communities being victimised due to their race, religious beliefs and/or culture
- Childcare, by having more child friendly times for parents to attend physical activities and by providing free childcare so that parents can attend training and educational courses

- Overcoming isolation: provision of social opportunities – for particular BME groups, between BME groups and the wider community
- Further research into issues of minority ethnic communities who live in more crowded conditions
- Better data collection when people engage in services (including independent and Third Sectors) so that there is better evidence of need.

PRIORITIES

The priorities identified for the future were:

- Redesign of interpreting and translation services: this is ongoing and any loss of continuity of or drop in service quality is a risk to the capacity to provide care for minority groups
- Ongoing work to support cultural competence among staff should be prioritised.
- Assessing the need for mental health services for minority groups – including needs of refugees in relation to post-traumatic stress disorder
- Needs assessment and continual development of services for all minority ethnic groups. For example for refugees and asylum seekers, there is little known about this group in Edinburgh other than of those on the Syrian VPR scheme. People often don't contact services until they have become unwell or are in distress which makes solving their problems more difficult.
- Improving access to care, particularly improving the ability of the Access GP Practice to move families on to other General Practices within the Health and Social Care Partnership. This is largely to do with 'closed lists' and general capacity problems.

CURRENT SUPPORTS FOR PEOPLE FROM MINORITY ETHNIC COMMUNITIES IN EDINBURGH - DRAFT

This section provides an overview of the health and social care related supports which are currently in place or being considered in Edinburgh. There are three broad types:

- Voluntary sector provision, specifically to address the health needs of ethnic minority communities
- Support through mainstream services – i.e. those which are available to the general population
- New and proposed initiatives

VOLUNTARY SECTOR BASED INITIATIVES

The Edinburgh Integration Joint Board (EIJB) supports a range of voluntary sector provision across the city which is intended to meet ethnic minority health needs.

The initiatives supported by the EIJB work with a wide range of ethnic minority groups including: South Asian, Chinese, Polish, Syrian, Arabic, Roma, Central and Eastern European (CEE), Black Minority Ethnic groups as well as migrants and refugees. The range of services provided includes counselling, GP referral service, volunteer befriending service, health improvement service, language skills, skills for living and working and integration sessions.

The following projects highlight the type of initiatives which support cultural bridging within the city. See further examples of organisations working in this field in Appendix 2.

Feniks (Polish) provides a Polish Counselling Service and Conversation Cafes across the city. The project comprises of a group of professionals (psychologists, educators and psychotherapists) who fill a gap in the psychological services available to the Polish community in Edinburgh. The aim of the project is to help individuals living away from their homeland to face the challenges which result from immigration.

The Welcoming (Migrants/ Syrian Refugees) provides English language classes, integration and Scottish culture activities as well as skills for living and working in Scotland. The project is also part of the Edinburgh Syrian Resettlement Scheme providing dedicated resources to meet the needs of Syrian refugees. The project is currently supported by the EIJB to deliver health and wellbeing activities, an information, advice and employability programme for refugees and integration activities for all migrants and refugees.

Health All Round (Central and Eastern Europe/Roma) provides a volunteer befriending service, a GP referral service and English language classes. Health all Round supports and manages a link worker service to promote the uptake of NHS & voluntary sector services by CEE and Roma people as well as access to support to gain employment.

MECOPP (Chinese/South Asian/Gypsy/Travellers) supports Minority Ethnic carers and those in receipt of care to access the supports and services necessary to undertake or sustain a caring role. The organisation provides the following services: multi-lingual advice and information; advocacy and casework support; education, training and learning opportunities; social and recreational activities; and, practical support in the home via the domiciliary care at home service. MECOPP also supports statutory and voluntary sector partners through policy and workforce development. MECOPP also delivers a number of projects including self-directed support for South Asian and Chinese communities with a focus on community brokerage and micro-enterprise, health improvement for Chinese people aged 45+, Skills Development Scotland (SDS) legal rights project, specialist support for South Asian people with dementia and their carers' and an oral history project.

Nari Kallyan Shangho (NKS) supporting South Asian communities (Indian, Bangladeshi and Pakistani) in Edinburgh through one to one support as well as educational and health promotion workshops and activities.

SUPPORT FROM STATUTORY SERVICES

A number of initiatives operate within statutory services to address the health needs of people from ethnic minority communities.

The **Minority Ethnic Health Inclusion Service (MEHIS)** aims to improve the quality of, and access to, primary health care services for BME and refugee communities across Lothian. MEHIS provides free and confidential, advice, information and support to black, minority ethnic and refugee communities. MEHIS have ethnic minority link workers (Indian, Pakistani, Bangladeshi, Chinese and Arabic) who speak various languages and can help service users to access primary health care services and perform an advocacy role regarding health services.

Primary Care Initiatives

Within Edinburgh, GP surgeries are now offering a range of services to address the needs of ethnic minority groups:

- Two GP practices offer Polish Clinics with Polish speaking GPs in South Edinburgh
- Muirhouse Medical Group is working in partnership with the Living In Harmony Initiative to improve its accessibility to ethnic minority patients. The medical group is currently revising its procedures, training and provision in the following ways:
    - Introducing changes to the registration system to allow reception staff more time to guide people through the process

- Meeting and training with the Minority Ethnic Health Inclusion Service (MEHIS) to introduce culturally sensitive procedures
- Redesigning their website to be more easily accessible and culturally appropriate to ethnic minority patients
- Undertaking Equality and Diversity training with *Living in Harmony*
- Developing an information sharing process with Pilton Community Health Project (PCHP) and *Living in Harmony*
- Offering a double appointment when an interpreter is needed

A nurse from the Health and Social Care Partnership has been working with the Syrian refugee settlement team as part of the welcoming committee which meets people at the airport. The nurse carries out an initial triage of health and decides if someone needs any urgent care, gives a talk on how to access health services and helps people to register with GPs.

The intermediary link worker service has 14 link workers in place throughout the city attached to various GP Practices and employed by third sector organisations. The service aims to:

- Tackle health inequalities and improve health and wellbeing
- Provide a person-centred approach
- Provide more resources for patients with complex clinical and social needs

As the focus of this approach is person-centred and tailored to the individual's needs, it provides an ideal opportunity for the needs of ethnic minority patients to be addressed in a holistic manner using both medical and community support.

The service is intended to support people with complex needs who frequently present at their GP surgery, to help them to gain more control and manage their health within a community rather than a clinical setting. If successful, it is anticipated that people will make fewer visits to their GPs, take less medication and make less use of emergency services. The service will provide opportunities for connecting people to non-medical sources of support or resources in the community which are likely to help with the health problems they are experiencing, allowing primary care staff to draw on non-medical options to support their patients.

FEEDBACK

Feedback from the engagement phase about the support available was positive. MECOPP, MEHIS, and ‘integration and Scottish cultural activities’ were thought to be working particularly well. English language classes were also well thought-of, but organisations noted the difficulties of getting people to attend these classes, and when holding classes in-house, they find they need to give incentives. One way to increase attendance would be to provide child care for ESL class attendees, and for them to be free and accessible. There was also a lot of positive feedback for the work of link workers and advocacy services.

It was acknowledged that engaging with people and supporting them to build confidence can take a lot of time. Respondents believed that the Third Sector is in the right position to provide this support and bridging.

It was also noted that not everyone is looking for ‘welcoming’ services, as they have lived here all their lives; better provision and promotion of other services is also needed.

SUMMARY AND NEXT STEPS

There is a complex association between ethnicity and health, with socioeconomic factors recognised as having an important role. An understanding of what contributes to poor health and wellbeing and the barriers and challenges to seeking and obtaining support (many being interrelated) helps to inform actions needed. This report includes an overview of the main contributors, from the perspective of people in minority groups and people involved in supporting them. These include:

- The impact of discrimination and racism
- Language barriers and literacy issues - affecting access and engagement
- Poverty and low socio-economic status
- Social isolation
- Culture and religion-specific issues which impact on health-seeking behaviours
- Stigma e.g. of mental health issues
- Impact of trauma and crisis in home country e.g. asylum seeks
- Interaction with the health care system – expectations versus reality.

Actions needed to address these include:

- Staff training including cultural sensitivity
- Recognition of the role of the Third Sector
- Effective community engagement
- Developing effective approaches to prevention including overcoming isolation.

Strategic and service responses sit at a range at a range of levels, including local and national government, health and social care partnerships, public health and the third sector.

NEXT STEPS

1. The report will be considered by the Edinburgh IJB's Strategic Planning Group, who will consider the findings and make recommendations for actions to the IJB.
2. The report will be shared with the groups who are working on developing the Strategic Commissioning Plans for Older People, Mental Health, Disability and Primary Care
3. Ongoing monitoring through the JSNA process will necessary, as the increasingly multicultural make up of Edinburgh means that we must regularly review access to services, health status and needs of minority groups.

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APPENDIX 1 FEEDBACK FROM ENGAGEMENT ON THE DRAFT REPORT

Feedback from Third Sector Organisations and Their Service Users on The JSNA Phase I Report: Health And Care Needs Of People From Minority Ethnic Communities

Introduction

As part of the development of the suite of Joint Strategic Needs Analysis (JSNA) papers, EVOC agreed to collect feedback from Third Sector organisations and users of their services about the Phase I report into the health and care need of people from minority ethnic communities. The Phase I report was based on:

1) Existing data about population demographics, health needs, disease prevalence, and the use of health and care services of the minority ethnic groups in Edinburgh.
2) An engagement event held by EVOC in October 2016, for staff members of Third Sector organisations working with minority ethnic communities.

This report, as Phase II of this exercise was undertaken with the aim of ensuring that:

- the health issues, barriers to accessing and using health and care services, and recommendations listed in the paper were full and complete;
- the approach, terminology and language used in the report was useful and appropriate;
- the findings in the paper included the views of Third Sector organisations' staff members and were representative of the feelings of service users of Third Sector services.

Methodology

Feedback from organisations

Twenty-five carefully selected organisations representing a range of minority ethnic communities, across age and gender groups, were contacted directly for feedback: six meetings between Third Sector staff members and the EVOC researcher were convened, and fourteen organisations submitted written feedback.

Feedback was collected between March-May 2017.

The request for written feedback was extended *en mass* to all organisations listed in the EVOC Redbook which included the tag 'Black & Minority Ethnic'. It was further extended to all the organisations in EVOC's networks, and was publicized in the EVOC newsletter and on EVOC's website. Written feedback could be given online (via Survey Monkey) or by completing feedback templates using Microsoft Word. In two cases, hard copies of the report and feedback template were posted with an addressed and stamped envelope.

Feedback from service users

Five organisations were invited to arrange focus groups for their service users, with service provider staff and the EVOC researcher. Secondly, all organisations were asked to provide two case studies, as examples of: a service user who has had a difficult experience when accessing health or social care services in Edinburgh, and a service user who has had a positive experience of accessing health or social care services in Edinburgh.

Results

We received feedback from sixteen organisations in total:

- 3 organisations as focus groups at existing group meetings.
- 5 organisations as one-to-one meetings with staff members.
- 14 individuals representing 11 organisations as written feedback (6 online; 8 using the feedback template).

A further five individuals began the survey monkey but did not leave feedback, and three of the organisations met with in person also gave written feedback. Another organisation did not leave specific feedback, but provided a relevant report.

Two of the planned focus groups were unable to go ahead, but written feedback was given in one case, and we met with staff representatives from the other.

Feedback was not received from ten of the organisations contacted directly, and one other did not feel that it would be appropriate for them to give feedback due to the nature of their service.

1. List of organisations present at Phase I engagement event

CAPS Advocacy
Deaf Action
Edinburgh Mosque
Equal Scotland
EVOC Community Activity Mentors
Feniks
Health 4 U
Health All Round
Health in Mind
LCIL
MECOPP
MILAN Senior Welfare
NKS
North Edinburgh BME transition
Pilton Community Health Project
Shakti
Sikh Sanjog

2. List of organisations that provided feedback for Phase II

Action for Sick Children Scotland*
Deaf Action
Drylaw Rainbow Club Day*
Edinburgh Chinese Elderly Association
Feniks
Health All Round*
Health in Mind: Equal Access
MECOPP
MILAN
Multi-Cultural Family Base
Nari Kallyan Shangho
NHS Lothian MEHIS
Pilmeny Development Project
Polish Family Support Centre
SCOREscotland**
Shakti Women's Aid
Sikh Sanjog
The Action Group- Black and Ethnic Minority Advice Services (BEMAS)
The Big Issue
Waverley Care: African Health Project
*Began SurveyMonkey but did not complete.
**Sent in relevant information but did not give specific feedback.

Not all minority ethnic communities living in Edinburgh have been represented in this list. This must be acknowledged. These include, but are not limited to, the Syrian community, the Nepalese community, the Kurdish community, the Sudanese community, the Arabic community, and the Pakistani community.

Summary of feedback

This section gives a brief overview of key points made in the feedback report. The full report is available on request.

There was some criticism of the scope of engagement, which involved only Third Sector staff rather than members of the public. However, whilst attempts were made to receive confirmation that feedback from staff was representative of the feelings of their service users, through focus groups and case studies, broader engagement was not possible given the resources available.

Specific feedback was given on the accuracy of some of the points made as well as terminology and use of language. The level of coverage – incomplete for some minority groups and extensive for others – was also highlighted.

There was general agreement with the findings of the Phase I report, which was supported by the personal experiences of Third Sector service users from minority ethnic communities. The majority of barriers identified and the recommendations mentioned had already been covered in the Phase I report. Most additional barriers or recommendations added in this report relate specifically to the groups each organisation is set up to serve, or represent a need to expand on a point already listed, due to more nuanced feedback. As expected, people tended to focus on negative experiences more than positive ones; many staff and service users did express satisfaction with existing services, but this tended to be general, rather than pinpointing specific points. There was strong support for many of the existing services involved in cultural bridging initiatives in Edinburgh, and some forward thinking and positive suggestions for future steps.

Comments about Overall Approach

The work was well-received in general by those who responded, and respondents were very keen to have the findings taken forward to make improvements for the lives of minority ethnic groups in relation to heath and care needs. However, there were some who expressed frustration with the continued need to ask these questions of BME people, and felt pessimistic about contributing, as based on past experiences, they felt that these types of engagement have not resulted in much change.

There are many existing and up-to-date pieces of work which were not used to inform the Phase I report, which have already asked many of the same questions as this project, and

provided details about the specific health needs of different communities (these are included in the reference list at the end of the main report).

Some recommendations in the Phase I report are too broad, and the feedback called for suggestions for actions, rather than aspirational statements seeking to solve large problems.

In the written feedback, the Phase II data collection stage was criticised for involving only Third Sector staff rather than members of the public. Whilst we did try to receive confirmation that feedback from staff was representative of the feelings of their service users, through focus groups and case studies, we recognise that more than 3 focus groups would be needed to do this empirically, but this was logistically impossible.

APPENDIX 2. LIST OF VOLUNTARY ORGANISATIONS

Important note: the following is based on the most up to date information available to us, but there may be organisations missed who work exclusively with people from minority ethnic communities or participated because they have experience working with service users from minority ethnic communities.

CAPS Advocacy CAPS is an independent advocacy organisation for people who use or have used mental health services. We are completely independent from the people who fund us and those who provide other services to the people we work with. We provide individual and collective advocacy in East Lothian and Midlothian. We also host several experience-led projects across Lothian. http://capsadvocacy.org/

Deaf Action Deaf Action delivers a range of services to the estimated 950,000 people in Scotland with sensory support needs, including those who are blind, partially sighted, deaf, deafblind and hard of hearing. As part of a Scottish Government funded project we are establishing a benchmark for future dual sensory loss services in Scotland. http://www.deafaction.org.uk/

Equal Scotland Equal Scotland is a national equality and diversity organisation. We research, identify and address gaps in the equalities landscape across all protected characteristics. We aim to work with all stakeholders to champion and sustain essential and impactful programmes. https://equalscotland.org.uk/

Health 4 U Health 4 you CIC is an emerging social enterprise aiming to help BME women in the East and Southeast of Edinburgh to improve their health and personal wellbeing. We intend to provide a diverse range of projects that, in addition to serving the community, will offer opportunities for disadvantaged women to gain employment with us and volunteering experiences. http://www.health4you.co/

Health In Mind: Equal Action We provide support for men and women from BME communities, who are experiencing feelings of stress or isolation and are unable to access information about the services available https://www.edinburgh.gov.uk/directory_record/699592/health_in_mind_equal_access

Lothian Centre for Inclusive Living (LCiL) is a user controlled organisation which supports disabled people, people with long-term conditions and older people, to live independently in their communities. http://www.lothiancil.org.uk/

North Edinburgh BME Transition This group was formed after Community Organisation for Race Equality (CORE) closed down. The aim of this group was to identify the continuing needs of the minority ethnic community in the area and how they might be addressed after CORE's closure. http://www.totalcraigroyston.co.uk/wp-content/uploads/2013/04/Living-in-Harmony-Report.pdf

Pilton Community Health Project We use a social model of health - looking at how health is affected by everyday life and is as much about the quality of your emotional and social situation as about your experience of disease or disability. The Living in Harmony project aims to create more opportunities for friendships between different ethnic communities in North Edinburgh, and to

tackle any barriers which may prevent people from Black and Ethnic Minority backgrounds from accessing local services. http://www.pchp.org.uk/projects/living-harmony

Shakti Women's Aid helps BME women, children, and young people experiencing, or who have experienced, domestic abuse from a partner, ex-partner, and/ or other members of the household. http://shaktiedinburgh.co.uk/

Sikh Sanjog was set up in 1989, under the name 'Leith Sikh Community Group.' Its aim was to provide support for women in the Sikh community who had been settling in Edinburgh since the 1950's http://www.sikhsanjog.com/

Elderly Chinese Association We offer a range of services for older people from the Chinese community. Day care, information and advice on welfare rights and benefits, recreational and social activities, lunch club, home visiting project and a support group for carers http://www.evocredbook.org.uk/organisations/edinburgh-chinese-elderly-support-association/001b00000065uv4AAA

Multi-Cultural Family Base At MCFB in Edinburgh we work with children and their families who are experiencing difficulties. Some of these are practical, such as housing or financial problems; others are more personal, such as dealing with discrimination or emotional issues http://www.mcfb.org.uk/

Pilmeny Development Project The overall aim of the Pilmeny Development Project is to support local residents and groups and to encourage appropriate self-help initiatives towards the identification and resolution of their problems. This means we work with local people to identify and deliver actions which contribute to sustainable development of both individual and groups in this part of Edinburgh to improve their quality of life.
http://www.pilmenydevelopmentproject.co.uk/start

Centre Polish Family Support Centre is an organisation established in 2009. We are a growing charity focusing on providing support to the Polish minority in Scotland. We offer comprehensive support for disadvantaged people through offering counselling, social and advocacy services, principally targeting the difficulties Polish people face after leaving their native country http://www.pfsc.co.uk/home/4591478247

Saheliya is a specialist mental health and well-being support organisation for black, minority ethnic, asylum seeker, refugee and migrant women and girls (12+) in the Edinburgh and Glasgow area. Sahliya's mission is to promote mental well-being by combating the effects of discrimination and abuse, reducing the stigma of mental health, and improving access to mainstream services. http://www.saheliya.co.uk/

SCOREscotland Strengthening Communities for Race Equality Scotland (SCOREscotland) is a voluntary organisation serving the minority ethnic communities in the West of Edinburgh. The organisation strives to eliminate racism in our society by working for and with those who are affected by racial discrimination http://www.scorescotland.org.uk/

The Action Group- Black and Ethnic Minority Advice Services BEMAS is for carers of children with a disability or additional needs, from a Black and Ethnic Minority Community. We offer 1:1 advice and group sessions to support you in your caring role.

https://www.edinburgh.gov.uk/directory_record/699875/the_action_group_-_black_and_ethnic_minority_advice_service_bemas

Waverley Care: African Health Project For over a decade, our African Health Project has worked with Africans living with HIV in Scotland in one-to-one and group settings to bring more stability into people's lives http://www.waverleycare.org/waverley_care/african-health-project-support/