The needs of Somali visually impaired people in Sheffield.

Gina Higginbottom, Robin Story, Kaltum Rivers.
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Acknowledgements

Our thanks go the visually impaired people of Somali origin in Sheffield who participated in this study and their carers. The Horn of Africa Blind Society (HABS) originally conceptualised the research questions in particular we would like to thank Mr Abdi Mohammed, Mr. Robin Story and the research team members, Abdi Hafid, Mohammed Bashir, Carmen Calvo and Dr Rosemary Barber who participated in the advisory group. We would also like to thank the service providers, voluntary groups and associations who gave time in their busy schedules to participate in the study. Finally we would like thank the Sheffield Health and Research Consortium who generously funded this study.
Coming to this country and living in Holland before, there is not much difference. Both are not home in terms of language and cultural differences. I feel a bit scared walking about just in case I have to speak to anyone. After 4 years I still don’t know the British culture. I’m sure the people are nice, they are, aren’t they?
KR16 p2/3
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List of Abbreviations

VIP | Visually impaired person
VI  | Visual impairment
HABS| Horn of Africa Blind Society
R   | Respondent
In  | Interviewer
SRSB| Sheffield Royal Society for the Blind
FGI | Focus Group Interview
UK  | United Kingdom
1. Background to the study:

In 2003 the principal investigator of this study was approached by HABS to develop a research study to investigate the health and social care needs of visually impaired people (VIP) of Somali origin in Sheffield. During 2003, a working collaboration was established and a research proposal developed. Subsequently, the proposal was successfully submitted for funding by the Sheffield Health and Research Consortium and project staff appointed in 2004.

Horn of Africa Blind Society

The Horn of Africa Blind Society was launched in March 2001 as a company limited by guarantee. It became a registered charity in 2004 (UK Registered Charity No. 1106583, Company Reg. No. 04613071). Members of HABS’s Executive Committee are listed in Appendix 1. The society based in Sheffield, UK, aims to improve the lives of blind and partially-sighted Somali-speaking people in both the UK and the countries of the Horn of Africa starting with Somaliland.

Objectives in Sheffield

1. To assess the needs of blind and partially-sighted Somali-speaking people
2. To design services and provide support using volunteers to meet these needs
3. To refer clients to existing services and ensure that such services are appropriate to needs
4. To work to remove negative stereotypes from blind and visually impaired people about their abilities
5. To increase the awareness of the local Somali community of the issues affecting people with visual impairments
6. To seek funds to continue this work

Objectives in Somaliland

1. To establish local management committees to further the work of the society in the Horn of Africa as laid down in a memorandum of understanding
2. To advise, support and assist with resourcing these local management committees
3. To work to remove negative stereotypes from blind and visually impaired people about their abilities
4. To increase the awareness of the local community and government and non-government organisations of the issues affecting people with visual impairments
5. To seek funds to continue this work

Progress in Sheffield

The Sheffield Royal Society for the Blind estimates that about 150 of the 8,000 Somali-speaking people in Sheffield are blind or partially-sighted. The first task of HABS was to ascertain the needs of this group. The University of Sheffield was approached and with a grant from the Sheffield Health and Social Care Consortium the University conducted a research project during 2005/2006.

While the research was in progress, the Society’s Chairman, Abdi Mohamed, with the help of volunteers, trained teachers in Somali Braille and made people aware that blind people could operate computers using screen-reading software. In addition a website (www.hornofafricablind.org.uk) was constructed.

In January 2006 with a successful Lottery grant HABS appointed a Development Worker for three years to provide information and services to meet those needs identified by the research project that are within the society’s capability. Where services are already provided by other agencies, the society’s volunteers will advise people how to gain access and make use of them.
**Progress in Somaliland**

The society’s aims extend to developing services for Somali-speaking blind and partially-sighted people in the Horn of Africa.

The Society has already appointed under a ‘memorandum of understanding’ a national representative, Ahmed Hussein, and a Regional Representative, Ahmed Yusuf Hersi. Abdi Mohamed, the society’s chairman, visited Somaliland from 20 April to July 2005. During his visit he held discussions with the President and head of state, the Ministers of Education and of Social Development, the Provincial Governor, the Mayor of Burao and many other civic and non-governmental officials and the society’s representatives. Abdi’s report of his visit is available on request from the society.

The temporary Burao Centre for blind and visually impaired people was officially opened on 12 May 2005, by the Governor of the Togdheer Region. Abdi Mohamed trained 11 braille teachers using braille typewriters brought by him from the U.K. The equipment also included desktop computers, embossing machines and the appropriate stationary. The training course took 4 weeks of intensive and rigorous work designed to produce proficient braille teachers capable of instructing the blind and visually impaired people effectively in the shortest time possible. These braille teachers were handpicked and selected for their educational standards and professional attitudes, and consisted of 6 women and 5 men of high calibre. The funding for starting the centre and running the first course for the braille teachers was provided by the society, LAXMAR (a community-based organisation) and the Municipality of Burao.

1.2 Introduction

**What is visual impairment?**

The statutory definition of blindness is that a person should be “so blind as to be unable to perform any work for which eyesight is essential”. There is no similar definition of partial sightedness, however in practice this category refers to persons who, although not blind within the meaning of the 1948 Act, are substantially and permanently disabled by defective vision caused by congenital defect, illness or injury (Anderson 2003 p12).

The incidence of visual impairment is high within some ethnic communities (Bruce et al 1991). The Horn of Africa Society (2003) estimate, that approximately 150 people in Sheffield of Somali origin are blind or visually impaired. In considering the needs of Somali populations in England, it is true to say that a paucity of information exists. Studies that do exist are local and tend to focus on the psychological and emotional well being of Somali populations following displacement due to civil unrest (Silveira et al. 2001, Silveira and Ebrahim 1998). Little attention is afforded to health and social needs of Somali blind people. However, a significant study recently concluded by Morjaria-Keval (2005) focused on access to services by VIP from minority ethnic communities. Johnson and Scale (2000) conducted a study that reviewed visual impairment in ethnic minority populations in general. They concluded that research into ethnic minority health issues had “tended to ignore visual impairment” (Johnson and Scale 2000 p.59) and that this is a research priority. In this respect, visually impaired Somali people can be regarded as a marginalised minority within a minority who may experience a double jeopardy in their ethnicity and visual impairment. One of the research priorities established by Johnson and Scale (1999 p.60) was to establish the extent to which eye disorders prevail within different ethnic groups and the accessibility of services. The issue of access to services by Somali blind people may be further compounded by language barriers.
1.3 Research Aim
The overall aim of the study was to investigate and establish the health and social care needs of VIP Somali people residing in Sheffield.

Research Questions
This research focused on the needs of the Somali VIP living in Sheffield; the purpose of the research was to investigate:

• How many individuals interviewed are registered i) blind, ii) partially sighted?
• How many are aware of registration?
• What eye conditions do they experience?
• What do they express as their requirements with regard to sight loss e.g. Education, rehabilitation, mobility, communication and information needs?
• What services for blind people in Sheffield are they aware of?
• Do they access these services?
• What services would best meet the needs of Somali blind people in Sheffield?
• What are the perspectives of carers of Somali visually impaired people?

These research questions it was anticipated would enable the needs of visually impaired people of Somali origin in Sheffield to be made more explicit and be of value to service providers and policy makers.

There are a multitude of problems that affect Somali people in the UK, such as language barriers, lack of information about services, immigration status etc, and visually impaired members of the Somali community may experience greater challenges than the wider Somali community living in UK.

1.4 Literature review

Aims and Objectives:
1. To review the available literature that deals with the needs of the Somali visually impaired people.
2. To discover any gaps in the information and knowledge of the needs of the Somali visually impaired people in the UK. It will provide us with a chance to propose an effective way to address the needs of the Somali Visually Impaired people in Sheffield.

Introduction:
A number of research studies have focused more generally on the welfare of Somali people, including Harris (2004), Ahmed (1989), Kleist (2003) Alasow (2002) Cole and Robinson (2003), Elam, (2003). However, almost all of these repeat the same conclusions and recommendations.

There are at least 139 articles identified by the Information Centre for Asylum Seekers and Refugees, of the studies which focus expressly on Somali populations most were published in the 1990’s (Harris, 2004).

With this in mind, this review will summarise some of the literature available with regard to the needs of the Somali people who experience disability, in particular the visually impaired and partially sighted. The review will also address the gaps in the services that are available. The deficits in service provision have provided areas for further exploration with participants in this study.

Some of papers reviewed will be looked at in terms of migration history; others will be reviewed as to whether they give accurate information about the Somali people in the UK and if they have identified the health and social care needs of the Somalis. The reviewed papers will only be commented on in this report, for those that have been excluded please see the methodology section below.
Methodology
The methodology for the literature review was developed in collaboration with an information scientist from the ScHARR Library, University of Sheffield.

Literature search strategy
A comprehensive literature search was undertaken informed by systematic review principles (although this is not a systematic review). The review strategy covered four main areas:

- Somali visually impaired people (including their needs)
- The needs of visually impaired people from other ethnic minorities
- The needs of disabled Somali people
- The needs of visually impaired people in general

All the searches were originally undertaken September-October 2004 and updated in early 2006. The search strategies and results were carefully documented to ensure a transparent and replicable approach. The search results were downloaded into Reference Manager and keywords assigned accordingly.

Sources searched
A wide variety of sources were searched. Please see Appendix 2 for the search strategy.

1.5 Findings of the Literature Review

Somali and Somaliland
Somalia was formed after the two colonial territories Italian Somaliland and British Somaliland were merged following the departure of the colonial powers. The British settled in Somaliland in 1886 and established a protectorate in 1889. Later, the Italians who settled in the Southern parts of Somalia and, the French took part in this colonization of Africa and occupied what is now known as Djibouti. Before the western colonial powers divided Somalia into different parts the Egyptians were present in parts of Somalia in particular the north (now the self declared republic of Somaliland).

In 1960, following the withdrawal of the colonial powers, Somalia was formed. In 1969, following a military coup, Siad Barre took control of the country and ruled through a military style dictatorship. Political oppression resulted in civil unrest and conflict, and in 1988 the first bombardment of civilians started in northern Somalia.

In 1991 southern Somalia experienced similar civil unrest and the dictatorship government was overthrown. Somaliland then announced its independence from Somalia, although international governments do not recognize it yet. Civil unrest is still present in Somalia. Many Somalis in the Diaspora have experienced these oppressions and persecutions in the hands of the military dictatorship, hence the reason so many fled to both neighbouring countries and the west.

Ethno-history of Somali people in the UK
Somalia lies on the east coast of Africa bordered by Ethiopia to the northwest and Kenya to the west. Somalia is an Islamic country and its people are largely nomadic pastoralists, herding sheep, camel and goats in the semi-arid pasture of what is now Somalia, although the search for grazing takes them across contemporary borders into neighboring Ethiopia, Kenya, and Djibouti. The Somali people historically share a single ancestry, religion, language and culture that bind them together. However, the tragic civil wars that have taken place over the past 16 years have damaged the country’s economy and stability and hence have affected the health system. Over nearly two decades, millions of Somalis fled to neighbouring countries as well as to western countries for protection and sanctuary (Ahmed, 1989, Kleist, 2003).
Somalis are often labelled as asylum seekers and refugees when discussing new communities in the United Kingdom (UK). However it's important to look at the migratory history of the Somalis in Britain.

The Somali people were attracted to Britain as seamen at the end of the 20th century, and because of the colonial links within British Somaliland, it was possible for the men to immigrate and work as sailors in the UK. Therefore, Somali people have been living in Britain for more than a century. After they established themselves, Somali seamen were joined by their families and became part of British society (Alasow 2002, Harris 2004).

Alasow stated in his report:

"The presence of Somalis living in Britain dates back to 1900. All the major ports including Cardiff, Liverpool, South Shields and London’s East End show records of Somalis living there before the First World War. At that time, many Somali young men immigrated to Aden in Yemen, which was then a British colony and an important port. There were others who were brought to Britain by their employers in Somalia, which was also a British colony at that time. Many Somalis found work as seafarers on British ships" (Alasow, 2002, p13)

Harris (2004) has also found that although there is a large Somali community scattered around London, particularly in the east end, there are also large Somali communities in other areas in the UK. He has stated:

"Other Somali populations reflected in the provenance of reports include (in order of number of documents): Wales (especially Cardiff), Bristol, Sheffield, Birmingham, Manchester, and Leicester" (Harris, 2004 p12).

Each of these communities has been simultaneously a visible but an invisible community (Harris 2004). In a recent research project, Cole and Robinson (2003) explicated the historical antecedents that have configured Somalia in the 21st century. These are, attempts by the colonial powers to seek control of the country, conflicts with neighbouring countries and internal clan warfare. Although Cole and Robinson (2003) acknowledged the presence of the Somalis in the UK for more than 100 years, they have mentioned the growth of the Somali population in the UK, as being a result of the civil wars that started in 1980s. They have estimated that by 1992 up to a third of the Somali population were facing starvation and many were fleeing Somalia to neighbouring countries (Cole and Robinson 2003). Kliest has also stated

"...overall geopolitical development from colonialism to the so-called ‘new post cold war world order’ has significantly structured migration from Somali regions into the West" (Kliest, 2003 p1).

With the rise and fall of asylum applications related to the ever-changing immigration policies, there is no exact record of the number of Somalis settling here in the UK. The number of applications according to the refugee council has risen from 6,020 in 2000 to 65,000 in 2001 (Cole and Robinson, 2003). A major problem is the lack of an accurate data regarding the number of Somali people in the UK. As Harris found in a recent research report commissioned by the Information Centre about Asylum and Refugees (ICAR) (Harris, 2004).

A recent advisory panel on country information found that there is inaccuracy in the information held at the Immigration and Nationality Directorate about Somalia. In this report the authors mention the use of outdated data and sources. They have also stated that although the Country Information Unit (CIU) of the Home Office mentions disabled refugees, it fails to address the severity of the situation in Somalia and the plight of disabled Somali people (Black and Abdi, 2003). Lack of reliable data is becoming a major obstacle to examining the needs of the Somalis in the UK (Harris, 2004, Cole and Robinson, 2003).

The 2001 UK wide census has failed to recognise the Somali population as a specific category. Whereas those who were born in Britain might still classify themselves as black African in tick box surveys, some might tick the black British box. This has led to further uncertainty as to the true number of people of Somali origin residing in the UK (Cole and Robinson 2003). Furthermore, research that uses the census classifications tend to present findings regarding black Africans as a homogenous cohort.

In Sheffield the recent census report carried out by Sheffield Hallam University (2001) found that although the number of Somalis might be growing, at the time of research, it was estimated that the population of Somali people in Sheffield were 2,040. However the research team stated that the study only concentrated on four areas in Sheffield. This report was requested the Somali Community Association (Gibraltar St) in Sheffield. Whatever the reason the exact number Somali population in the UK is not known.
Carder (2003) highlights the immediate welfare needs of the Somali refugees. The health, social and welfare needs of the Somalis in the UK have been discussed in other research projects, some of which were targeted specifically at health needs.

In summary, we can conclude that the relocation of Somali people to the UK is not a new phenomenon, but that due to civil unrest there are a growing number of Somalis in the UK. However, what is not obvious is the extent to which their needs whether health, social or welfare are met. The following section will consider the needs of the visually impaired, the specific needs of visually impaired ethnic minorities and what we know about the needs of Somali disabled people.

The Somali communities in this country face a multitude of problems, in particular an inability to access services provided by their local authorities. In addition they face discrimination, poverty and most of all alienation. On arrival, as might be expected many of the British social and cultural ways are completely new to them, which adds to the challenges they face. For many Somali people, arriving in a new and alien country brings about problems associated with cultural adaptation, such as learning a new language and a different set of cultural norms. This may also bring about a questioning their own values and those of their host countries such as issues associated with entering a different system of schooling (Ahmed, 1989; Wiggs, 1994; Pearson, 1986).

Addressing health matters amongst the Somali community in the UK has been tackled in several papers and reports such as Silveira (2001). A good example is a recent feasibility study carried out by the Centre for Social Research for the Department of Health (DOH). This study addressed the health and cultural aspects of the Somali community in London. However, the health needs of Somali people who experienced a disability were not discussed in this report.

In 1994 The Community Health Project was set up in Sheffield to address the health needs and assist the Somali community with access to health and social care services. In its initial conference it was expressed that there were barriers that prevented the Somali community from accessing existing services. However, this project did not address the needs of the disabled people specifically. Disabled people and the elderly were mentioned in one of the workshops; however, there was no set target to put forward their needs (Musa, 1994).

The needs of VIP impaired people in general

The needs of the visually impaired are not limited to physical requirements, VIP have emotional, psychological, social care, health and welfare, technological and communication needs. All these issues need to be taken into consideration when exploring how services might be best configured for VIP.

According to the Royal National Institute for the Blind (RNIB) (2001), two million people in the UK are affected by sight loss, two-thirds of whom have an additional disability or suffer from a serious health problem such as deafness, arthritis or diabetes. Significantly, 90 per cent of blind and partially sighted people are aged over 60 - a population group, which is set to rise steadily (RNIB, 2001).

However, Owen et al (2003) estimate that there are currently 214,000 people in the UK with visual impairment caused by age-related macular degeneration. This number is expected to increase to 239,000 by the year 2011 (Watkinson, 2004, Macnaughton, 2001). In order to reduce health inequalities the needs of the visually impaired people have to be addressed. The information needs of the visually impaired have been investigated by Beverley and Booth (2004). In this review they found that that there is a specific requirement for accessible information.

On 31 March 2003, 155,00 people were on the register of partially sighted people. This is an increase of around 6,500 (4%) since March 2000 and more than double the figure at March 1982. There has been an increase in the number of partially sighted people on the registers for most age groups since March 2000. The largest increase is in the 5-17 age groups (16% since March 2000) (Anderson, 2003), which may be the result of more efficient screening services. However, as yet there is no accurate data for visually impaired ethnic minorities; this is required by local authorities to plan appropriate services. Ethnic monitoring of visual impairment is necessary in order to achieve this.

Visual impairment is one of the most prevalent and disabling conditions that arise in later life, yet its impact on the lives of older people has received little attention compared with other problems such as impaired mobility and dementia. As a result, health care professionals have insufficient knowledge of the health and social care needs of this growing population, which makes it difficult to develop appropriate services and define best practice (Hanson et al, 2002).
Visually impaired people should not be thought of as single large group who share a common set of defined needs. Specific needs can be identified for those visually impaired people from different age, cultural and ethnic groups, as well as those with additional complicating health problems (Ahmed et al 2003; Jelley, 2003; Davies, 1997; O’Hagan, 1998; McCloughan, 1999, Alexander, 2004).

**Mobility:** Access to and use of public transport, for example use of timetables, assistance when travelling, access to guide dogs and equipment.

**Welfare:** Health, housing and social care, including access to all available services, adaptation of homes and personal care. Access to leisure activities.

**Rehabilitation:** Gaining the confidence to live independently, mobility training. Advice on personal safety issues at home and elsewhere.

**Education and employment:** Access to tailored training schemes and employment.

**Information:** Access to suitably presented information concerning the issues above.

There is an obvious need for health information to be available to anybody who requires it. Access to health information needs to be specifically tailored for those with visual impairment and more so for those with additional language barriers (Jelley, 2003).

**Needs of visually impaired people from ethnic minority communities**

A Study carried out by Rahi in 2003 found that families from ethnic minorities and lower socio-economic groups are less likely to be visible in research (Rahi 2003). Evans and Banton (2001) found that black people with a disability have often found themselves falling between services for black and services for disabled people. They have also concluded that there needs to be a strategy to involve black people in shaping services (Evans and Banton, 2001).

The general needs that have been mentioned above apply to black and minority ethnic visually impaired people as well. However, due to language barriers, cultural constraints and migration status, their access to services is much more limited. Evans and Banton (2001) stated that one of the major strategies in involving black disabled people in services is to use various communication techniques such as audio tapes, providing transport and accessible venues as well as being aware of cultural needs.

In addition, newly arrived disabled asylum seekers and refugees often get overlooked and information about their particular needs is rarely available (Roberts and Harris, 2002, Brunett and Fassil, 2003).

**Needs of Visually impaired Somali people**

Black and minority people with a disability are often overlooked, in addition to this there has not been as far as we can establish any report, paper, research or work that solely focuses on Somali blind people in the UK. This research project will fill this research gap and address the needs of the visually impaired Somalis in Sheffield.

Language difficulties can hinder the delivery of effective service. Language barriers lead to poor communication and confusion (Yee, 1997). Recent studies also report that language barriers present a major obstacle to minority ethnic communities accessing primary healthcare (Gerrish, 2004; Alexander, 2004). Gerretson et al (2004) found similar needs amongst the Somali refugees and asylum seekers in The Netherlands. They have found that although Netherlands health surveys are frequently conducted to assess the health needs of the population, due to language and cultural problems these surveys exclude (first generation) immigrant generations (Gerritsen, 2004). The language barrier plays a great role in affecting ethnic minority’s access to services as Agar (1990) refers in her report to Somalis in Tower Hamlets. She stated that language difficulties were one of the main problems leading to poor use of services (Agar, 1990).

Somali cultural and religious beliefs are embedded into their way of life. Somalis do not keep pets in their homes and many do not agree with the use of animal guides such as dogs, although it is not known whether this belief is based in religion or culture dogs are not accepted in Somali houses.
2 Research Design

The research is underpinned and informed by a participatory research methodology (Beresford and Evans 1999, Beresford 2000, Rhodes et al 2001) that involves consumers in the research design, data collection, data analysis and dissemination. This was achieved via the close and ongoing collaboration with HABS. All members of the core research team were members of HABS. Research with ethnic minority groups and hard to reach groups is often characterised by difficulties in generating the study population (Elam and Fenton 2003) and the potential for 'cultural clash' and culturally incongruent research practice (Higginbottom and Serrant-Green 2005).

Local knowledge has suggested that the Somali community in Sheffield is experiencing a degree of research fatigue. In this research because of the close collaboration with HABS, and that fact the research was the result of self-defined need by the Somali community and entirely consumer driven, it was anticipated that the challenges outlined above would be minimised. However this proved to be an optimistic view as a number of challenges were encountered, which we believe are largely related to the stigmatised nature of visual impairment in the Somali community. These issues are discussed in more fully in the findings section.

On going collaboration was achieved via monthly project meetings attended by HABS representatives. HABS were involved as active partners in all decision making processes including the interviewing and recruitment of all project staff. Research team members also attended HABS meetings.

2.1 Methods

We adopted a qualitative methodology using focus group interviews (FGI), and interviews to explore, describe and understand the health and social care needs of VIP of Somali origin in Sheffield.

2.2 Sample

In this study non-probability samples, a) purposeful and b) snowball samples were adopted (Murphy 1998 et al., Higginbottom 2004) with all three cohorts’, service providers and other key stakeholders, Somali visually impaired people and carers of Somali VIP. We attempted to achieve maximum phenomena variation (Murphy et al 1998, Miles and Hubermann 1994, Sandelowski 1998) to enable theoretical generalisations to be made which will have relevance beyond the local community. For example one participant was a new migrant of four weeks duration, whilst another had lived in the UK for 40 years. Please see Appendix 3 for a table that maps out the demographic characteristics of the study participants in the main sample.

2.3 Recruitment

Service providers, Somali groups/associations and other key stakeholders

Service providers, Somali groups/associations and other key stakeholders were generated by identification via existing databases. A letter of invitation was sent to all potential FGI participants, along with a free-post envelope to enable the potential participant to contact us. Most of the participants were sighted in these groups apart from the first FGI in which HABS members participated, some of whom were visually impaired. HABS informed members via their monthly meetings.

Somali Visually Impaired people

We used a snowball technique to generate the main study sample. Snowball samples are said to be very useful to generate samples from hard to reach groups (Murphy 1998 et al) as key informants within the study population inform others of the existence of the research study. In this study the community researchers/data collectors (Somali community members who we trained in research techniques) and HABS passed on information about our study to potential participants.
Carers of Somali Visually Impaired people

Again we used a snowball approach, in that the community researchers/data collectors asked each person they interviewed if they would pass on details about our study to their carer. However, this proved to be problematic in terms of cultural misunderstandings about the term ‘carer’. If a family member cares for a Somali VIP this individual is not usually referred to as a carer, but as the family e.g. wife, aunt, uncle etc.

2.4 Location

We conducted our study within the city of Sheffield which is a conurbation of 513,234 people (http://neighbourhood.statistics.gov.uk). Whilst Sheffield is a multicultural, multi-ethnic city, the degree of diversity reflects the national average, with smaller populations of minority ethnic people than Manchester, Nottingham, Leicester and Birmingham. In the 2001 census 91.23% described themselves as ‘white’, therefore around 9% of the population are from members of non-white minority ethnic groups, although the last census had a category for black populations which accounted for 1.7%. It is not clear exactly what the number of people of Somali origin residing in Sheffield is. This is because many individuals are ‘chain migrants’ meaning that they may have first sought asylum in another EU state which means EU citizenship may have been conferred prior to the point of entry into the UK. As EU citizenship is conferred prior to entry into the UK, these individuals do not feature in refugee or asylum seeker statistics.

2.5 Data Collection tools

The research employed the principles of maintaining rigour and robustness in qualitative research as described by Murphy et al (1998). An explicit and reflective research methodology was adopted facilitating a transparent audit trail. Three methods of data collection were used in order to increase the comprehensiveness of the findings (Murphy et al 1998).

Focus Group Interviews

We used FGI to scope out the broad areas of investigation and four in total were conducted. The FGI provided a mechanism for establishing the relevant issues to inform the development of the semi-structured interviews, establishing the breadth, nature and extent of the issues under investigation. The topic guide was developed in consultation with the HABS. Morgan’s (2001) approach to moderation of FGI was utilised. FGI were useful in this study as the method enables individuals who are visually impaired to articulate their views as opposed to written responses, such as in questionnaires. Additionally, this data collection tool does not discriminate against people who may speak English as a second language (Higginbottom 1998). Because of the expertise within HABS, one of the FGI was conducted in Somali and back translated. Some service providers could not attend the FGI; therefore we conducted individual interviews with these participants.

Semi-structured Interviews

The major themes elicited in the focus group interviews were further developed in the semi-structured interviews with VIP, contributing to the iterative process (Silverman 2002) in order to establish the needs of visually impaired Somali people and the barriers and obstacles that exist in relation to accessing services. All data were tape-recorded, translated and transcribed (please see section 2.7 regarding language issues).
Telephone Interviews

Participants were generated via a snowball technique. All participants in the semi-structured interviews were asked if they have a carer willing to participate, other carers were contacted via Somali Community Associations. We used telephone recording equipment to tape the interview at a prearranged date and time.

Table 1: Data collection tools and participants.

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<thead>
<tr>
<th>Phase</th>
<th>Data Collection Tools</th>
<th>Participants and number</th>
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<tbody>
<tr>
<td>Phase 1</td>
<td>Focus Group Interviews (n4)</td>
<td>HABS members</td>
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<td></td>
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<td>Service providers</td>
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<td></td>
<td>Individual Interviews (n4)</td>
<td>Somali groups and associations</td>
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<tr>
<td>Phase 2</td>
<td>Individual Interviews (n32)</td>
<td>Visually people of Somali origin</td>
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<tr>
<td>Phase 3</td>
<td>Telephone Interviews (n5)</td>
<td>Carers of VIP</td>
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</table>

2.6 Data analysis

Qualitative data analysis has been criticised in the past because of a lack of transparency in the process of analysis (Miles and Hubermann 1994). In order to avoid this opacity we have elected to use the Framework method for data analysis developed by the National Centre for Social Research (NCSR). Framework provides a systematic, transparent and reputable approach to qualitative data analysis (GH and KR attended NCSR training on Framework). The validity and robustness of Framework is evidenced in the large numbers of commissioned research undertaken by the National Centre for Social Research on behalf of statutory agencies.

Framework, allows for rapid retrieval of data and comparison between and within case analysis (NCSR 2001). It is most appropriate for use by a team of researchers as was the case in this study. Framework is specifically recommended (Ritchie and Spencer 1994) for qualitative data analysis in applied policy research. The open and transparent approach facilitates consistency within the research team’s approach to analysis. Framework is dynamic, flexible and can accommodate new issues as they emerge. Framework can be used for analysing interviews and focus groups, both of which were used in this research.

Data were analysed until data saturation was achieved i.e. when no new themes or categories emerged.

Analysis of the data therefore consisted of 1) Ordering and summarising data 2) Interpreting data. Specifically analysis commenced with familiarisation, reading of the proposal, transcripts and reviewing of the topic guide and field work notes, followed by

3) Identification of recurring and significant themes
   Develop a working framework of key themes and sub-topics

   INDEXING
   Apply numerical series to working framework
   Label or code transcripts numerically
   Adapt framework in light of gaps

   PILOT CHARTING
   Preliminary charting of transcripts using working framework – adopt new framework in light of gaps or overlap

   Summarise/synthesise verbatim data within finalised thematic matrix

   Abstraction and interpretation

Figure 1: Charting
Ref: National Centre for Social Research (2001)
2.7 Language Issue

Documentation

The research team in this study comprised several bi-lingual speakers (Somali and English)

- Research Assistant
- Community researchers/data collectors
- Members of HABS whose expertise we could draw upon

During the appointment process, language tests were administered to potential project staff by members of HABS to ensure our team members had an appropriate level of fluency in both English and Somali.

All project information was available in both English and Somali versions:

- Participant consent form
- Participant information sheets
- Brief summary of the project, including project aims

The documents mentioned above were also available in an audio-taped version to ensure that visually impaired people participating in this study could access in an appropriate format the information they need. The production of the tapes was facilitated by HABS in conjunction with Sheffield Talking News.

Translation and interpretation

The collection of data was facilitated in both English and Somali depending on the requirements of the participant/s. This included not only the individual interviews but also the focus group interviews as a Somali speaking co-worker co-moderated the groups. Audio-tapes in some instances were transcribed in both English and Somali. We were fortunate to employ a project secretary who was a bi-lingual speaker and translator English and Spanish, this meant that team members were highly sensitised to issues of interpretation and translation. We also consulted with experts in the field who were experienced in translation and back translation.

All the semi-structured interviews with Somali VIP and their carers were conducted in Somali, the first language of the participants. We developed our own model of translation for expediency and efficiency, each tape was simultaneously translated and transcribed. The person who conducted the interview, on the whole, worked with the project secretary to translate the audio-tape, for which our secretary completed a simultaneous transcription. The advantages of this are that any areas that lack clarity or misunderstanding can be immediately rectified. If there were doubts concerning the meanings of a specific word immediate assistance can be sought. We are not aware that this model has been described fully in the literature and we hope to focus an academic paper on this topic. Our translations were also guided by the perspectives on Brislin’s model of translation offered by Jones et al (2001). Although we did not have the resources to fully apply this model, a modified version was applied to our data progressing through one cycle of checking.

Source to Target to Source to Target to Source

bilingual #1 bilingual #2 bilingual #3 bilingual #4

FIGURE 1. Brislin’s Translation Model (Jones 2001)
To ensure rigour, we also selected randomly a number of tapes for independent translation checks by a professional company. The results of this independent check verified the meaning of translation although some deviances were noted which might largely be framed as grammatical expressions.

### 2.8 Theoretical and conceptualisations considerations in researching ethnicity and health

Ethnicity as a concept that is different from the concept of ‘race’ has risen to prominence in health related research, literature, health, and social care service provision (Bradby 1995). However, it is worthy of note that this increased focus is characterised by a lack of consistency and terminology (Sheldon & Parker 1992). The concept of ethnicity moves beyond perceptions of ‘phenotype’ into a complex coalition of the sharing of culture, values, traditions and perceptions of belonging that interface with every aspect of the lived human experience (Mac an Ghaill 1999). This is distinct from nationality or old understandings of the concept of ‘race’ and is not necessarily related to geographical locations or national state boundaries, as is in the case in migrant communities and those who relocate as asylum seekers and refugees. Relocation of the Somali community to many different Western nation states evokes the notion of ‘diaspora’. The original Greek meaning of diaspora is the spreading of seeds across territories, the implication that these seeds (people) will form new roots in the new environment. In this sense the term ‘diaspora’ embraces a past history in the sense of where people have come from and the influence of the new location. Whilst the seeds have spread, they can only become mature if the environment is conducive to their development (Anthais & Lloyd 2002).

We adhered to the principle of self-assignation of ethnicity (Bradby 2003, Nazroo 1997) that is participants were given the opportunity to self-assign ethnicity. The biographical details of the participants can be found in Appendix 3. A small number of participants preferred to describe themselves as black African rather than Somali.

### 2.9 Ethical and Research Governance Issues

We received ethical approvals from the Local Research Ethnic Committee in North Sheffield and the research governance body, the NHS Sheffield Health and Research Consortium. It is perhaps worth mentioning that the study was anonymously selected for an independent governance review and all the required procedures, processes documentations were found to be in place.
3 Findings – Focus Group Interviews

The purpose of the FGI was to scope the perspectives of service providers and other key stakeholders to establish whether there existed dissonance between the service providers’ perspectives about the health and social care needs of Somali VIP in Sheffield and the perspectives of Somali VIP themselves. We organised the data into the following broad themes:

- Socio-cultural perceptions of blindness and visual impairment
- Identified needs
- Information and communication

In addition to the FGI we conducted 4 individual interviews with service providers who could not attend the FGU, their perspectives are incorporated into the above findings.

3.1 Socio-cultural perception of blindness

Visual impairment and blindness in Somalia

Visual impairment and blindness is highly stigmatised in Somalia. The Civil War in the country has resulted in a greater number of people with visual impairments due to trauma experienced from landmines and explosions although the exact number is not known. A negative attitude towards blindness prevails; therefore individuals may be reluctant to identify themselves as visually impaired. If you are totally blind, it is as if you do not exist: 

“being blind totally means that this person does not exist” FG1 p5.

Translated from Somali

Denial of VIP may be embedded in the culture because of the negative perceptions of VIP.

“...so there is a difficulty here, the partially sighted people, to accept that they are blind because they automatically get that label that they are disabled to come to anything where they can work. they cannot learn, life, finished, so that is er one of the difficulties” FG1 p5

Translated from Somali

Some participants were of the view that unless an individual was totally blind they would not consider themselves as a VIP, although this may not be true of all Somali VIP. In Somalia a VIP would tend to stay close to home and not go out, especially as there are no institutions or services that support VIP. In Somalia a person is either sighted or blind.

Attitudes to visual impairment and blindness in England

Individuals who migrate to England often still hold negative attitudes towards visual impairment. Therefore it is possible that a VIP person of Somali origin may not be sensitised to their full potential, even though greater provision is made for individuals with VIP in England:

“within the Somali community is that many people don’t want to advertise themselves as partially sighted, er so in fact that is another difficulty and we need to change that into a positive so that people access information, education which is suitable for them. Er and I think that is one step before we send the information, we need to identify people and convince them to come forward and say that they are partially sighted and they need this type of services, before that they will be you know er hidden”. FG1 – p5

Translated from Somali
"the background that the Somali community came from is that a blind person don’t do this all this kind of stuff, you know these kinds of things we are discussing, a blind person sits at home or under a tree, so to get the idea that you can take a bus or you know that needs a lot of information, to convince this person, that you can do this and you can do this. So it is that background of Somali experience is not one that the blind people can move by themselves". FGI – p7

Translated from Somali

Individuals may therefore need encouragement from others within the local community to maximise their potential:

"Er In fact the lack of encouragement comes from how Somali people see er the blind person or a partially sighted person ...because back home there is no education where for the blind or even the disabled people” FG1 – p5

Translated from Somali

There was a general agreement especially in FG1 that the issue of learned helplessness was significant in that if family expectations of the VIP are low, then the individual may not realise their potential. Independence may not be fostered; other studies have noted the notion of a ‘learned helplessness’ as a significant factor in the experience of visual impairment in ethnic minority communities in general (Morjaria-Keval and Johnson 2005).

Guide dogs or Assistance Dogs

There was general agreement in the FGI that VIP of Somali origin would find guide dogs unacceptable. However there appeared to be a lack of agreement as to whether this was because of religious edicts, Somali traditions or both:

"well if it’s not religion then why did you stop us using dogs or being or being friends with dogs. So, it’s almost as if though, the religion should say it’s not religious and there is nothing wrong with this more to do with the culture so it’s not religion”. FG1 – p5

Translated from Somali

Dogs are not generally used as pets in Somalia. A view was expressed that family and friends may see themselves as being replaced by a dog and that this was not acceptable. Somalis who are ‘westernised’ may be more accepting of dogs, but it was felt that this would not extend to accepting a dog in their homes.

More detailed perspectives were shared in FG3 (Somali groups and associations), the key points as articulated (verbatim) by participants are summarised as follows:-

- Dogs are dirty and should not be allowed in the house
- Blind people should not use dogs; in Somalia the people help the blind
- Dogs, it is not halal to keep them
- You cannot go to a friend’s house if you have a guide dog
- Social Services advised a Somali VIP to have a dog but he refused
- You cannot go to a relative if you have a dog
- Other Muslim communities are not seen with a dog
- There has to be a clear explanation of the religious perspective regarding the use of guide dogs
- There has to be an alternative [mobility guidance] if dogs are not allowed
- The belief about dogs will change one day
- The religious scholars have to be consulted
- Islam does say that if it [guide dogs] helps that you are allowed this
- Other Muslim communities e.g. Pakistani use dogs
- Somali culture always clashes with religion that is the problem
- If a Somali VIP had a dog this would remove you partially from the community as people do not want you in their homes with a dog
However a report produced by Morjaria-Keval and Johnson (2005 p29) established the following:

‘... a recent ruling has been made by the Sherrat Council that Sharia (Islamic) law does not prohibit the ownership, use, or contact with guidance or assistance dogs. Lord Ahmet a prominent Muslim member of the House of Lords notes that:

"Islam is a religion that cares for people. Although it is not encouraged to keep a dog in the house, if the dog is owned for reasons of safety it is permitted (halal). When a disabled person is accompanied by a trained dog, such a dog becomes a blind person’ eyes... Essential to the independence of a disabled person”

The viewpoint expressed above does seem to differ from the general perspectives held about the value and use of guide or assistance dogs to a Somali VIP in England and expressed in the FGI.

3.2 Identified needs

Access to appropriate services

FGI participants perceived language to be the major barrier to Somali VIP accessing services in the city. It is notable that none of the participants of FGI could identify the existence of specific English language courses for the newly arrived refugee or migrants. This differs from other nation states such as Canada and Sweden where new migrant are actively encouraged to acquire language skills. Although some services do provide interpreters, this usually needs to be made explicit on any referral letters. For example, in the case of the secondary care trust in Sheffield, the need for an interpreter must be specified on the GP referral letter and this information is sometimes absent.

A consensus existed within the FGI that perhaps if a Somali VIP may be reluctant to participate in groups or organisations if they were the only VIP attending, as this experience may compound feelings of isolation:

“It’s very difficult for people who feel that they are in a separate group to join other mainstream groups in ones” FG4 p10

It may be more appropriate to provide outreach services to Somali VIP rather than expecting for Somali VIP to seek services. A good example of outreach services are the ‘Sight Loss Fairs’ facilitated in the Midlands area). Often the VIP needs patience in order to access services because of a number of barriers and obstacles are often encountered during the process, so a degree of tenacity is required. This has been reported several times by study participants.

Other issues highlighted by service providers was the need for accurate monitoring mechanisms to ensure enough and the correct type of information to be conveyed in advance of appointments, e.g. ethnicity and language group, so that translations services could be booked.

Respondents felt that providers need details of the language group of patients rather than ethnic group alone.

“Obviously working in patient information actually somebody’s ethnic grouping is no help to me whatsoever. I mean the language grouping. And actually it’s a much better way of identifying particular groups in lots of respects than the broadly drawn fields that we tend to use for ethnic monitoring if we actually use language minorities” FG4 p11

Problems were also encountered with ethnic monitoring as when individual ticks black African – service provider does know that the individual is Somali:

“One of the things that just happens in monitoring ethnic minorities especially when you want to find out about Somali people, loads of the monitoring forms don’t have Somali. they will have African and loads of Somali people will tick Black African” FG4 p9
It is interesting that the data elicited in this domain is quite limited, and in many respects this is indicative of the fact (as will be explained later), that only a small number VIP of Somali origin are receiving services whether these are voluntary or statutory.

There was an awareness regarding the availability of specific service for the VIP such as those provided by the Sheffield Royal Society for the Blind (SRSB), although the cultural congruence of the service was questioned. SRSB has a meeting each month for newly registered individuals; however this service is very much focused on the needs of the wider community. The SRSB can cater for specific dietary needs but very few people of ethnic minority origin attend:

“I go down the first Friday of every month because on that date they have a new registration, which means people who’ve been registered as blind or partially sighted attend the centre and either social workers or [unclear] and various clients with spouses, friends, daughters, sons can go with them and they have a meal and it feels lovely. Because they all tell me [unclear] three course meal for £1.50 and they love it and if you’ve got a specific diet problem they will cater to those needs as well” FG4 p13

In general it was agreed that a very small number or no Somali VIP used the services of the SRSB. However, a suggestion was made that perhaps a ‘Somali’ day might be facilitated in the future.

3.3 Primary and secondary health care

Primary Care

Acquiring a GP is critical for a new migrant or asylum seeker as they are also gatekeepers of services, although the evidence in this study suggests there is a degree of heterogeneity in the Somali community in Sheffield, in terms of migration history:

“You need a GP to get into the system, to get a clinic appointment, to come to a clinic”. FG4 p17

However, the point was also made that within some cultures, primary health care staff are not viewed as having the same expertise as acute staff. This may mean that primary health care services are viewed as having less value. Individuals with eye problems may be under the care of a GP may sometimes be inappropriately sent to the Optician:

“Right, loads of people think the optician is the miracle worker that makes everybody see but if you’ve got a problem with the back of your eye no matter what glasses you get, you will never be rectified? But, but, if you don’t understand eye problems even though you are a nurse and perhaps a GP, you won’t know the problem, so therefore sending them to the optician is not going to help, but then when it goes to the optician, the optician should then refer into a hospital or back to the GP and say, GS whatever number it is and say query this, query that, we’d like hospital appointment, we’d like to see ophthalmologist. And then that should be acted upon”. FG4 p19

The view was expressed that many medical staff (doctors and nurses) are limited in their insights regarding the needs of individuals with VIP:

“He can’t see the toilet to pee in, he won’t go if you left him a drink there because he won’t know there is a drink there, he won’t know his foods there and if you shut your eyes and I’m talking to you I’m not talking to you, I’m talking to the next person. So, how basic, and that is, I’m sorry, that is as basic sometimes, that I have to be”. FG4 p18

Many safety issues were highlighted around medications and administration of medicines for VIP:

“The group that I have of people with visual impairment looking at the information have identified without question that the primary information need in health care is information on medication. Because they have real problems er, one of the real biggest problems it’s actually knowing have they got the right medication at the cupboard? Is it their medication? How often should they take it? How to avoid somebody with a visual impairment picking somebody else’s, er, you know, and all sorts of things these are huge issues” FG4 p30
It was believed by service providers in FG4 that a legal requirement existed to ensure that medications are labelled in a format that the user can understand. A very good example was given of a VIP (although not of Somali origin) who was prescribed eye drops but could not instil these even with a magnifier.

**Secondary Care**

Participants suggested that if an individual is partially sighted, as opposed to blind, there may be difficulties with the assessment tools which are used in the secondary care system, as the tools are written. Many Somali older people are not literate in their own language which was only developed as a written language in 1976. In addition to this further examples were given of what might be perceived to be the cultural inappropriateness of the current configuration of the low vision unit. For example low vision testing is conducted in a public area which VIP of Somali origin may find inappropriate.

Some services such as the Secondary Care Trust in Sheffield, do have extensive frameworks in place to ensure that the needs of individuals with disabilities who use their services are fully met. The Royal Hallamshire Hospital has a disability impairment group (including members of HABS) who advise on service provision including environmental issues. In fact a number of improvements have been made to the environment to meet the needs of VIP.

Training is also available at the RHH to enable all staff to be sensitive to needs of VIP, however this training is voluntary. In addition the trusts are currently piloting a scheme whereby patients are met and accompanied during a visit. It seems that there may be potential to extend this service to individuals with VI.

### 3.4 Access to Housing, Mobility and Education

**Housing**

Service providers expressed concern that current information systems meant that almost all information that was available to VIP was in a written format:

> “You know there is, there is a small ads in the, in The Telegraph which I knew give you lovely pictures, [laughs] in the Estate Agent windows and they are the notices that you can get sent around by Sheffield Homes, or in beautiful print, but for blind people this doesn't work and for people who don't speak English it doesn't work either”. FG4 – p25

However, other participants shared information regarding the systems that existed in Sheffield Homes to meet the needs of VI. For example the Sheffield Homes website has been specially adapted to enable a VIP to use a device called ‘Browse Allowed’ which means the mouse is passed over the pages on the website and an audio version is played for VIP or individuals with limited literacy. This however, is an English audio version and is not necessarily useful to those who have a limited command of English.

Data in this domain is mainly focused on examples of VIP people being placed in appropriate housing:

> “X knows another example of a disabled blind lady who was [moved?] to a block of flats and was left there and because [inaudible] she couldn’t go to the bathroom and then [inaudible] she was found by some people two days later, and she is here in Sheffield, she lived to tell the story”. FG1 p13

Participants however, employed by Sheffield Homes, identified a special service ‘Home Finders Team’ who have a specific remit to meet the housing needs of those with impairments and special needs. The Home Finders Team also has links with medical staff and an occupational therapist so that a housing assessment can be conducted. However, as will be clear from the findings in the main study sample, the availability of this service was not known to the VIP in this study. Sheffield Housing also has a disability monitoring group. In addition front line staff are given substantial amounts of training to meet the needs of those who experience a disability. However, it is not clear the extent to which individuals have received training in the provision of culturally sensitive care.
Mobility

The majority of the VIP participants in this study were relative newcomers to Sheffield. The challenges of mobility in a strange and new environment were perceived by some participants to be a major challenge:

“They need to find out how to cope with their daily lives if let’s say if they live by themselves, they need to cope they need to find out how to cope with mobility, how to travel safely in this new different, er, set up, which can be extremely challenging where they don’t necessarily understand what’s being said by anybody including bus drivers”. FG4 p12

There was a general agreement that some training did take place for bus drivers in South Yorkshire to enable them to meet the needs of VIP:

“They [bus drivers] do have [training] that already but it’s very short, it’s very brief and it’s very focused, it’s, it’s very focused on physical impairments and there are loads of problems with bus drivers not being fully aware of the problems needs not just of blind people” FG4 p4

Whilst another participant thought bus drivers were quite good. However, there are huge challenges for VIP when redevelopment is taking place as this often results in road works or relocation of bus stops, as the VIP has no way of knowing about this:

“... I crossed at Paternoster Row three times on that island which I thought it was there but it has actually been changed, and I got myself muddled up with some traffic on every single occasion and to be rescued, and when you come to think of it, how would do blind people of any sort manage to find out that that bus service has been cancelled” FG4 p15 VIP

The large print timetable that Sheffield Transport produces is no use to a VIP. Some Somali VIP in Somalia would not have access to any form of transport so convincing them, that they can go out and take a bus is a difficult task. Therefore a general lack of understanding about the availability of mobility options for Somali VIP may exist.

Bus and train staff are trained to meet the needs of VIP but a VIP would tend to take a taxi FG1 p10

“...Taxis - we actually we use taxis more [inaudible] – because the customer can get to the destination without having to walk?” FG1 p10 Translated from Somali

A view existed that in general there is reliance by VIP of Somali origin on community members for mobility support. However, it is worth considering the extent to which an older person of Somali origin without a disability might travel alone. It could be the case that in general an older person is usually supported by a family member.

Education

Service providers had little to say on this topic, in this study the silences and absences of data are as revealing as those domains in which a great deal of information was elicited, in that the lack of data may indicate a general lack of services or information in the particular domain under consideration.

3.5 Rehabilitation, information needs, family issues

In comparison to the main study sample only a very small amount data was elicited in the FGI on these topics. One participant highlighted issues of security in relation to VIP in general:

“They are running two systems in Sheffield that are easy to use, one of them is there is one district that has district heating and you just push the knob on or off, and the other one is night storage once again where you push the knob along... And the front door is a key issue for blind people because like this morning where I live, there was a knock on the door, we live in quite an isolated place and there were two young voices there and, er, they said, can we have some water please for our radiator? Just a cup of water. And I really didn’t know what was going on. I didn’t know if they were kosher or not, because I imagined they’ve got a car, and if they have a car, what would they want a cup of water? And the motor
wasn't running, so I didn't know what it was. I'm not sure if they knew if I was blind or not, and I didn't actually want to inform them about that ... and so, any way, I trusted them got the kettle full of water and they poured it. But that's the type of issue. When someone comes to the front door, er, you should really be able to find out who's there, and what they want” FG4 VIP p26

It was generally believed that the VIP of Somali origin in Sheffield ought to be able to access appropriate educational provision, but this seemed to be unlikely, indeed an example was given of a specific programme for VIP in Sheffield:

"I went to an IT course in Sheffield College and for I went to 9 of the 12 courses. I didn't learn anything. For 6 of the 9 that I went to they didn't even have the software connected up and we had to mime we had to up arrow 11 times and then write out twice and then [unclear] ridiculous! And they knew less about the speech output software than the people in the group who none of us knew anything really. It was absolutely appalling!” FG4 p13 VIP

Access to education was thought to be very important especially access to English courses as without a command of English, participants viewed this has a 'double disability'. A point was also raised about educational support for the children of Somali VIP. It was recognised by some FGI participants that the most appropriate educational provision for VIP was located in Birmingham:

"There are 2 Colleges in England and Wales that deal with visually impaired people and blind people, and 20 years ago there would have been altogether about 180 students. And now one college has 250. The extent of all the other colleges we may have 500 college places in England and Wales for blind and partially sighted people of any origin and a load of students. Even when I was at college here, there were students there from Africa, China, Korea who actually have come specifically sponsored by their governments. So on a percentage of education places for anybody else visually impaired is quite small, it's a battle for all of us who are visually impaired” FG1 p6.

It was agreed that accessing information was a major problem for Somali VIP if they had limited fluency in the English language. Since they were not able to read information, oral fluency was paramount in effective communications.

It is worthy of note, however, is that the secondary care Trust in Sheffield has been working closely with SRSB to produce audio-taped information for VIP. This also includes tape recordings the consultation between the health professional and patient. The patient can take home the tape, and re-listen to the conversation. So examples of good practice do exist. All leaflets in the Trust are translated into five languages and can be translated into Braille. If required the Trust will sent out letters by email which might be more appropriate for a VIP who has the appropriate technology to convert the email.

Some participants made reference to the use of technology, IT equipment with internet access and braille. In some community venues, resources are available such as a braille printer and a Somali braille book provided by HABS at the Somali Physical Disability Group also 5 computers are available for braille literate people. However, individuals in general are not aware that computers are available with speech output (FG2). Somali people in general are keen on using technology, this may be related to the fact the many are members of transnational families, but the cost of equipment might be prohibitively expensive. The telephone, both landlines and mobile phones, were said to be a very good communication tool for VIP.
4 Findings – Individual interviews with Somali VIP

The findings from the main study sample are organised into five key themes as follows:

- Socio-cultural perceptions of blindness and visual impairment
- Identified needs
- Information and communication
- Family and social networks
- Migration issues

Biographical details of participants can be found in Appendix 3, however the following extracts are provided to illustrate some of the personal biographies of participants:

Profile of visual impairment

A number of participants give vivid accounts of how they became blind or visually impaired. Some of these follow:

Then I became blind, but before those 6 days after my tooth was taken out I had my baby. That’s the two months I was telling you about that I had the infection. I was taken from the north of Somalia to Mogadishu (Hamar) and they were giving me just medication, just small medication. So those two whole months there was in infection in my head after that I was being sick all the time. I was seriously ill, I got weak I was always lying down and I couldn’t walk. Nobody knew what was happening to me, so one day I fainted and I lost consciousness. My eyes were completely dark, that’s the day my eyes went and when I regained consciousness in the morning I was taken to hospital, they checked my head, and what they found is that all the skull of my head had been smashed, that’s when they gave me an operation. They cleaned the infection, they tried to get rid of the infection, I was at hospital for a whole month and I was neither dead nor alive. When I left the hospital I was just too ill and as a result of that I became epileptic.

In You became epileptic?
R Yes. The year I lost my sight I became epileptic as well. Just a few months after I became blind I started having fits.

I became blind in 1989 as a result of shrapnel during the Somali Civil War. That was when it happened to me. I got blinded instantly but I went through different situations and I overcame the problems gradually and now I am a different person.

When I first came to this country I used to do everything; I used to sew, I used to knit decorative things for the house, and there was nothing that I could say that was wrong with my eyes. I feel that maybe an air went into my eyes and I had a mole in my eye, you can hardly see it now. Secondly I thought I had cataracts. The man while I was under general anaesthetic thought the mole was infected and he scraped it away. He said we removed the infected mole and I forgot to tell people that it was just a mole that has always been there. Since then I can’t see anything with my eye so they made it worse. I can only see your hand movements. I can’t see clearly your face and the clothes you’re wearing. And about my other eye [unclear] I may have pain on this eye, but at least I can see well with this one.
4.1 Socio-cultural perceptions visual impairment/blindness.

In the individual interviews only 9 participants shared views or comments on what might broadly be termed socio-cultural perceptions of visual impairment and blindness. Of the 9 participants from whom we did elicit data, their comments are rather brief. The ‘silence’ of participants on these issues is very interesting and perhaps linked to the stigmatisation of blindness and VIP within the community. We observed that in general VIP participants were able to discuss socio-cultural issues in generic terms, but seemed reluctant to comment on their own visual impairment. This contrasts with the data elicited from service providers, other key stakeholders and carers from whom we elicited quite a wealth of information on this topic.

Visual impairment and blindness in Somalia

Most participants became visually impaired prior to relocation to Sheffield. Few participants made direct reference to their experience of VIP in Somalia; in fact very little data was elicited in the section:

> When a person becomes old and weak, whether it’s their eyes or any other part of their body, they can’t do much. They have to face a lot of difficulties, and those with eyesight problems face the greatest difficulties. There are no specialist doctors for the eyes. KR17 p4

Translated from Somali

Attitudes to visual impairment and blindness in England

In general, a view existed amongst participants that VI created a burden for others in the UK:

> I use the phone just to call my family. I would not say they are my carers but they do come around and take me to their house after I call them (participant laughs here)…. Well, we are old and blind, just a burden!! KR17 p2

Translated from Somali

> The Somali community are helpful but no one is going to spend every day with you. I would much rather be at home, but it is not safe to go home. I mean, home is not safe yet, you know that, don’t you? KR18 p3

Translated from Somali

> Myself? To go outside. Yes, its part of being healthy, to be able to walk outside. M20 p5

Translated from Somali

The primacy of this view may be related to the fact that kinship and family living patterns may be very different in UK than in Somalia, where extended family living arrangements are much more common. Thus the burden of caring for a VI may be shared amongst family members, whereas in the UK sighted family members may tend to live in more nuclear family situations.

One participant expressed the view that he/she was immensely grateful for everything the British UK government had done:

> The British government has looked after us: they gave us housing, income support, and I’m absolutely grateful for everything they’ve done for us. AB47 p6

Translated from Somali

Few of the participants referred to their own self-perceptions of visual impairment. Where comments were made, they tended to emphasise the notion of the burden created for other family members:

> My son and his family live here but I don’t like bothering them. I don’t have any social activities: who wants a half-blind elderly lady!! I don’t think anyone would entertain me or those who are the same… Why would I go out? I don’t work, I don’t study, I can’t see much. KR13 p7

Translated from Somali

It is clear that becoming visually impaired or blind creates a situation where the individual must undergo a huge life transition and this demands a reappraisal of the individual’s personal biography. In this respect, sudden visual
impairment may be compared to the diagnosis of a chronic illness and the biographical disruption experienced at this time. Charmaz (1983) terms this 'loss of self', and this experience can also be compared to the concept of 'biographical disruption' that Williams (2000) describes the following extract illustrates this:

*Two different things, here and Somalia. When I got blinded, I had never seen before a young blind person before. I had only seen elderly blind people. So, first time, when this happened to me, even when people made me stand up I would fall down because I didn't even know how to walk. I was feeling ashamed to be blind. I would hate myself. Those were my own feelings so many other people thought the same about me, that there was no life for me. Then I went back to Somalia after I had been in England. I had been like a new person. I don't know what they say but I had a normal life.*

*Translated from Somali*

**Registration**

Only 2 of the participants had heard of the registration system for blind and visually impaired people in the UK, which would seem to suggest an urgent need for information regarding this critical dimension to the experience of visual impairment. Registration in the UK might be regarded as the key to a VIP unlocking services. AB46 did receive information about registration around the time that HABS was launched.

Only two participants AB46 and M056 appeared to be registered:

*"I've been registered for a long time. I came to this country in 1991 and after 1 year I became registered in London. When I moved to Sheffield, my file was transferred to Sheffield from London and at the same time I was sent a person from the Sheffield offices straight away who came to visit me, asked me to fill in a form and ask me to sign it. So now I am registered in Sheffield as well."*

*Translated from Somali*

**4. 2 Identified needs**

A great deal of data was elicited in this section, which perhaps is an indication of the many unmet needs that blind and VIP Somali people in Sheffield have. An inability to speak English or English as a second language is a major barrier in relation to accessing services, this is compounded by the forms or materials in which the information is conveyed usually written:

**Access to services**

The Somali population in Sheffield in general may encounter difficulties in accessing health and social care services. This may be the result of a lack of awareness of existing services, language and cultural reasons for not using some services such as the cervical screening. VIP usually often rely on relatives who themselves might not know about the existing services or the services for VIP impaired in the UK did not exist in Somalia and therefore they do not expect.

Most participants were not receiving any statutory help or support in relation to their VI, although a small of participants appeared to be receiving some voluntary support:

*R  I don’t receive any help or assistance [government] regarding my visual impairment. A woman comes to help me an hour a week*

*In  How many days a week do they come to see you?*

*R  The whole seven days, but just one hour per day. They come from the Home Care. It’s just one hour a day to try and make lunch for me, and they come from the Somali group in Home Care.*

*In  Is it the Home Care run by the Somalis?*

*R  Yes, but I don’t receive anything from anybody else.*

*In  So you are saying the visitors from Home Care just spend one hour per day to help you?*

*R  Just one hour, just enough time to make lunch.*
What about help with your children?

R Childcare? No, not childcare.

What about help and assistance with your daily life?

R No, not help with the household or daily living. Interview M20 p2/3

Assistance with daily living appeared to be the most frequently identified form of unmet need. This was expressed as a need for home visiting or home help:

I don’t speak any English and I’m elderly woman unlike you young people. I can ask the Somalis and I can communicate with the Somali people. But these people we are living with in this country, I don’t speak their language. So I just wait for my son to arrive, so if I need things to be fixed in the house or things from outside, my son does it for me. And they are always sending letters, and I just keep looking at those letters and they just pile up if he doesn’t come and read them. He comes to read them because he is one of the children we made sure he received a good education. And also when he came to the country he learnt a lot more than we taught him. So he comes and reads the post, but I don’t know anything about these letters or reading them or what they want, and I can’t speak English, so they may be about these services you are talking about. But how should I understand if I don’t even speak the language? After my son reads them, he tells me what they are about. KR13 p4

Most participants had little or no knowledge of statutory and voluntary services that may be able to assist with issues relating to their VI:

I would have liked to receive more social care because I’m someone who can’t do much for myself, whether is inside or outside the house. For example, if I have a fit, which is the worst fear I have, nobody would know. So I would actually like to receive more care. M20 p4

Often individuals struggle to understand the facilities and services available to people with disabilities on arrival in the UK. As the following participant commented:

...another problem which I am still suffering of, is to understand the system and to know the opportunities that are available for disabled people like me. AB45 p3

People who require help don’t care where it comes from, as long it meets their needs e.g. Statutory or an independent agency AB45 p7

There appeared to be a need for care workers to come to the home and provide home care. Many participants would like to be supported and have assistance with housework, but at the same time maintain a measure of independence. However this does of course raise the need for language considerations to be taken account of, as a care-worker who did not speak Somali may be able to provide only limited support:

It would be effective to us to send us a Somali speaking person. The English people although they are actually kind, but if we don’t understand each other it’s a problem. AB47 p3

...we know the needs of the people and what we would like is care providers to come and do the home care for us, to help us around the house. We don’t want to be left out and we would like to be supported, to be independent and we would have liked to have someone to help us with housework. We shouldn’t feel alone. AB47 p2

I can’t do any housework as I used to. I would like them to help me with that as well. But it would be helpful if they were Somalis or they spoke Somali. It wouldn’t help me if they didn’t speak any Somali. KR13 p8
The following participant stated that he had no idea of any organisation that helps Somali VIP with housing, education or any other aspect of their lives:

*If we go back to the basics, I have no idea of any project that provides total help to Somali blind people with housing, education or home life when they come to this country. But we need to get something like that. If there is nothing like that, we need to get it. It’s essential. If somebody is thinking about covering these needs it’s very important. AB45 p7*

*Translated from Somali*

Later he states is aware of HABS, but feels they are limited in what they can provide for example HABS cannot provide transport and they have no means to get their staff trained in relation to needs of blind people. The organisation does not have the funds or the ability to do this:

*I know this organisation and I am a member. That organisation has not got the power to cover the needs for these people, whether it’s the system of education of this country or life of this country, or financially, and how to get the opportunities of education for the blind people, transport, etc. And even if there is not transport they haven’t got the means to get the trained people. That organisation hasn’t got the power yet to cover those needs for the blind people. Whether it’s financially or skills to do things. The organisation is ready to do these things but it hasn’t got either the funds, the skills or the services. It’s vital to get another organisation to help this organisation how to do these things. It’s essential. AB45 p7*

*Translated from Somali*

The main barrier in accessing services for VIP born abroad is language. In this respect the findings in the main study sample are concordant with those views elicited in the FGI. Many individuals do not know of the existence of services and agencies or where their offices are located:

*In fact the main problem or the worst problem that I faced in this country was the language barrier. And it doesn’t only affect my education but my whole life. And that is the main problem that I face so far. And I still don’t have a full command of the language. And that is main reason that is making me study and do courses. AB45 p3*

*Translated from Somali*

One participant however, had arrived in England via Sweden and made the following comment:

*Well, actually it’s better here at least I’ve got home care here in the UK. M20 p4*

*Translated from Somali*

**Primary and secondary health care**

A small number of participants commented on the primary and secondary care they had received in Somalia prior to migration:

*Yes, they didn’t know. Then I became blind, but before that 6 days after my tooth was taken out I had my baby. That’s the two months I was telling you about that I had the infection. I was taken from the north of Somalia to Mogadishu (Hamar) and they were giving me just medication, just small medication. So those two whole months there was in infection in my head after that I was being sick all the time. I was seriously ill. I got weak I was always lying down and I couldn’t walk. Nobody knew what was happening to me, so one day I fainted and I lost consciousness. My eyes were completely dark, that’s the day my eyes went and when I regained consciousness in the morning I was taken to hospital, they checked my head, and what they found is that all the skull of my head had been smashed, that’s when they gave me an operation. They cleaned the infection, they tried to get rid of the infection, I was at hospital for a whole month and I was neither dead nor alive. When I left the hospital I was just too ill and as a result of that I became epileptic. M20 p1*

*Translated from Somali*
A number of participants were in regular contact with their GP in the UK and primary care services for treatment and management of ongoing chronic conditions e.g. back pain, diabetes. Some participants were also treated by their GP for their eye conditions and a number had received operations. A small number had been told by their GP that it was too late for further treatment of the cause of their visual impairment:

... I have problems with my eyes, with my back with my legs. And nobody seems to be helping. And my son says it's because it's old age. KR13 p4

Translated from Somali

I have really terrible time in seeing things and this doctor keeps sending me home with drops. He doesn't check if I can see or not. He's always giving never ending drops. KR13 p8

Translated from Somali

Some participants appeared dissatisfied with the primary health care services they were receiving in the UK; although there existed some doubt as to whether this was the actual service provided or the language challenges created during communication:

My family doctor never refers me to any specialist. For my back I have been addressing it for a long time. I don't know if it is the people who translate or him, but it seems strange. M20 p2

Translated from Somali

I'm registered with a doctor but I don't know where he's based location-wise. The last time I saw him, it was a long time ago and someone interpreted for me, took me there and brought me back home. KR11 p5

Translated from Somali

I was ill, and the woman who took me there to interpret for me didn't speak good English, and she took me there because she was a Muslim and Somali, she wasn't getting paid to do this, and this was good of her. But the problem was they gave me a medicine and I had really bad side effects, or maybe they gave me the wrong medicine! In the end, when we went back to them, they told me I shouldn't have been on that medication, it could have poisoned me. So nobody would have actually found out if I had died in my house. And the doctor didn't investigate why and how that medication was prescribed to me, and I don't have anyone and I don't speak English, so who's going to go and ask them? KR11 p8

Translated from Somali

One participant reported that her GP had advocated quite a lot for her, ensuring she received her hospital appointments and had written a letter concerning her mobility.

Secondary Care

A number of individuals appeared to be on the waiting list for eye operations:

Only the doctors know about it. I'm waiting for the operation for this other eye, I haven't heard anything yet. Maybe if they operated on this one it would get better. I'm still waiting for the operation. M21 p2

Translated from Somali

Housing

Some participants had no idea at all who had arranged their housing, which had been allocated on arrival.

The same issues were highlighted in this domain, as in the general statements made about access to services. Speaking English as a second language of having no English, the forms in which information is conveyed often written, means that the VIP is totally dependent on others to address their housing needs and issues. Often the acquisition of a home was arranged in the first instance by family member of friend who had a command of the English language:

It's Housing Association. My son arranged this because he's renting from them as well. KR13 p6

Translated from Somali
However, even though participants may have acquired a council or Housing Association Tenancy the home did not necessarily meet the needs of the VIP, in fact, the lack of adaptations to the home and the need for these was a very common theme in the interviews with VIP:

The stairs are really difficult for me. My bedroom and toilet are both upstairs. KR13 p8

Translated from Somali

Well, I live on my own. I came here to join my family, my son, his wife and his children. They live in a small house and I could not live with them. KR18 p2

Translated from Somali

R Thanks to God I have no problems with the house, but I hope I would get a more suitable accommodation with adaptations for me.

In If you say this is not quite suitable, what would be the right type of house for you?

R I would need a house on the first floor, because I am having to go up the stairs. As a blind man if the house with stairs doesn’t have a lift, in London it’s forbidden to give a house to a blind person. Secondly,...

In Can I just interrupt you? Is it one or two flight of stairs in your house?

R It’s only one flight of stairs. I don’t go two flights, but it has about 14 steps. So I think it’s not the right house for me. Secondly, it’s too small for me. I’m looking for something bigger and on the first floor. Even inside the house all the adaptations for the house are missing.

In What kind of adaptations are missing in your house?

R For example, even in the bathroom there are a lot of facilities missing. Rails, the shower. Also, in the kitchen there are adaptations missing. So I need a house with all those adaptations.

In Do you mean this house doesn’t have any type of adaptations for blind people?

R Yes, not at all. M056 p7

Translated from Somali

One participant described their experience of relocating:

It's the Government one. The Council, Somalis, whites and other blacks had rented a house in the same area. We were there for 2.5 months. So they sent me keys of a new house, saying we are giving you a new house to live in. There was a man called X who took me to the housing. This house was in the middle of all these black people's houses, black youths. Then I was worried they were going to beat up my grandsons. Then I asked X if there were any other Somali people living there. When he said 'no' I refused that house. Mr X never helped me after that. He used to take me everywhere and help me. And my friend wasn't living in the area then. Mr X said if you keep refusing the house they give you I can't keep on taking you to places. I went to another organisation run by another man called Z. I told them about the situation. All this time we were living in this smelly house and I told them I didn't feel safe in the new house I was given, that's why I refused. They said if you refuse the new house you have to live in the old house. KR10 p12

Translated from Somali

It is clear from the extract above that the participant experienced a threat to their own personal security. In addition the quotation highlights issues around intra-ethnic relations, the use of the term 'black' seems to imply that the participant does not regard themselves as a member of this group.
Other issues about housing were focused on the lack of adaptations to the home that were perceived to be needed by the VIP in this study, however it is worth noting that often participants experienced multiple health problems not just visual impairment:

I would actually like a downstairs toilet. I don’t like the fact that the toilet is upstairs and every time I need it I have to go upstairs. Also, the bath, it’s very difficult for me to get out of the bath and I can’t get up once I’ve had my bath. If there was a shower, that would also help. KR13 p6

Translated from Somali

The issue of getting in and out of the bath was mentioned very frequently and the provision of a shower was the most frequently mentioned adaptation required.

A small number of participants reported that they had received adaptations to their homes in respect of their visual impairment. One participant appeared to be in dispute with her landlord:

The people who did all these adaptations have since left the housing department and if X was still there, they wouldn’t be trying to kick me out. When I went onto the waiting list, they told me I had priority. When they gave me the house and I refused to be looked after I didn’t even know what they were offering, they are threatening to kick me out and put me in sheltered housing. So they took me to court and when the court day arrived, my lawyer mixed up the days so we missed the appointment. So they gave us priority and they gave us notice to move out. They are not looking at my situation when they are doing this, and the date when I will be evicted is on the 5 May. My son is always trying to find someone who can help us. He always goes to Howden House and they always say it’s nothing to do with them. And they always come to me and they ask me to sign some papers to say that they did help me in the house, and my care needs. KR12 p7

Translated from Somali

It is clear from the above mentioned quotation that considerable difficulties are experienced negotiating systems and acquiring advocates to ‘get things done’.

My home is too cold. I am an elderly man, a pipe burst in my home and the council did not do anything for me, when they promise to fix the pipe they always send me a letter saying they came around and I was not there. And if I follow up the visit they always say we will see. KR14

Translated from Somali

In summary, housing and the difficulties encountered in obtaining appropriate tenure emerged as a major area of concern for VIP of Somali origin in Sheffield. The perspectives shared constitute a major area of unmet need. These findings very confirm the research findings of Morjaria & Johnson (2005) with VIP from a number of ethnic groups.

Mobility

Mobility and the challenges associated with this again were highlighted by participants as a major area of concern which appeared to significantly effect the quality of life of VIP Somali people in this study.

Only one participant mentioned receiving mobility training, (although this was unusual) this participant had just relocated to Sheffield from London:

Yes, I got a lot of training, including catching the buses, the trains and also map walking. They gave me a lot of training but the most difficult was the buses. Going to the bus station and train station, when the bus and the train comes, the difficulty is knowing when to get on the bus or the train. They trained me on how to do this. M056 p4

Translated from Somali
Most of the Somali VIP in the study would not venture out of their homes, unless accompanied by a relative or a friend. Most individuals had not received any mobility training since their sight loss. A very small number did use public transport; often they had rehearsed this journey with a friend or a family member:

> The bus that takes me to the Post Office and brings me back home and my blessed son taught me where to take the bus and where to get off. I only know that bus. And in this area there are quite a lot of Somalis so I can walk to their houses. They live very near to me. I often try to walk to the Somali houses but the only far away place I go it’s the Post Office where I get my money from. And that’s not even that far when you are on the bus. KR13 p2

Translated from Somali

> ...yes, when I have to travel or going somewhere or anything else I can’t do myself or my carer can’t do, other people do it for me voluntarily, like friends. None of them get any payment for this work. They are friends and relatives. M056 p3

Translated from Somali

In fact it’s very hard to use public transport for Somali blind people. And it’s one of the main problems that I have encountered. The most difficult thing is going to the train station. There are two options: one is getting a taxi, and the other is catching the bus that passes near my street. I use both options. But the problem with the bus option is that I don’t know how to get to the bus stop and nobody has showed how to get there. At the same time I haven’t met anybody who has worked with me to teach me the way to that bus that takes me to the train station and where to get off the bus. The other option is to take a taxi every time. But it’s very expensive to take a taxi every day. It’s another problem. But I don’t have any choice but using this option if I don’t have anybody to show me the way to the bus, and getting off the bus. I am forced to do this every time. I’m at my second year of this course I’m doing. The first year I was financing everything myself: taxis, trains, etc. sometimes I would get some help from my friends, like giving me a lift. Now this second year I am receiving help for travelling. They said if you cannot afford to use public transport, we will provide a form of transport for you. AB35 p3

Translated from Somali

The fact the individual in the above extract appeared to completely self-finance during the first year, seems to suggest that appropriate financial support systems were not explored or perhaps unknown to the individual.

However, a small number of participants used public transport with the assistance of others:

> I use the buses but I always ask people to come with me because I don’t know the places. So I rely on other people. KR17 p2

Translated from Somali

One participant who had recently relocated to Sheffield from London appeared to be much more confident about using public transport:

> I What differences there are between catching buses and trains in London and here in Sheffield?
>
> R The difference is very big. One is a lot easier than the other. In Sheffield there are hills and the roads are more difficult than in London because they are winding. In London you are taking one street and it takes you to another one, you turn left, turn right and it takes you were you want. So London is easier when you go walking. It was very easy for me to take the tube in London, I could just ask the person next to me and it was easy. Sheffield is easier in the sense that it’s less populated so you don’t have to wait so much when you go to places.

In What type of difficulties have you met regarding transport, whether it was in London or in Sheffield?

> R Here now, if I don’t have a relative coming with me I always go by taxi. In London I’d go to places in bus and the tube. If I was going to a place that wasn’t communicated by tube or bus, I would catch a taxi from the station nearby. M056 p4

Translated from Somali
In Have you encountered any problems with the language?

R Not a lot because if I get stuck with something, or if I get lost, I phone somebody and explain what has happened to me. So if I lost my way, I just go to the nearest place for a taxi or transport and I get back. M056 p4

Translated from Somali

I had a wheel-chair but it got broken and nobody has ever fixed it. And I don’t know who to complain to, who to speak to, who to report it to. And it’s there and it’s not much use to me. M26 p4

Translated from Somali

Other participants stated that they had no one to take them out at all:

No, I don’t have anyone to take me out. I’ve been in this house for four years and I have never been out. I sometimes worry that I may get rheumatism or heart problems. M20 p3

Translated from Somali

I use public transport and sometimes taxi, but because I don’t speak English I don’t know how to contact the taxi men. KR18 p1

Translated from Somali

Education

In relation to early education in Somalia, this was limited for many participants. This of course may be related to the nomadic lifestyle in Somalia which characterised the early lives of many of our participants:

In I see...Have you ever received any education in Somalia or in the UK?

R What?!!! No! I lived in the bush and we had animals to look after so nobody educated me. We had camels and cows and sheep. We had quite a lot of those. And you could say we were quite well off because of those. We had a good life. At that time not many people actually knew about medication, especially in that area. People used to learn the Quran, but the girls weren’t educated even in the Quran because they always had to look after the animals and the family. So, no, I haven’t been educated! And now, in the UK, I am too old. My grandchildren are growing up and my son who brought me in the UK is my youngest and I have seven children. KR13 p1

Translated from Somali

I was a nomad and some of the time I was just staying in small towns and I didn’t follow any education. KR17 p2

Translated from Somali

Not enough, only a little bit. I went to the Quranic school, but not the government schools. In fact, I hadn’t done a proper education that could help me in this country. M056 p2

Translated from Somali

Only two the VIP participants had studied for educational qualifications in England:

When I arrived in this country, the second phase of my educations started. That is the College where I am in. It is called Queen Alexandra College in Birmingham. I started in September 2003. AB45 p1

This particular participant also attended college in Sheffield, but appeared to make little progress, but was later referred to a more appropriate educational institution in Birmingham:

I tried to go to the local college, The Sheffield College. I started and after a month somebody told me about this college in Birmingham for blind people, which had more opportunities for me than this other one. Then it was a matter of how to get there. Before this course I hadn’t made any progress on my education in the weeks spent at Sheffield. AB45 p2

Translated from Somali
As with the first participant specific courses to meet the needs of VIP are generally only available outside Sheffield, this of course creates new challenges to be overcome, e.g. travel and lack of support from family members:

Yes, I found some special schools outside London and one in Birmingham. They are boarding schools. One of them is in Surrey and most of the blind people in London used to go to that school in Surrey which is outside London, I didn’t go there. But I attended other language centres in London. It was only 1 hour commuting every day and I learned braille there and English. M056 p3

Translated from Somali

Welfare benefits

Most of the participants in this study stated that they knew little about benefits. Usually the VIP is dependent on a friend or relative to advise about these, and of course they may not be fully of all entitlements:

Somebody told me there is some sort of welfare benefit for the elderly people. When I tell my son he says you’re already taking that money. So I don’t know what I’m missing. So I don’t get anything else. KR13 p4

Translated from Somali

However one participant did say they knew about benefits and financial assistance:

Also, I knew about housing entitlement and benefits. MO56 p3

Translated from Somali

One participant (a new migrant of 4 weeks) was not receiving any benefits: Most commonly participants were receiving housing benefit or a state pension, although some stated they were not receiving benefits:

The children as well are going to school now so they need all the facilities and expenses: transport, clothing, etc. We don’t even have housing benefits. That’s the Government side. We haven’t received anything yet. We haven’t been to other refugees agencies yet. As the people said to me from the start, you won’t receive anything for 6 months [because of Refugee status]. But I tried the agencies that help elderly people and they sent me a letter and they said the person who brought you over here who is full-time worker is responsible for your benefits. Also I wrote to the Benefits Office about the children and they said as well if your daughter is working you won’t get anything. After that we gave up but our situation is very very bad... I should say, as you know in this country we need housing benefits to pay the rent, also my daughter who’s working, she is married now and she’s thinking about moving away, and now they are asking for more than £300 for the rent. Also the bills for the house, like electricity, gas, and everything is falling on us and we only have God left. And we are up to here, we are waiting for the Government and agencies in this country to send us all this financial help and we are waiting to hear from them. M32p 2

Translated from Somali

It would seem likely that many of the VIP participants in this study are not receiving their full welfare entitlements, because of lack of knowledge of the welfare system and the difficulties encountered in obtaining appropriate forms of information.

Security

The findings of this study reveal that Somali VIP in Sheffield face some very real challenges regarding the maintenance of their own security and that of their home. This is compounded by the language barriers that many VIP faces, as sight loss means that the individual is totally dependent on oral sounds for communication. Many of VIP participants in this study lived alone, which contrasts with the commonly held assumption that individuals of Somali origin live in large extended families. Most expressed feelings of anxiety and fear about their homes being broken into a night:

I’m really scared. I don’t go out at night. At soon as it gets dark I stay indoors. And if somebody knocks at the door at night, I always say, who is it? In Somali. I’m too scared. KR13 p6

Translated from Somali
My visual impairment makes me vulnerable and I always feel scared. KR18 p2

Translated from Somali

I don’t feel any insecurity in my house but outside my visual impairment does not allow me to see who is knocking at my door, so I have to ask the person to speak loudly. If they don’t speak Somali I usually stay indoors and call my daughter-in-law. But she lives far away and by the time she arrives, they are gone!!! I am sorry but I just cannot speak to them. Sometimes they leave a letter, but how can I read it and know who they are? It’s a waste of time, isn’t it? KR18 p3

Translated from Somali

It is not clear the extent to which the participant in the above extract is really describing language communication issues or a fear of other individuals from ‘other communities’.

The participant in the following extract describes a very different threat to her community, describing an attack which happened when they first arrived in the UK:

One example is when I first arrived in the UK I went to the hospital, while waiting at the reception a woman talked to me out of the blue, she pulled my hair, threw me to the floor and beat me really badly. There were loads of people waiting to be seen, but no one came to my assistance. I couldn’t see any Somali people in the waiting room if I could scream in Somali. This woman was white and a bit younger than me, and much stronger. I was sitting when she just attacked me and she was younger than me… It made me afraid and made me think that anyone I come across is about to attack me. So that attack and the fact that I live on my own make me very worried and very unsafe. KR11 p5/6

Translated from Somali

Mundane events and daily living can present as serious high risk activities for VIP:

But wearing the glasses helps me, although I can’t see with one eye. If there is a cup right in front of me, it would seem close to me when in fact is further away. And if I try to pour a cup of tea for myself, I have to be very careful because I usually pour it on myself. M21 p4

Translated from Somali

Services do exist in Sheffield to enable VIP to receive training and rehabilitation in respect of daily living; although none of the VIP of Somali origin in this study had engaged in such training, this would have considerable bearing on the home safety.

Rehabilitation and training

Only one participant in this study had received any form of training (mobility):

Well, about the VIP it would be nice if they received training. The British Government wants to train people on how to live independently nowadays, so they should give blind people their chance to get training, so they can live independently, so they can walk without relying on anyone. AB47 p2

Translated from Somali

First of all whatever other people need, we need as well. Secondly before we even deal with our needs we need to see how we can be integrated into the society, how we can live an independent life so that we can look after ourselves. So we should receive training regarding these two things. And also elderly women who are house-bound, the British Government should recognise their needs since they are already helping them; they should finish their job and give them further assistance. AB47 p3

Translated from Somali
Employment

It was felt there were many different barriers to gaining employment, but all were interlinked culture, language and disability. This is also linked to lack of education:

These things we are talking about are all interrelated. Therefore these are the barriers that prevent them from working, whether it's the culture, the language or the disability. Therefore we need to find a solution for these social problems which are lack of education, lack of information, isolation, etc. If we do something about those, we can empower people and integrate them in society. AB45 p8

Translated from Somali

One participant stated that they have acquired work/employment in an unpaid capacity:

There are some jobs that blind people can do. Some of them are skilled and some are labour but I haven't looked into it. For about 2 years I've been a member of the Committee of African and Caribbean disabled group and we were helping the people with housing, health problems, etc. M056 p3

Translated from Somali

Social life

None of the participants in this study said they had an active social life or regular leisure activities:

No, I don't see anybody and I don't do any activities. And in this area most of the women have children they are looking after all day, taking them to school and back. And I don't know where their husbands are gone! Maybe they've run away from them!! And there are loads of women struggling with children and they are single mothers. So I don't usually bother them. They have enough on their plates. So I don't go to see them and there aren't many elderly people like me. KR13 p7

Translated from Somali

The Somali community are helpful but no one is going to spend every day with you. I would much rather be at home [Somalia], but it is not safe to go home. I mean, home is not safe yet, you know that, don't you? KR18 p3

Translated from Somali

There appeared to be support for a Somali community centre that could specifically meet the needs of VIP Somali people.

Yes, I would [like to attend] women's gathering, Quranic gathering and most recently there was a charity activity and religious gathering in the area. I went to that one but it was daytime, that's why. Some people were talking about sending used clothes back home, another woman was talking about ritual practices, and I enjoyed myself. But it was daytime. KR10 p16

Translated from Somali

I usually go to the Somali places were I can see my Somali fellow, I go to the Somali tea house to chat with the people, otherwise it would get too boring for me. KR14 p5

Translated from Somalia

4.3 Information and communication

Obstacles and barriers

Many obstacles and barriers to obtaining information were mentioned. In general Somali VIP required information about the departments and services they need to aid them in daily living:

If I had the power to cover the needs of these people, in fact there is a lot to do: I would start tackling the main priorities first. I think one of the most important things is giving information that helps people with these needs. In this information there should be contacts about education, financial help and the rest of services providing social benefits. All those who are specific to the blind people. Their addresses and
contact details and who they are. How to contact them. That’s the main thing. That is all related to these
direct problems. AB45 p9

Translated from Somali

Oh yes, there is a problem when you don’t know much about the country and you cannot communicate
properly. That’s the main barrier therefore I need some people to help me with the language. I have
visited two places where they teach languages and both of them said we only take new people in
September every year and we have no places at the moment. So I need that side of education to learn
the language. And that’s how the situation is M32 p3

Translated from Somali

I need to get somebody to give me some details about people who can help, especially about diabetes
and eye-sight. M33 p2

In contrast, one participant resident in England for a long period of time 48 years as an economic migrant who
came to work in steel industry, alluded to the fact that language barriers were not a problem.

Also identified was the fact that often VIP would have to wait for a friend or relative to read written materials that
arrived at the home, this often meant that delays were encountered or appointments missed.

Technology computers, emails, phones, Braille software

The telephone emerged as an important means of communication for many participants, but not all were confident
in using the phone because they either did not speak English nor had a poor command of English language.

Only two participants mentioned the availability of specialised IT equipment those respondents who did refer to
technologies, highlighted the cost of obtaining equipment of this nature:

The truth is that the equipment used by blind people is very expensive. And that equipment sells in the
market at a price that I cannot afford. And so far I don’t have any individual or any group who are ready
to help me financially to buy these things. And I have no idea now who I can go for help about this
expensive equipment. apart from my own pocket, my friends and my family. AB45 p3

Translated from Somali

It could be for instance that in common with the general population, use of IT equipment is influenced by age;
the two participants using IT were younger than many of the older people in this study.

This participant had managed to borrow a computer but this was a rare occurrence and the only example in
this study:

For example for me, in my course, when they saw me they lent me a special laptop computer and they
said you can use it while you are doing this course. The computer is not the only thing I need, but it’s one
of the most important ones. The computer is like my pen and paper. When I tell the head of my course
this, that my computer is my pen and paper, he agreed with me. AB45 p3

Translated from Somali

Because of the availability of this equipment this respondent felt he had overcome many of his earlier
communication problems, but again this was rare.

You mean, a computer with the audio in Somali? People who make these special laptops are big
companies. That’s another subject. The issue is not getting computers that talk in Somali but there are
other ways to do things. You have to learn the language and that’s easier than bringing a computer in
Somali. It doesn’t mean that if people don’t know the language they don’t need to use the computer.
That’s not what I mean. The way they are learning is to get this equipment with audio, listening to the
sentences, where the computer teaches the words and their meaning by repetition. And it’s part of
helping to learn the language. So we can’t say if you don’t know the language, leave the computer,
you can’t use it. You can still use it and learn from it. AB45 p10

Translated from Somali
R Yes, I've attended computer classes in those centres I told you before but I haven't used one for the last 3 years.

In It's that a normal computer or one with special for blind people?

R It's special for blind people.

In then you're familiar with computers.

R Yes, I am.

In If you had one, could you use it?

R Yes, but I would need to remember all the techniques on how to use it.

In When you sit in front of the computer, can you remember how to type?

R Yes, I can see every letter in my mind.

Yes, I use it. I know how to send e-mails, how to write messages, send them, etc. But there is still a lot I need to learn about it. I need to learn more about Internet.

In What do you think now about computers? Are they important for your life? In what way can they help you?

R As we all know, all the life and information is in the computers so it's very important, and everybody who has the time for it needs them. If you need to write anything, if you need to send e-mails or anybody needs to contact you from the other side of the world. It's very useful. M056 p6

Translated from Somali

4.4 Family and social networks

Not all the participants in this study lived with family members, some lived alone. In addition the concept of a 'carer', as in the Western conceptualisation is not one that is predominant in Somali culture. For example if a family member cares for a particular individual, than the person is not regarded as a 'carer' per se but has a husband, wife, aunt, niece, nephew etc:

I use the phone just to call my family. I would not say they are my carers but they do come around and take me to their house after I call them (participant laughs here) KR18 p2

Translated from Somali

A small number of the participants interviewed had younger dependent children.

Ethno-history/motivation for migration

All the Somali visually impaired people were refugees from the Civil War in Somalia. Some individuals had arrived via other European countries, under family reunion schemes:

My son brought me to the UK but he has his family and his own children to look after. So I am the only one who lives in this house. It's a one bedroom flat. KR13 p4

Translated from Somali

I was born in Somalia. I have always lived in the countryside. We had livestock, mainly camels.

KR18 p1

Translated from Somali

Carer issues

In general Somali families are obliged to care for their ill, elderly and people with disabilities. In the case of Somalis living abroad, this obligation would rest with the closest relatives:

They [family] do the shopping for me, my son comes to see me in the morning before he goes to work, if not he comes in the evening. He takes me to the GP, he translates for me, he interprets for me. And everything and anything that I need from the housing and Social Security he takes me to them. KR13 p7

Translated from Somali
Some, but not all participants stated that family did everything for them:

The Government assists me with an income and my daughter supports me and cooks for me, cleans and she does everything for me. The Government does help me but my daughter does a lot more than she is expected to. M26 p1

Translated from Somali

I use the phone just to call my family. I would not say they are my carers but they do come around and take me to their house after I call them (participant laughs here) KR18 p2

Translated from Somali

Sometimes, older VIP who migrate as part of a family reunion find family members are not in paid employment which means they may not be able to provide support for the VIP:

But p is working now and all our pressure and needs depend on her. M32 p2

Only one participant mentioned that his carer was receiving financial support:

I was within the caring system for the last 10 years. So the caring money comes from 2 sources: one from the Income support and the other is caring money from another section. So the person is getting payment. M056 p8

Translated from Somali

Participants appeared reluctant to ask family members for help unless the journey or appointment was essential, therefore did not ask to be taken out on social excursions. Data elicited regarding self-perception of visual impairment and blindness indicated that the notion of ‘being a burden’ for the family was significant.

A view was expressed by several people that perhaps if they had remained in Somalia family would have cared for the VIP in the tradition way:

There is one woman who helps me. She is young and she helps me a lot. But I don’t want to ask too much, so it’s only when I have appointments and really important phone calls that I call her. KR11 p7

Translated from Somali

Unusual in this study the following participant speaks about the assistance she received from her next door neighbour:

Yes, because I go every 3 days to see a Somali woman next door and I cook there because she has a cooker. She helps me with the cooking. I take my food and she helps me cooking. Then I bring the ready food and I put it in the freezer and it lasts for 3 days. KR15 p3

Translated from Somali

The extract above highlights the importance of intra-ethnic networks in being able to access appropriate forms of support, that are culturally and ethnically relevant to the VIP.

Isolation/marginalisation issues

In general a picture emerged of isolated individuals who had little opportunity for a life outside the home either in economic or social terms. In this respect Somali VIP can be considered to be experiencing a triple jeopardy in relation to status as migrants, the language challenges and their sensory disability. Most of the participants were elderly and experienced multiple health problems:

No, I don’t have anyone to take me out. I’ve been in this house for 4 years and I have never been out. I sometimes worry that I may get rheumatism or heart problems.

Yes, there is air outside and I’ve never had the experience of it. Fresh air is a medicine in itself. Yes. And legs, legs need to walk and stretch, otherwise your legs get stuck and you almost forget how to walk and you become physically disabled. Another thing is your heart can just give up if you don’t exercise enough. So I need to walk. M20 p3

Translated from Somali
We don’t want to be left out and we would like to be supported, to be independent and we would have liked to have someone to help us with housework. We shouldn’t feel alone. AB47 p2

The quotation above seems to indicate, that although support is required, independence is also important.

**IN** Have you ever received any help from community organisations?

**R** No. Never seen them!

**In** There are other organisations that are specifically for VI people. And there are Somali organisations. What help have you received from them?

**R** Nothing. But I’ve heard there are community run by Somalis but they are too far for me. I don’t go to them but if I had to attend an appointment, my son takes me there. KR13 p8

Translated from Somali

Some individuals continued to be estranged from their family:

*I would have liked my children to be here, to be honest, if there was anything that anybody could do for me that would be my only wish. So I won’t feel lonely all the time* KR11 p8

Translated from Somali

The participant in the extract above alludes to the notion of a ‘transnational family’.

**Family relationships**

Although some participants lived quite close to family relatives, often reluctance existed to contact family members:

*My son and his family live here but I don’t like bothering them.* KR18 p3

Translated from Somali

The assumption that all Somali people who migrate to the UK are part of close knit extended families may be incorrect:

*We are a big family, but these are two men [sons]. A daughter would have been much closer to me. Men always look after their families and forget their mothers. Do you understand?.. But when they come to visit me I get all happy and when they say ‘How are you, mum?’ that makes me happy. There is nothing compared to a son calling you mother. And my grandchildren call me ‘granny’, there is nothing compared to that!* KR10 p10

Translated from Somali

The quotation above is interesting as the participants alludes to the notion of ‘gendered relationships’ in that patterns of obligations and caring may be different between mothers and daughters and mothers and sons.

**New country**

The more significant issue for the participants in this study arriving in the UK is their ability to speak English. An inability to communicate, means that many Somali VIP are reluctant to leave their homes, for fear of being spoken to in English and being unable to respond.

A number of participants had relocated from other EU nation states such as Sweden as part of the family reunion programme:

**In** So was Sweden better than the UK in terms of services?

**R** Services? No, not difference.

**In** Are they worse?

**R** Well, actually it’s better here at least I’ve got home care here in the UK. M20 p4

Translated from Somali
Well, about culture, we Somalis always have the Somali culture no matter where they go. I pray 5 times a day, so if I actually wanted to learn about the British culture it would be impossible because I don't speak the language. I always cross the road when I see English people because I don't want them to speak to me as I can't reply. KR13 p5

Translated from Somali

The extract above may indicate that the participant has no desire to engage in British culture or in a sense to be acculturated into British culture. This may be a manifestation of the involuntary migration an asylum seeker or refugee experiences.

One participant related that a Refugee organisation assisted on arrival in the UK:

Refugee housing I think, she helped us with all the decoration and wallpapers and curtains. So we decided to move here, she put six beds. So you see some people helped us some didn’t. KR10 p14

Translated from Somali

Cultural clashes

A few examples were given by participants that might broadly be termed issues of cultural conflict:

Coming to this country and living in Holland before, there is not much difference. Both are not home in terms of language and cultural differences. I feel a bit scared walking about just in case I have to speak to anyone. After 4 years I still don’t know the British culture. I’m sure the people are nice, they are, aren’t they? KR16 p 2/3

Translated from Somali

Elderly people have always been looked after their families back home. They used to cook for us, they used to clean for us, they used to do our laundry. We had a lot of help back home. The reason why we left our home was because of the Civil War and the fear of being killed. So we would like this lovely Government that gave us protection and homes to live in, to help us elderly people and to complete the services they already provided and we are grateful for having what we have, but it would be nice if we had full care provision. KR11 p2

Translated from Somali

Some participants expressed concern about their ability to access a prayer room, which might indicate to some extent how individuals prioritise different aspects of their lives:

R I cannot go to a place where I cannot pray. It’s hard for me culturally and religiously to do something out of character.

In Culturally?

R Yes, culturally. If there is no mosque or a room to pray, I cannot go anywhere during the praying times.

In So, if you have an appointment during prayer times, what do you do?

R If I don’t even know what to say to them, when I want to pray I can’t communicate with them, so I miss my prayer. If I could only explain to them, then they would have taken me somewhere to pray. KR11 p6

Translated from Somali

One participant mentioned that they would not feel confident to eat the food in the UK outside the home.

Carer perspectives

Much of the data elicited from the carer’s interviews echoed the perspectives in the main study sample; the data from the carers interviews confirmed the data in the main study for expediency, only those issues which uniquely differ from those perspectives in the main study sample are reported in this section. All the carers interviewed had other responsibilities besides caring for their VIP relative; this might be paid employment or caring for young children. The main form of communication with the VIP was via the telephone, in some instances the carers had arranged to have the telephone installed. In terms of family relationships carers were partners, niece or nephew.
In general the carers spoke more freely about the socio-cultural perceptions of blindness and visual impairment both here in the UK and in Somalia. This is perhaps related to the fact that they were not offering viewpoints about themselves, and therefore were more able to express viewpoints freely. Carers acknowledged the continued isolation of the VIP in the UK and that traditional attitudes towards VI very much persist following migration. This carer shared very eloquently socio-cultural perceptions of blindness:

My god! Well they see blind people as if though they do not exist and not counted. Even when they are counting how many in the family they do not is not counted in the community anyway. They are discriminated even if the person lost their sight as child they grow up with that kind of negative include them in. They belief that a blind person is not going to change anything in their live and that they will never going to contribute anything to them. When people are counting how many Somali families live in an area, they do not include the house of a blind person. Because they are not going to be any use to the community, and if the blind person is in family with siblings usually the parents do not count the blind one they would say "i have five children and that" if you ask them well you have six children they will reply "well he/she is not counted what can she /he see". A blind person is seen as burden just like that fridge that you fill in when it's empty. So all and all blind person reaction; they keep that feeling inside all their lives! CR1 p4

Translated from Somali

It was evident that carers of VI we interviewed were more able to speak about the stigmatisation that VIP experience:

...yes they are stigmatised! They are isolated and they would isolate themselves unless there is someone they trust and can rely on. For example I have only lived in this city for one year only my auntie has lived here three or four years, yet there is no one in Sheffield she can call a friend. We don't have any relatives here anyway, but there are so many Somalis here she could have made friends with other communities might be but she does not speak English, and she does not have any Somali friends because of her visual impairment. CR1 p4

Translated from Somali

Perspectives such as that shared above are significant as this presents a challenge to the notion of a very close, cohesive community, who ‘look after the own’ which might be an assumption that members of the dominant community hold. None of the carers we interviewed received a ‘carer’ allowance

It is clear that the participants in this study hold multiple identities in relation to their visual impairment. This includes religious, ethnic and cultural affiliations, their status as refugees or asylum seekers and membership of transnational families. Our findings in this respect very much confirm earlier work by Atkin et al (2002) whose work focused on young deaf people of Asian origin.
5. Discussion

The findings of this study indicate that many of the health and social care needs of the VIP of Somali origin who reside in Sheffield are fundamental in nature. It is perhaps useful to view the findings within the context of the framework offered in Maslow’s hierarchy of needs (1970). Maslow’s theory maps out those dimensions of the human experience those are essential for existence in a hierarchical fashion.

![Maslow's Hierarchy of Needs](image)

Figure 1: Maslow’s Hierarchy of Needs

In a contemporary western society such as the UK in the 21st century it is a somewhat sobering fact that the some of the participants in this study could not claim to have the first level of Maslow’s (1970) hierarchy of needs met. For example at least one person could not exercise or take ‘fresh air’ as they had no carer to escort them outside their home. Almost all of the participants in this study felt a level of threat to their own personal security and safety, despite the huge growth in electronic and technological equipment; most of the VIP in this study did not have adequate security systems in their homes. A presumption exists that individuals of Somali origin live in large extended families, yet in this study a profound degree of isolation was expressed by most, indicating a lack of social acceptance and belonging. All of these factors coalesce to impact on the self-esteem of the individual; it is likely that a degree of psychological distress and that the quality of life for individuals within the study population is poor because the fundamental needs as described by Maslow (1970) are currently not met. It is therefore not surprising that only a small number of individuals (2) have self-actualised and acquired an education or have an active social life, as for most participants in this study their fundamental needs remain unmet.

The process of engagement with the Somali community and the HABS has been fully comprehensive and extensive, we have successfully drawn upon the PAR model of research, to conduct ‘social action research’ (Johnson 2006).
6. Recommendations for the Horn of Africa Blind Society

- There exists the potential for much closer collaboration between the Horn of Africa Blind Society and The Sheffield Royal Society for the Blind at a local level, this would enable a greater number of Somali VIP to become aware of the services of the SRSB and potentially to become registered as a VIP which is imperative, as in many instances, registration is the key to services. Collaboration between HABS and SRSB on specific event/s for Somali VIP.
- Potential exists for greater collaboration between HABS and the Royal National Society for Blind and perhaps linking with international groups such as Unite for Sight (http://www.uniteforsight.org/).
- Outreach work in the form of home visiting needs to be undertaken by the Development Worker firstly to help alleviate the social isolation that many Somali VIP experience, secondly to act as a conduit and referral agency to the specific agencies and service providers whose services can improve quality of life for Somali VIP.
- Greater collaboration with local Somali groups and associations locally and in the region.
- Outreach work in the Somali community, including exhibitions, fairs in geographical locations with large Somali populations.
- The development of professional publicity material including a poster or stand to be used at a local event/s and in formats accessible to VIP.
- Awareness raising within the local Somali community of the needs and potential of VIP in the UK.
- Lobbying of local service providers to ensure information is provided in an accessible format.
- Hosting of a dissemination (in respect of the findings of this research) conference to which all key stakeholders and service providers are invited.
- Development of an information and resource pack for Somali VIP and their carers

Recommendations for service provision:

- Participants in this study were generally unaware of services that might meet their needs, often because information about such services is provided in inappropriate written format. In order to ensure that highly marginalised groups, such as the participants in this study can access services, new forms of delivery of information must be developed. In addition outreach into the community may be needed to make initial contact, this might be in the form of linking for example with the Nurse Consultant for Refugees and Asylum Seekers, in addition to local community groups
- Participants in this study expressed a number of unmet needs, these were largely clustered around service provision and assistance that focused on fundamental and basic needs for daily living, in particular:-
  - The acquisition of English language skills, specific programmes are needed for the Somali VIP.
  - Obtaining appropriate housing, with the correct safety features and adaptations emerged as a significant unmet need. Whilst strategies are in place in Sheffield Homes and Sheffield City Council to meet the housing needs of visually impaired people, these mechanisms were unknown to the participants in this study. Alongside this, there is an urgent requirement for Somali VIP in Sheffield to have their safety and security needs met. The installation of a shower was the most frequently mentioned home adaptation that participants felt in need of.
  - Help and assistance with housework and shopping, this was the most frequently expressed unmet need in this study.
  - Mobility requirements: many of the participants lacked the mechanisms to achieve mobility outside their home
  - There exists an urgent imperative for social support to alleviate social isolation, and perhaps the provision of a service/venue where VIP of Somali origin and their families might meet.
• It is unlikely that VIP of Somali origin will seek education or employment until their fundamental needs for daily living are met; however Sheffield lacks the specific educational programmes to meet the needs of VIP. Programmes that have existed in the past according to participants perspectives have failed to fulfil expectations.

• Some service providers appear to offer a model of good practice which others may wish to emulate e.g. the Royal Hallamshire Hospital; however during this study we did not have the opportunity to evaluate this from a service user perspective.

Recommendations for future research

• A further national study exploring the quality of life for individuals for VIP of Somali origin is urgently needed using quality of life standardised assessment tools. Many of these tools have been used internationally, with diverse cultural groups and therefore would seem to have a level of cultural congruence.

• A study exploring the notion of 'stigmatised diseases and illnesses within the Somali community

• Research exploring changing patterns of family and kinship with the Somali community

• Evaluation of service developments and innovations designed to support Somali VIP
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Appendices
Appendix 1: Horn of Africa Blind Society Executive Committee

**Chairman:** Abdi Mohamed (student)

**Secretary:** Nigel West (Voluntary Action Sheffield)

**Acting Treasurer:** Nigel West

**Members:**
Mohamed Issa (Project Coordinator) Director
Adan Jama (Community volunteer)
Mohamed Haaruun Mohamoud (Student)
Saada Osman (Support teacher/trainer)
Robin Story, MBE (formerly VSO Field Director, Nigeria; member of the Anglo Nigeria Welfare Association for the Blind)
Alan Thorpe (Activities Manager, Sheffield Royal Society for the Blind) Kaltum Rivers

**In attendance:**
Development Worker Carmen Calvo Rodriguez

Four members of the committee are blind or have visual impairments and five members of the committee speak Somali.
Appendix 2: Literature Search Strategy

1). Electronic bibliographic databases
12 electronic bibliographic databases were searched covering the medical, nursing, health-related and social care literature:

- AMED
- Arts and Humanities Citation Index
- ASSIA
- CDSR
- CENTRAL
- CINAHL
- DARE
- EMBASE
- HMIC
- MEDLINE
- Science Citation Index
- Social Science Citation Index

2). Research registers
Specialist research registers (e.g. Index to Theses and the National Research Register) were also searched.

3). Internet
Systematic Internet searches were also performed. Many of the online information used were accessed via the Google search engine; other websites that were targeted included the Somali UK website and the RNIB website as well as DoH websites.

4). Hand searching key journals
The most recent editions of key journals, which are not indexed on the databases named above, will be searched by hand for further relevant articles. These key journals were identified from searching the various databases and consulting experts. Other important journals that are not indexed on the various databases and which came to light either as the search is undertaken or that are recommended by experts were also be hand searched.

5). Scanning reference lists in key articles:
This was especially useful in identifying relevant sources of ‘grey’ literature, for example conference proceedings. Citation searches were undertaken on key papers and authors.
Search strategy

A combined free-text and thesaurus search was undertaken in the major databases. Boolean logic (AND and OR) was used to combine different search terms together. A sample search strategy (Ovid Medline) is provided below:

1. Somalia/ (691)
2. somali$.tw. (778)
3. horn of africa$.tw. (47)
4. africa$.tw. (58419)
5. exp Africa, Eastern/ (21597)
6. Ethnic Groups/ (25965)
7. ethnic$.tw. (29051)
8. Refugees/ (3904)
9. "Emigration and Immigration"/ (16010)
10. refugee$.tw. (3017)
11. immigrant$.tw. (6404)
12. immigration.tw. (2984)
13. "Transients and Migrants"/ (5683)
14. migrant$.tw. (4117)
15. African Continental Ancestry Group/ (19893)
16. black$.tw. (45789)
17. bem$.tw. (1051)
18. or/1-17 (184912)
19. Visually Impaired Persons/ (257)
20. exp Vision Disorders/ (37017)
21. exp Eye Diseases/ (279046)
22. blind$.tw. (113982)
23. glaucoma$.tw. (23249)
24. cataract$.tw. (24453)
25. conjunctivitis.tw. (5191)
26. ((visual$ or vision$ or sight or eye$) adj2 (impair$ or disab$ or handicap$ or disorder$ or disease$ or loss)).tw. (22205)
27. trachoma.tw. (1462)
28. exp disabled persons/ (27681)
29. handicap$.tw. (14571)
30 disab$.tw. (57820)
31 or/19-30 (475012)
32 18 and 31 (6896)
33 "health services needs and demand"/ (19658)
34 needs assessment/ (9373)
35 need$.ti. (55030)
36 require$.ti. (52985)
37 or/33-36 (130412)
38 32 and 37 (148)
39 or/1-3,8,10-12 (13422)
40 or/19-27 (395917)
41 39 and 40 (157)
42 (somali$ or africa$ or ethnic$ or refugee$ or immigrant$ or migrant$ or black$ or bem$).ti. (55529)
43 (visual$ or vision$ or eye$ or sight$ or blind$ or ophthal$ or orthopt$ or optician$ or trachoma or cataract or conjunctivitis or impair$ or disab$ or handicap$).ti. (212539)
44 42 and 43 (672)
45 44 and 37 (21)
46 (visual$ or vision$ or eye$ or sight$ or blind$ or ophthal$ or orthopt$ or optician$ or trachoma or cataract or conjunctivitis).ti. (154647)
47 (need or needs).ti. (33299)
48 46 and 47 (246)
49 or/38,41,45,48 (551)
50 limit 49 to human (506)

**Search restrictions**

No date, language or publication type restrictions were applied to the searches. This helped to give an indication of the type and volume of literature excluded by applying the inclusion criteria listed below.
Address
School of Nursing and Midwifery
The University of Sheffield

Contact
Dr Gina Higginbottom
g.higginbottom@shu.ac.uk

Web
www.snm.sheffield.ac.uk

Copies of this report are available on request in Somali audio-taped versions and braille.

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<tr>
<th>Code</th>
<th>Age</th>
<th>Gender</th>
<th>Self assigned ethnicity</th>
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<th>Nature of visual impairment</th>
<th>Occupation</th>
<th>Other disabilities</th>
<th>Registered blind?</th>
<th>Religion</th>
<th>Reasons for migration</th>
<th>Date of migration</th>
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<th>Braille user?</th>
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