

# Doctor of Clinical Psychology Portfolio

## VOLUME I

Psychological distress and access to services among a community sample of the South Asian population in South East England.

Word Count: 28,570

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*October 2014*

*Submitted to the University of Hertfordshire in partial fulfilment of the requirements of Doctor of Clinical Psychology (DClinPsy).*

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## ACKNOWLEDGEMENTS

I would like to extend my gratitude to the many people who have provided support, help and encouragement to me, without whom I would have not been able to complete this thesis. My supervisors, Dr Barbara Mason and Dr David Wellsted provided consistent, pragmatic and calm support, not to mention inspiration for the directions to take my work.

My partner, Lee, has been patient, encouraging and supportive throughout the process of my working through the demands of the DClinPsy. He, my close friends and family have provided me with much needed light relief, enjoyment and support throughout my work and continued to be available to me, even at times when I was unable to be available to them.

I would also like to share my thanks with my fellow DClinPsy students and friends, who helped me to think through both pragmatic and emotional demands of our work.

To all those who have provided me with support in the last three years, thank you.

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## ABSTRACT

South Asian people are less likely to have their mental health needs recognised and experience inequality in access to services, compared to the White British population in the UK. Attempts through government policy to improve equality in mental health care and outcomes have had limited success.

The aim of this study was to explore access to and experiences of services among people of South Asian origin living in the UK who were experiencing distress. An anonymous survey was distributed in GP surgeries and online, collecting a community sample of 103 adults who self-identified as South Asian. The survey contained questionnaires measuring distress, quality of life, acculturation and access to and experience of services for mental health.

Between 33% and 50% of the sample was above the threshold for distress, depending on the measure used, while 40% reported a low quality of life. Those who were unemployed had greater levels of distress. Half of the sample had sought help for emotional problems in the past, with the majority seeking help in the NHS. Greater acculturation was associated with reduced distress and a higher quality of life. Seeking help from services was predicted by experiencing distress, being female and having a physical health problem.

Clinical implications for mental health service delivery as well as the need for further research relating to the recognition of mental health problems in primary care are discussed.

# INTRODUCTION

## Context

### **International Context**

The Movement for Global Mental Health evolved from the Global Mental Health series in The Lancet in 2007 and bolstered international recognition of mental health as a global health issue. In 2007, the first of a six-part series in the Lancet was published: 'No health without mental health' (Prince, Patel, Saxena, Maj & Maselko et al., 2007) outlined the need for the recognition of mental health as a major health priority and that understanding, recognition and intervention for mental health problems must be embedded within health systems globally.

### ***National Context***

Mental health services have been a part of the National Health Service (NHS) in the UK since its inception, and the provision of these services and their accessibility has grown. However, with a large multicultural population in the UK, attitudes, perceptions and beliefs about the mental health of a wide range of people must be considered in service development and delivery.

The National Service Framework for Mental Health (NSF-MH) set out key targets for improving access to mental health services (Department of Health [DoH], 1999). It specifically identified people from black and minority ethnic (BME) groups as people disproportionately represented among the different pathways of mental health care in the UK. The NSF-MH coincided with the Race Relations (Amendment) Act 2000, which was extended to cover public bodies, such as the NHS. This amendment ensured that discrimination on the basis of race, culture or ethnicity was unlawful in the UK and emphasised the responsibility of public services to actively promote equality and target discrimination against people from different racial and ethnic groups.

National Institute for Mental Health in England (NIMHE, 2003) released a policy document aimed at improving mental health services and tackling inequalities in mental health services for BME communities living in England. In the same year, the Department of Health presented a consultation document for Delivering Race Equality in Mental Health Services (DoH, 2003), which outlined suicide, pathways to care and acute inpatient facilities as specific areas of concern. Suicide and pathways to care were particularly noted for areas for people of South Asian origin. They noted higher suicide rates for women born in India, and South Asian people being less likely to have their mental health problem recognised when presenting to their GP.



The consultation was followed by the implementation of a five-year action plan for Delivering Race Equality in Mental Health Care (DRE) in 2005 (DoH, 2005), which was based on three 'building blocks':

- more appropriate and responsive services
- community engagement
- better information.

The purpose of the DRE was to provide a comprehensive programme of work to achieve equality for BME users of mental health services in access, experience and outcomes. Progress was reviewed in 2009, which acknowledged that improvements in delivering race equality had been faced with key challenges, including the complexity of BME communities, the problems in using statistics as a means of measuring improvements, high expectations and the impact of external changes.

In 2011, the Department of Health (DoH) published the No Health without Mental Health policy paper. Again, this stipulates a specific target for improving mental health outcomes by promoting equality and reducing inequality. It highlights three aspects to the reduction of mental health inequality:

- tackling mental health problems
- tackling inequalities that are a consequence of poor mental health, and;
- tackling inequalities in service provision, including access, experience and outcome.

The No Health without Mental Health paper acknowledged that in spite of many previous initiatives, to address inequalities in mental health care, such as the DRE programme (DoH, 2005), there remain significant differences across ethnic groups in access to, experience of and outcomes from the UK mental health services. At the beginning of 2014, the Department of Health identified 25 priorities for essential change in mental health. Twelve of these priorities related directly to access to mental health services, of which one specifically targeted tackling inequalities (DoH, 2014).

Ethnic inequalities in mental health service provision in the UK have been, and remain, on the political and health agenda. Many national and local government initiatives have been introduced to begin to challenge and redress inequality at every level of mental health service provision. However, the outcomes from these programmes have, to date, been unsatisfactory in redressing inequalities in mental health. This research seeks to contribute to the understanding of access to mental health services, as one facet of addressing inequalities in mental health service provision and use.

## Terminology

A systematic review of literature (Ma, Khan, Kang, Zalunardo & Palepu, 2007) found that the methods of reporting ethnicity in studies in general medical journals were suboptimal, with highly variable terminology used. This represents a problem in the way in which conclusions may be drawn from literature relating to ethnicity and how health findings can be applied across cultures. This is seen in much of the literature yielded in the literature search for this thesis: the majority of the literature referred to 'Asians', 'Latinos', 'Europeans', 'Whites' or 'Blacks', without defining what was meant by these terms.

In the context of this research, the term 'Asians' presented a significant challenge in interpreting the literature, due to this potentially representing the whole Asian continent. This problem in the literature has been highlighted by Lewis-Fernandez, Raggio, Gorritz, Duan & Marcus et al. (2013), who developed a rigorous 16-item checklist to assess the way ethnicity, race and culture are reported in psychiatric publications. The checklist provides a helpful guide for considering how ethnicity has been explored and reported on in the literature and where possible, this will be commented upon in the review of the literature in this thesis.

Definitions of ethnicity, culture and race are inherently contextual as is evidenced through the need for all studies and reviews dealing with these topics to carefully define their terms (Cauce, Paradise, Domonech-Rodrigues, Cochran & Shea, et al, 2002). 'Ethnicity', 'race' and 'culture' are often used interchangeably and interpreted differently; as such, it is essential that these terms are clearly defined for the context of this thesis.

### ***Ethnicity***

Ethnicity is a multifaceted concept and cannot be considered as one purely of biological or genetic origin (Durà-Vilà & Hodes, 2012; Rutter & Tienda, 2005). It relates to the shared values, culture, religion, language and structure of a social group, which are all transmitted through generations but are transient and flexible depending upon the context, for example through migration (Rutter & Tienda, 2005). Ethnicity may also be recognised by the boundary with another ethnic group, which may raise awareness of difference between the groups. This awareness can result in each group developing a sense of collective identity. However, an ethnic identity can also be assigned by others (Durà-Vilà & Hodes, 2012; Rutter & Tienda, 2005).

The categories of ethnicity used in social research in the UK, such as that selected for use in this study by the Office of National Statistics (ONS, 2011) are a compromise between the vast heterogeneity of identities within an ethnic group and the need for a system that has utility in research (Durà-Vilà & Hodes, 2012). For the purposes of this study, 'ethnicity' is defined in using the terms and categories of the UK Office of National Statistics (ONS, 2011).

## ***Race***

Race may be described as a social construction, categorising people based upon their physical appearance, but in particular their skin colour. Historical conceptions of race as based in biological difference have since been found to be false through the course of genetic research. Research has found that the concept of a 'pure' race does not exist and that there are larger differences within traditional racial categories than there are between them (Fernando, 2010).

The term 'race' will not, therefore, be referred to hereafter in this thesis, with the exception of where it has been explicitly used in cited literature.

## ***Culture***

Defining culture is complex and other associated factors, such as nature, social context and ethnicity, make defining culture as a distinct and separate construct challenging (Cauce et al. 2002; Eagleton, 2000; Kirmayer, 2001<sup>a</sup>). Understanding of 'culture' more broadly has developed in recent years, from being considered a static set of systems, to a more transient set of constructions that develop through individual, community, social and organisational ideologies and practices (Kirmayer, 2001<sup>a</sup>; 2001<sup>b</sup>). The majority of definitions incorporate those aspects of an environment that are human-made, both subjective, in terms of values, rituals and practices and beliefs, and objective, such as buildings, art and literature.

Eagleton (2000) (as cited in Kirmayer, 2001<sup>a</sup>) described three uses of the word 'culture'. First, it is used as a standard of refinement or sophistication; second, it is used as a sense of collective identity on the basis of language, ethnicity and religion; third, it is used to describe a system of values, beliefs and customs.

Cauce et al. (2002) talked about the difficulty in separating culture from context, because one is often used to define the other. However, they described culture as a social context in which social norms, values, language, beliefs and institutions are shared by people within that context. For the purposes of this thesis, this definition of culture is used.

## ***Black and Minority Ethnic (BME) Groups***

The terms 'black and minority ethnic (BME) groups' and 'ethnic minority' is used in this thesis to refer to people who form a distinctive group on the basis of their ethnicity, of which there are fewer than the majority population of the society where they reside. In a British context, people of White British ethnicity form the majority of the population. Those residing in the UK of an ethnicity other than White British, are considered to be an 'ethnic minority'.

It is important to acknowledge that there is significant heterogeneity captured within the terms 'BME', 'ethnic minority' and 'South Asian' (defined below). These terms encompass a wide variety of people from different religions, cultures and countries within them. There is,

therefore, significant variation *within* different minority ethnic groups (Commander, Odell, Surtees & Sashidharan, 2003) and care should be taken to avoid assumptions of 'sameness' on the basis of being identified as part of a minority.

### **South Asian**

Within this study, the term 'South Asia' is used to refer to the countries on the Indian sub-continent, including India, Pakistan, Bangladesh, Nepal, Bhutan and Sri Lanka. Within this thesis, a person who has self-identified as 'South Asian' is considered to have familial heritage originating from any one of these countries.

It is acknowledged that these countries span a vast geographical area and there is a huge range of religious, cultural and ethnic diversity. For example, the Punjabi region has a strong cultural identity and spans the Indian and Pakistani borders (Bhui, Bhugra, Goldberg, Sauer & Tylee, 2004). The sample in this thesis, therefore, must not be considered as a homogenous sample, but one in which there are geographical similarities in their region of origin and broad similarities in culture that differ from the dominant culture of the UK.

The term 'Asian' when used in a British context, usually refers to 'South Asian' as defined above. However, in an American context, 'Asian' can be used to refer to anyone originating from the Asian continent. This presents significant challenges when interpreting the literature, in which terms are often not defined or optimally reported (Ma et al, 2007). Where literature refers to the term 'Asian', this will be clarified when reported, where possible.

## **Literature Review**

### **Strategy of Literature Review**

Search terms were defined to enable a systematic search of the literature (see Appendix 1). The literature search using these terms was rerun on three occasions, to capture any new literature published during the course of the project.

The initial literature set was screened for relevant papers. Citations within the papers identified from the literature review were cross-checked against the search returns. Those that were deemed appropriate for and relevant to this research topic, but that had not been returned in the initial literature search strategy were sought and obtained.

### **Mental Health in South Asian Communities in the UK**

There is a large body of research highlighting disproportionately lower levels of access to mental health services by individuals of black and minority ethnic origin (BME). In their policy document, the National Institute for Mental Health in England (NIMHE, 2003) outlined how BME groups share a number of features, including disadvantage and discrimination, particularly in health and health care. The document highlighted that people from BME groups suffer from poorer health outcomes (both physical and mental), reduced life expectancy,

greater difficulty in access to health care, more coercive pathways into and less satisfaction with mental health care, than the majority white population in the UK.

The Department of Health commissioned the Ethnic Minorities Psychiatric Illness Rates in the Community (EMPIRIC) study (Sporston & Nazroo, 2002) to carry out a national study into ethnic differences in mental health in the UK. They compared data for the largest ethnic groups in England: White, Irish, Black Caribbean, Bangladeshi, Indian and Pakistani<sup>1</sup>. They found that South Asian people were more likely than any other ethnic group to have visited a doctor in the last six months but that South Asian women were the least likely to report having visited a doctor for stress-related or emotional problems.

There have been inconsistent findings in studies exploring the prevalence of mental health problems among South Asian people, with some suggesting that rates of depression are lower in South Asians when compared to white British people (Bhui, 1999). However, a study exploring depression among Punjabi people in London (Bhui, 2004) using a culture-specific screening instrument found that compared with English counterparts, depressive diagnoses were more common among Punjabis. Furthermore, there has been evidence to suggest that common measurements of distress or mental health problems in the South Asian population may underestimate prevalence (Williams, Eley, Hunt & Bhatt, 1997).

Goodman, Patel & Leon (2008) found that British Indian children appeared to have lower rates of mental health problems. In order to explore whether these differences were representative of a 'real' health advantage, or merely symptomatic of reporting differences across different ethnic groups, they further explored the possible explanatory factors for this observed difference in a follow-up study (Goodman, Patel & Leon, 2010). In the follow-up study, parent, lay-person and clinician administered assessments were carried out against DSM-IV diagnostic criteria of 13,836 White British children and 361 British Indian children. They found that British Indian children had a large advantage over their White British counterparts for externalising (behavioural) problems but no difference for internalising (emotional) problems; differences in educational attainment had a mediating role but socio-economic risk factors did not explain the difference. A key strength of this study was the population-based sampling, with a representative proportion of White British and British Indian children in the general population when compared with data from the 2001 Census (Office for National Statistics [ONS], 2001). However, data pertaining to acculturation, religion, religiosity and the children's migratory generation were not collected and would need to be explored further to gain insights into mental health equity. Longitudinal follow-up of the participants would have been advantageous to explore whether the observed advantage for British Indian children was preserved into adulthood.

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<sup>1</sup> Sporston & Nazroo (2002) defined the term 'White' as a general white population living in England. It is therefore unclear whether this population was White British only, or included White Other as well, including minority white populations, for example, Eastern European.

Inconsistent estimates of the prevalence of mental health problems in the South Asian population in the UK are likely to be due, in part, to the way in which mental health is not only assessed and measured but also conceptualised and reported. This remains a significant challenge in any research into the prevalence of mental health problems in minority ethnic populations. It is important to consider, therefore, the different factors that influence the mental health of ethnic minority populations.

## **Factors Affecting the Mental Health of Ethnic Minority Populations**

There are many social, psychological, cultural, economic and political factors that influence the experiences of psychological distress among ethnic minorities. These factors will be explored further in this section.

### ***Migration***

In recent history, there has been a significant increase in globalisation, which is inextricably linked with migration (Koehn, 2006). There are many reasons why people may migrate from their country of origin to another country. These reasons can include an active choice in search of perceived opportunities, or to escape persecution; alternatively, migration may be forced or decided by others. Regardless of the reasons for migration, those who migrate must undergo significant change in all areas of their lives, including the loss of social networks and moving home. In many cases it involves moving from the familiar to the unknown. Although globalisation has brought significant social and economic advantages, it is also associated with disadvantages to migrant communities and individuals including marginalisation, unemployment, increased poverty, and poorer access to health care and education (Bhugra & Minas, 2007).

Furnham & Shiekh (1993) presented the migration-stress hypothesis, which suggested that the larger the sociocultural differences between an individual or family's country of origin and the country to which they migrate, the greater the stress they will experience and, consequently, the greater the risk for mental health problems. The majority of migration occurs from poorer, collectivist cultures to richer, more individualist cultures (International Organization for Migration, 2005). Within this, therefore, is a necessary process of adaptation for migrants to new and unfamiliar societies and cultures. The potential negative impact upon the mental health of those people who are left behind in countries that people emigrate from as well as the role of acculturation on the mental health of migrant communities requires urgent further exploration and research (Bhugra & Minas, 2007).

### ***Epidemiology and Pathways to Care in Country of Origin***

In most epidemiological studies globally, estimates of prevalence are based on those who meet criteria for diagnosable mental disorder in accordance with the psychiatric nosology of either the DSM (APA, 1994; 2013) or the International Classification of Diseases (ICD-10:

WHO, 1990). Given the dilemmas in using a fixed psychiatric nosology to apply across the global range of cultural variations, then it is probable that epidemiological studies may not accurately capture the incidence of psychological distress or poor mental health experienced by diverse populations around the world (Kirmayer, 2006).

As an example, studies of the epidemiology of mental disorders in Bangladesh report a wide range in the prevalence of mental disorders, ranging from 6.5% to 35% (Giasuddin, Chowdhury, Hashimoto, Fujisawa & Waheed, 2012; Hosain, Chatterjee, Ara & Islam, 2007; Islam, Ali, Ferroni, Underwood & Alam, 2003). The estimated prevalence appears to vary depending upon whether the studies were carried out in rural or urban areas. Although these findings relate only to Bangladesh, it illustrates the complexity and challenges faced when comparing the epidemiology of mental health problems in one country with those in another. Furthermore, there are likely to be several personal and socio-demographic differences between groups of people who migrate from and those who remain in their country of origin.

### ***Culture and Acculturation***

Culture permeates every aspect of psychological distress: the sources of distress, how it is experienced, the way the way in which it is described and interpreted, means of coping and seeking help and the way in which society responds to it (Kirmayer, 2001<sup>b</sup>). There is clearly a complex and diverse relationship between culture and health (Salant & Lauderdale, 2003) and the clinical implications of culture are unquestionably far-reaching. For ethnic minorities in the UK, if there is a mismatch between the cultural idioms of distress, then this is likely to have a further negative impact on individuals who may feel their experiences are not understood. There is a large body of literature relating to measuring culture within the South Asian immigrant populations but the proliferation of studies reflects the heterogeneity.

Berry (1990; 1997) described acculturation as a process of adaptation to a new, host culture. Although acculturation as an adaptive process has become the dominant paradigm of acculturation in applied psychology, there remains debate about its suitability (Schönpflug, 1997; Chirkov, 2009). Criticism of the paradigm of 'acculturation as adaptation' has been due to the minimisation of the importance of complex social, cultural and psychological factors that contribute to acculturation (Schönpflug, 1997; Chirkov, 2009) and that it does not have the sophistication to adequately account for the complexity of stress associated with immigration (Uppaluri, Schumm & Lauderdale, 2001; Salant & Lauderdale, 2003).

There have been a number of studies commenting on an association between the level of acculturation, help-seeking behaviours and access to services for people who are living in a new culture or country to that of their origin (Salant & Lauderdale, 2003; Palmer, Macfarlane, Afzal, Esmail, Silman & Lunt, 2007). Burnett-Zeigler, Bohnert & Ilgen (2013) carried out an American study using nationally collected data of 34,653 people who responded to a survey studying alcohol and drug problems and associated mental health problems. The survey

included questions about acculturation and ethnic identity and participants categorised themselves into Black, Hispanic or Asian ethnicities<sup>2</sup>. The authors found that higher scores on their measure of ethnic identity reduced odds of lifetime psychiatric diagnosis across all ethnicities after controlling for socio-demographic characteristics. Conversely, higher scores on acculturation measures were associated with increased odds of lifetime psychiatric diagnosis, again across all ethnicities. The authors suggested that increased acculturation may be associated with having left behind or lost an aspect of one's culture, such as language, cultural practices and social interactions (Burnett-Zeigler, et al., 2013), which may in turn impact on an individual's sense of identity and self. With such a large sample of people, it would have been feasible to have more carefully defined categories of ethnicity, providing greater opportunity to explore and hypothesise about more subtle nuances between the ethnic groups.

Other research, however, has suggested that greater acculturation is associated with improved mental health. Bhui, Stansfeld, Head, Haines & Hillier et al. (2005) carried out a cross-sectional, school-based population survey of 2623 adolescents (aged 11-14) in East London to explore how cultural identity and acculturation influence mental health. They found that those who made culturally integrated friendship choices had lower levels of mental health problems than their counterparts who were more marginalised, who chose friends from neither their own or another culture.

The association between acculturation and mental health is clearly complex and multi-faceted. Challenges in the conceptualisation and measurement of both 'acculturation' as well as distress have a significant impact on the understanding of their relationship to each other.

### ***'Ethnic Density Effect'***

There has been some research into the impact of 'ethnic density', that is, the proportion of an ethnic minority group as residents in an area, on the mental health of minority populations. The 'ethnic density effect' hypothesis suggests that those living in areas where the density of one's own ethnic group is high may have greater protection for mental health than those where ethnic density is low (Das-Mushi, Bécares, Dewey, Stansfeld & Prince, 2010). The protective effects of ethnic density may come from improved social support and social networks, or through improved buffering from racism and discrimination (Das-Mushi et al., 2010).

In their study on the impact of ethnic-density on mental health outcomes in England, Das-Mushi et al. (2010) found that Bangladeshi people in particular appeared to have the most consistent associations between higher ethnic density and reduced reporting of discrimination,

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<sup>2</sup> Burnett-Zeigler, Bohnert & Ilgen (2013) did not provide any further identifying information or definition of these terms. 'Asian', in this context, therefore, is likely to include those from the wider Asian continent, including Vietnam, China and South Korea.



improved social support and networks. They also found in the Bangladeshi group that high ethnic density may be associated with lower odds of common mental health problems. Bécaries, Nazroo & Stafford (2009) found some trends to suggest that experiences of racism are fewer in areas of high ethnic-density and that this may have an impact in turn on the health outcomes for those people. However, they had limited statistical power in their findings and recommended further investigation.

### ***Social Class***

Social class has been demonstrated to have an impact upon every facet of a person's life (Liu, Pickett & Ivey, 2004) including health and mental health. Previous research has suggested that those who have been labelled as being from a lower social class have been found to consider themselves as inferior and to hold more negative personal identities than those labelled within a higher social class (McMullin & Cairney, 2004; Pope & Arthur, 2009).

People from black and minority ethnic groups in the UK are more likely to be of lower socioeconomic status than those of the White British ethnicity (NIMHE, 2003). Lower socioeconomic status in itself has been shown to be strongly correlated with poorer mental health outcomes (Miech, Caspi, Moffitt, Wright & Silva, 1999) and acts as a barrier to accessing mental health services (Hernandez, Nesman, Mowery, Acevedo-Polakovich & Callejas, 2009).

### ***Social Support and Family***

South Asian cultures tend to place more of an emphasis on 'collectivism' as opposed to the 'individualism' that is more dominant in British culture (Morris, 2012). Collectivist societies function on the support of relationships, favour interdependence and the self is viewed as a part of a larger system or network, such as a community or family. By comparison, individualist societies favour individual attainment, independence and self-reliance (Morris, 2012).

A literature review by Albert, Becker, McCrone and Thornicroft (1998) exploring the relationship between social networks and how people used mental health services, found that social networks were smaller among those with severe mental health problems than those of the general population. Furthermore, they found that less social support was associated with more frequent episodes of hospitalisation. Qadir, Khalid, Haqqani, Huma and Medhin (2013) carried out a study of 277 women in Pakistan using psychometric self-report measures to explore the associations between perceived social support, satisfaction in their marital relationship and their mental health. They found that increased social support was associated with greater marital adjustment and satisfaction, which then indirectly reduced the risk of depression.

South Asian communities with large familial, social and community networks, may therefore have some protective advantage for mental health problems. However, this could also act as a barrier to either seeking professional help or not presenting to mental health services until mental health has deteriorated to an extent that it cannot be managed without professional help (Leong & Lau, 2001). The role of stigma and shame within families and social networks must also be considered in this context. This will be discussed further in this chapter.

### ***Racism and Discrimination***

Overt and covert racism directed towards individuals or groups are likely to increase the risk of vulnerability to mental health problems (Bécares, Nazroo & Stafford, 2009). Racism and discrimination continues to be widely reported in the UK (DoH, 2005; NIMHE, 2003). When considering the impact upon South Asian people, particularly South Asian Muslims in the UK, there has been a reported rise in racism and discrimination in the aftermath of the terrorist attacks in the USA on September 11<sup>th</sup>, 2001 (Abbas, 2004; Saeed, 2011).

Prior to this, in a study of 106 South Asian people in the UK, Hatfield et al. (1996) found that 44% of their participants identified racism and discrimination by the indigenous White community as a source of their personal stressor impacting upon their mental health. Of their total sample, 63% reported having experienced some form of hostility, disrespect or intolerance from members of the White British community.

Racism and racial discrimination are predominantly conceptualised as chronic stressors, but overtly racist acts directed at an individual may be considered as life events, or acute stressors (Chakraborty & McKenzie, 2002; Williams, Yu & Jackson, 1997), the consequences of which have been associated with poorer mental health outcomes (Greene, Way & Pahl, 2006; Williams, Neighbors & Jackson, 2002).

There are protective mechanisms against the negative impact of racism and discrimination on mental health, however. For example, in their study exploring the impact of perceived discrimination in a group of American adolescents, Greene, Way & Pahl (2006) found that having a strong ethnic identity and feeling positive about one's ethnic group had a moderating effect on the impact of perceived discrimination on psychological wellbeing.

### **Factors Affecting Access to Services for South Asian People in the UK**

There are many different factors that may influence how, when and why people may seek to access help from health services for psychological distress. Durà-Vilà & Hodes (2012) identified some contributory explanations for the observed ethnic variations in service use, including: family support, socioeconomic factors, stigma, alternative sources of help, and lack of culturally competent services. These, along with other factors will be considered in this section.

### ***Mental Health Services and Pathways to Care in Country of Origin***

The WHO Mental Health Atlas (WHO, 2011) provides an estimate of mental health resources available for people with mental health problems around the world. Understanding the mental health infrastructure available to people living in South Asian countries helps to place services in the UK into context. Of course, many people of South Asian origin living in the UK have never lived in a South Asian country, however, cultural conceptualisations and expectations can permeate through generations.

Table 1 summarises some of the information available in the Mental Health Atlas for South Asian countries, compared with the UK.

*Table 1: WHO Mental Health Atlas Data for Mental Health Care in South Asia and UK*

Country	Income Category (World Bank Criteria)	Mental Health Policy	Expenditure of Health Budget on Mental Health	No. professionals in mental health workforce per 100,000 pop <sup>n</sup>		
				Psychiatrists	Psychologists	Nurses
<i>Bangladesh</i>	Low	Yes	0.44%	0.07	0.01	0.20
<i>Bhutan</i>	Lower Middle	Yes	<1%	0.28	0	UN
<i>India</i>	Lower Middle	No	0.06%	0.301	0.047	0.166
<i>Nepal</i>	Low	Yes	0.7%	0.18	0.04	0.25
<i>Pakistan</i>	Lower Middle	Yes	UN	0.185	0.259	7.384
<i>Sri Lanka</i>	Lower Middle	Yes	UN	0.29	0.09	2.92
<b>UK</b>	High	Yes	10.82%	17.65	12.84	83.23

\*UN = Data unavailable

With comparatively few resources available, as suggested in Table 1, the accessibility of services for mental health problems for the population of South Asian countries, particularly in rural areas, is clearly limited.

Research in Bangladesh and India has suggested that people tend to approach a range of services for help with mental health problems, such as their friends and families, native or religious healers, hospitals, private practitioners or other medical organisations (Giasuddin, Chowdhury, Hashimoto, Fujisawa & Waheed, 2012; Trivedi & Jilani, 2011). Research with South Asian people in the UK, has suggested that those with strong religious beliefs may seek to access help for mental health problems outside of the mainstream health care system, for example, through spiritual guidance and care (Hatfield, Mohamad, Rahim & Tanweer, 1996; McCabe & Priebe, 2004). Native and religious healers in Bangladeshi culture are widely thought to bring relief to mental distress through the rituals they perform or through holy verses, because problems with mental health are often conceptualised as coming from evil spirits or 'jinni' (Giasuddin, et al., 2012). However, in the context of limited availability of services for mental health problems from trained mental health professionals in South Asian countries, the use of traditional healers may be a consequence of the absence of trained clinicians, rather than a preference (Chowdhury, 2012).

It is possible that limited pathways to care in South Asian countries of origin may influence the expectations of the availability of care from services in the UK also. Pathways into care for psychological problems may be unfamiliar and therefore daunting to approach. The extent to which this may affect individuals or families accessing help from services is likely to be influenced by the number of generations that a family has resided in the UK.

### ***Communication***

Successful identification of mental health problems and subsequent interventions rely upon effective and culturally appropriate communication (Bhui, McCabe, Weich, Singh, Johnson & Szczepura, 2013). Use of family and friends as interpreters during assessment for health problems is inappropriate; the use of interpreters with experience in mental health settings can help to alleviate some of the linguistic and communication barriers (Bhui et al., 2013; Johnson, 1999; Kai, 2005). It is important to acknowledge, however, that people from BME communities for whom English is their first language, continue to experience dissatisfaction and inequality in mental health care (Johnson, 1999).

Fenton & Sadiq-Sangster (1996) carried out a qualitative study with South Asian women in Bristol and found that participants described mental distress using specific terms different from English speakers. In another qualitative analysis of attitudes towards mental health in a British Pakistani group of people, Tabassum, Macaskill and Ahmad (2000) found that language was among one of the most common reasons people did not seek help for mental health problems, particularly among women.

In a large American cohort study, Sentell, Shumway and Snowden (2007) explored the influence that English language proficiency had on access to mental health treatment among ethnic minority participants<sup>3</sup>. In a sample of 41,984, they compared self-reported use of mental health services among those who reported having a mental health need, with English language proficiency. They found that non-English speakers had significantly lower odds of receiving mental health services when they required them than English speakers. Sentell et al. (2007) concluded that this may play a significant contributory role to ethnic disparities in mental health service access.

It is possible that one barrier to accessing mental health care in the UK may be poor recognition of mental distress due to use of different constructs and idioms of distress and need. This, in turn may lead to people being unheard or misunderstood due to underlying differences in conceptualisations of the causes and interventions for psychological distress (Bhui et al., 2013). Difficulties in communication can arise from many different social and personal factors, including age, gender, socioeconomic status, education and perceived power of both client and clinician, but cultural factors may amplify these limitations in

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<sup>3</sup> Sentell et al. (2007) identified five categories of 'race': White, Black, Asian/Pacific Islander, Latino and Other. They did not provide any definition of these terms.

communication. Furthermore, this is likely to compound inequalities that arise from the other social determinants (Bhui et al., 2013).

### ***Presentation and Somatisation***

There is a long-standing and persistent perception of 'non-Western' people being prone to somatise their distress (Kirmayer, 2001<sup>b</sup>). That is, express and experience their psychological distress in terms of physiological symptoms (e.g. headaches) as opposed to psychological symptoms (e.g. nervousness). However, rather than being more likely to 'somatise' their distress, alternative cultural idioms of distress within South Asian cultures and the use of language influence the way in which people present their experiences (Burr & Chapman, 2004; Farooq, Gahir & Okere, et al., 1995; Kirmayer & Young, 1998).

Burr & Chapman (2004) commented that there have been varying estimations of the prevalence of mental disorders among people of South Asian origin, depending on the measures and/or diagnostic frameworks used. Their study found that rather than women not experiencing distress and apparently 'somatising' more than Western counterparts, they use language of physical symptoms to express their distress, which may then be interpreted by others as 'somatising'. This may account for the finding in the EMPIRIC study (Sporston & Nazroo, 2002) that South Asian women were the least likely to report having consulted a doctor for stress-related or emotional problems than any other ethnicity.

International epidemiological research has identified that although psychological problems such as depression and anxiety occur globally, the expression of the symptoms, interpretation of their cause and meaning and social response varies significantly across different cultures (Kirmayer, 2001<sup>b</sup>).

### ***Pathways to Care in the UK***

There are significant ethnic disparities in the pathways into mental health care in the UK (Bhui & Bhugra, 2002; DoH, 2005; NIMHE, 2003). Furthermore, there is evidence that South Asian people are less likely to have their mental health needs recognised when they present to their GP (Bhui et al, 2003).

A cohort study of 8401 people (Cooper, Murphy, Webb, Hawton & Bergen et al., 2010) presenting to Accident & Emergency (A&E) departments with incidents of self-harm in three English cities, found no difference between the rates of self-harm among South Asian and White women, but higher rates for Black women aged 16-34. However, there were significantly lower rates of psychiatric referral for Black and South Asian women than for White women<sup>4</sup>. Another large study of access to mental health services for 1267 people in an inner-

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<sup>4</sup> Cooper et al (2010) provided clear definitions of their terms of ethnicity. 'White' referred to White British, Irish and White Other, therefore will have included some minority populations, who have been found to differ from 'White British' (see Sporston & Nazroo, 2002).

city health district in England, found that Asian participants, particularly Asian women, were significantly less likely to be receiving specialist mental health care beyond primary care than Black or White participants<sup>5</sup> (Commander, Dharan, Odell and Surtees, 1997<sup>a</sup>; 1997<sup>b</sup>). They found mental health problems were more common among Asians, who were also more likely to consult their GP, but were less likely than White people to have their mental health problems recognised, a finding later supported by Bhui, Stansfeld, Priebe, Mole & Feder (2003). A significant proportion of participants were excluded from the study because they were unable to complete interviews in English, which is a methodological limitation of this study but was not acknowledged by the authors. In addition, the authors did not acknowledge the likely influence of within-group differences that were not captured in the study, due to participants being grouped into only three broad ethnic categories.

A literature review found that people from Black and Asian<sup>6</sup> ethnic minorities in the UK have different experiences in access to, utilisation of and treatment offered by mental health services, compared to White British people (Bhui, 1997). The context of the community and society in which people live influences the manner in which they come into contact with services and the subsequent treatment they receive (Hernandez, et al., 2009). Ethnic differences in pathways to care, therefore, are influenced by cultural factors, familial beliefs and interactions between organisational and contextual factors (Cauce et al., 2002).

### ***Idioms of Distress and Seeking Help***

The cultural context of an individual and their family influences how problems are defined, understood and subsequently solved (Cauce et al, 2002; Hernandez et al., 2009; Kirmayer, 2001<sup>b</sup>). Acknowledgement of the need to increase access to mental health services for ethnic minorities in the UK, has not yielded the responses and improved equity in service use that was anticipated or hoped for by policy makers. This may be due to inadequate consideration of contextual and cultural factors of what 'help-seeking' might entail for different groups.

The typical Western dichotomous approach to mind and body, does not necessarily reflect the more unified conceptualisation of illness in other cultures and therefore a more holistic approach is likely to be more acceptable to a wider range of people (Hatfield, Mohamad, Rahim & Tanweer, 1996). In their study, Hatfield et al. (1996) found that the three most commonly ranked causes of mental health problems by the participants were: social stress (87%), family problems (54%) and the will of God (34%).

The National Survivor User Network (NSUN, 2014), carried out a consultation with black and minority ethnic mental health service users, to explore ethnic inequalities in the mental health care they received. They carried out three focus groups in England, consisting of 40

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<sup>5</sup> Commander et al (1997<sup>a</sup>; 1997<sup>b</sup>) defined 'Asian' as those from India, Pakistan and Bangladesh and specifically excluded those from Vietnam and China. They did not define 'Black' or 'White'.

<sup>6</sup> Bhui (1997) defined 'Asian' as those from the Indian Subcontinent.

participants in total. They and an additional 40 people completed an online survey.

Participants reported that the conventional Western medical approach to mental health and illness did not meet their own conceptualisations of their distress. Instead, participants tended to relate to their distress more in terms of their culture, race and identity and the oppressive experiences they had in relation to these. Psychological approaches to therapy in the UK tend to be based in scientific positivism, within an 'individualistic' society and a Western psychiatric nosology, which are not compatible with spiritual explanations of mental health problems that some people from South Asian cultures may hold (Morris, 2012; Tribe, 2007).

Emotional problems in some cultures are not considered a 'health' issue, but are conceptualised as socio-moral problem, which would therefore be more aptly dealt with by those who are familiar with the complex social network and ties of that person, such as other family members, or community or spiritual leaders (Kirmayer, 2001<sup>b</sup>). This is likely to influence whether or not the National Health Service is identified as a source of help for emotional problems or distress among the South Asian population.

### ***Cultural Competence in Mental Health Service Provision***

Cultural competence is the incorporation of cultural beliefs, values and practices into the understanding of a person's presentation to prevent inappropriate diagnosis and inform collaborative understanding of problems and delivery of appropriate treatment interventions (Brach & Fraser, 2000; Morris, 2012). The effects of migration and globalization mean that skills, expertise and sensitivity in responding to cultural diversity are needed more than ever in mental health services (Bhugra & Minas, 2007; Kirmayer, 2006). In recent years, there has been an increasing focus on developing 'cultural competence' within the mental health workforce to improve the appropriateness, responsiveness and effectiveness of services (Bhui, Warfa, Edonya, McKenzie & Bhugra, 2007; Brach & Fraser, 2000; Gurpinar-Morgan, 2012).

Two reviews of the UK literature in relation to the mental health of South Asian women, (Anand & Cochrane, 2005; Hussain & Cochrane, 2004) and a qualitative study of South Asian service users' perspectives (Bowl (2007) concluded that there is an urgent need to develop mental health services that are responsive and sensitive to gender, linguistic and cultural differences. A meta-analytic review of cultural compatibility of mental health services found that services with a focus on cultural competence improved their effectiveness by four times, when compared with services that were broadly adapted to serve individuals from a wide variety of cultural backgrounds (Griner & Smith, 2006).

In the NSUN (2014) focus groups, those raised in Africa and India talked of being unfamiliar with the individualistic culture in British society and how this permeated the way in which mental health care is delivered in this country, such as being isolated from the family and community. They also identified the Eurocentric and medical approach and how this approach

failed to allow for people to have different goals and aspirations associated with their culture. For example, there is a heavy focus in the UK and in recovery towards gaining independence, whereas in an Indian culture, a person's goals may be more about gaining interdependence with their family and community (NSUN, 2014). Many participants felt that the tendency for mental health services to immediately respond with medication as alarming and that this did not reflect a 'culturally competent' or holistic approach to mental health care.

Hernandez et al., (2009) carried out a literature review of organisational cultural competence in the United States and presented a conceptual model of cultural competence for mental health services. They found that ethnic disparities in access to mental health were driven by incompatibility between available services and the cultures and social context of the people they served. Hernandez et al. (2009) proposed a model of cultural competence that requires compatibility between four factors: community context, cultural characteristics of the population, organisational infrastructure and direct service support. Hernandez et al. (2009) did not report their literature search strategy, criteria or document the papers yielded in their search. It is therefore unclear whether their conceptual model arose from the literature, or if they presented literature that supported a pre-existing model. Nonetheless, their conceptual model addresses some of the criticisms of cultural competence within mental health services, by considering the need for a multi-level, multi-factorial approach to developing and delivering culturally competent mental health services.

Considerations of social class are often lacking in the consideration of cultural competence for clinicians. It is essential that the complex interactions between an individual's gender, ethnicity, religion, sexual orientation and social class are taken into account. The economic income afforded to clinicians working in the field of mental health allows the choice of living a 'middle-class' lifestyle. This includes freedom of choice, social support, knowledge of socially acceptable behaviours and etiquette, access to services and social mobility. These privileges are often unconscious in the lives of people with access to them, therefore if cultural competence training does not raise the awareness of social class in clinicians and they are unable to reflect on this, then this will impact their ability to work effectively across cultures (Spence, 2012). In a content analysis of clinicians' perceptions of South Asian people seeking mental health treatment, Ragosti, Khushakani, Dhawan, Goga, Hemanth & Kosi, et al. (2014) commented on the necessity for clinicians to have an understanding of the cultural values and beliefs that influence the way a person may conceptualise or present their distress; however, they did not comment on how the clinicians' own cultures may have influenced their perceptions of working with South Asian people.

There is an assumption that improving the 'cultural competence' of clinicians and organisations will reduce disparities in access to services, outcomes of interventions and perceived satisfaction with services (Brach & Fraser, 2000). However, Kirmayer (2001<sup>b</sup>)



reflects on the need to recognise psychiatry as being a cultural institution in itself and that as such, all mental health professionals bring with them their own culture and epistemologies. In this sense, interactions between professional and client in a mental health context should be considered as an intercultural encounter. Cultural competence is best conceptualised as a systemic and deep-rooted change in both organisational and professional practice. At an individual level, it is necessary for professionals to be more flexible in the way they assess, diagnose and intervene for people with different causal explanations, understanding, expectations and goals for recovery (Bhui et al., 2007; Bhui et al., 2013; NSUN, 2014).

### ***Stigma, Shame and Izzat***

Stigma within society and communities present a significant barrier to individuals and families accessing help for mental health problems. Thornicroft (2008) suggested that there is no known country or society in which those with mental health problems have the same value and acceptability as those who do not. There is large stigma around people with mental health problems in South Asian cultures, which impacts upon timely recognition and intervention for mental health problems and impedes a person's recovery (Shidhaye & Kermodé, 2013; Gilbert et al, 2004).

A qualitative study with first and second generation Pakistani women and the male heads of the women's households in the UK, found that social stigma and language barriers, particularly among women, were the most significant barriers to accessing mental health support (Tabassum, Macaskill & Ahmad, 2000). However, the qualitative methodology for this study was not adequately reported. Ragosti et al. (2014) also identified that stigma and denial of mental health problems presented a significant barrier for South Asian people engaging with mental health treatments, with concern about being labelled as 'mad' or 'crazy'.

Izzat is defined as the 'honour' experienced by others in one's family by one's own behaviour and there is often great pressure among women in South Asian cultures not to bring shame or reduce izzat within the family (Chew-Graham, Bashir, Chantler, Burman & Batsleer, 2002; Gilbert, Gilbert & Sanghera, 2004). Both studies used qualitative focus groups to explore attitudes to mental health among South Asian women and found that fears of loss of izzat and reflected shame were key reasons why South Asian women may not use mental health services. A quantitative study of 'Asian' (n=86) and 'non-Asian' (n=100) student women in the UK<sup>7</sup> explored external shame, internal shame and reflected shame/izzat in relation to attitudes towards mental health problems (Gilbert, Bhundia, Mitra, McEwan, Irons & Sanghera, 2007). They found that external shame, that is community attitudes to mental health problems, and izzat/reflected shame were significantly correlated with fears of breaches in confidentiality among the Asian group, but not in the non-Asian group. Fears about breaches in

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<sup>7</sup> Gilbert et al. (2007) did not define the terms 'Asian' and 'non-Asian'.

confidentiality have also been identified in other research (NSUN, 2014; Ragosti et al., 2014). This is likely to influence help-seeking behaviour and therefore access to services.

### ***Stereotypes, Racism and Discrimination***

Racism and discrimination can lead to psychological distress and poor mental health (Bécares, Nazroo & Stafford, 2009), however, these experiences also act as barriers to seeking help for mental health problems (DoH, 2005; NIMHE, 2003), which is likely to further compound the impact of racism on the mental health of people from black and minority ethnic groups.

The findings of the NSUN (2014) study suggested that many people chose not to seek help for their mental health problems due to fear of stigma and discrimination, either from the services or as a result of contacting services. Some also were concerned that due to being from a BME group, they feared they would have a discriminatory experience of the services they sought help from. The theme of racism emerged from the research and some considered this as a barrier to them seeking help.

Cultural stereotypes may also inhibit equality of access to services for South Asian people (Burr, 2002; DoH, 2005). In the focus groups in Burr's (2002) study, stereotypes of culture as predisposing South Asian women for depression were cited by mental health clinicians. This was underscored by an theme of considering western culture as superior and less repressed than eastern culture. These stereotypes, consequently hindered exploration of other causes for depression and alternative pathways to care were dismissed.

Individual experiences of racism both individual and institutional, combined with discrimination as a consequence of stereotyping, have a significant detrimental impact on individuals and families seeking and accessing help from services.

### **Culture and Assessment of Psychological Distress**

In light of the incompatibility of some Western approaches and the vast range of different cultural conceptualisations to mental health, it is important to consider how mental health services can adequately identify and address psychological distress for culturally diverse populations. The British Psychological Society's (BPS) Division of Clinical Psychology (DCP) position statement on the classification of behaviour and experience in relation to functional psychiatric diagnosis argues that there is a need for a paradigm shift on the basis that diagnosis does not fit with all modes of expression of human distress (DCP, 2013).

Nonetheless, it is important that clinicians are able to better recognise when clients are experiencing distress to the extent that they require further support and intervention, and that the intervention provided is appropriate for their needs.

## ***Diagnosis***

In their position paper on behalf of the Cultural Psychiatry Committee for the Group of the Advancement of Psychiatry, Alarcon, Becker, Lewis-Fernandez, Like & Desai, et al. (2009) reported that the development of the DSM-V opened up opportunities for sociocultural data to be incorporated into psychiatric nosology. Although there is now more guidance on culturally informed assessment than in previous issues of the DSM, Alarcon et al (2009) argue that it remains inadequate. The rhetoric about consideration of cultural factors in mental health diagnosis appears to exceed the reality of implementation in practice and the DSM-V continues to over-simplify sociocultural processes, resulting in essentialist, reductionist and ethnocentric approaches to understanding mental disorders (Alarcon et al. (2009).

The DSM-IV (American Psychiatric Association, 1994) provided a checklist of categories of information that was considered necessary to understand an individual's presentation in their cultural and social context. These guidelines contain four main domains:

1. the ethnicity and cultural identity of the person
2. the individual's explanations of their problems
3. features of the psychological and social context and level of functioning within that culture
4. the relationship between the clinician and the client.

However, this 'cultural formulation' is widely criticised for appearing as more of an afterthought, located in the appendices of the manual and does not consider the significant influences of socioeconomic status, social class, deprivation, racism, discrimination and power or the need for clinicians to be aware of the impact of their own sociocultural context (Alarcon, 2009; Kirmayer, 2001<sup>b</sup>).

## ***Assessing Psychological Distress***

There has been a large body of research and a proliferation of measures aimed at identifying mental health problems in different cultures, however, their universal application has drawn criticism (Bhui, et al., 2003). In an example of the problems of applying one measure across cultures, Williams et al. (1997) explored the levels of distress among a sample of 159 South Asian people and compared them with 319 people from the general population, matched for age. They used the widely used and validated GHQ-12 measure of distress alongside a psychosomatic measure and a self-report measure. They found that the GHQ-12 may underestimate the level of distress among South Asian women in particular. They found psychosomatic expressions of distress to be higher among women and those with limited English proficiency, suggesting this may be due to a language preference, means of expression of distress or higher incidence of stressful situations.

Previous research (Mason, 2003) set out to develop a new culturally competent measure of psychological distress within the South Asian community in the UK, using focus groups in the first languages of the participants and drawing out recurrent themes. These factors were developed into separate items in a new 30-item measure, the Problems Checklist (PC30). The PC30 was developed using the language and cultural idioms described by the people in the focus groups and the items were written in Urdu, Gujarati and English simultaneously by a writing team who included first-language speakers of each of the three languages.

There remain significant challenges at every level of providing appropriate, responsive and effective services for people across cultures. Adequate recognition of mental health problems when clients approach health services is paramount, as is gaining an understanding of what will encourage people to seek help from services when they need it. This forms the rationale for this study, which is outlined below.

## Rationale

Although the reasons for disproportionate levels of access and use of mental health services are clearly complex and multi-factorial, one factor may be that distress is not adequately recognised or reported for people within this population. It is possible that measures used to screen for mental health problems are not appropriate in the construction of problems and language used to describe them. As part of ensuring that services are more appropriate and responsive in accordance with the DRE (DoH, 2009), services will need to adapt the methods they use to identify psychological distress depending upon the people to whom they are providing a service.

In order to improve access to services for people in the South Asian population who are experiencing psychological distress, it is necessary to explore the factors associated with access to services, the types of services people choose to access and whether or not people seek to access services.

Much of the existing literature provides descriptive information about differences in prevalence, help-seeking and access to services but far fewer make attempts to explain the observed differences for South Asian people (Goodman, Patel, & Leon, 2010). This research aims to provide a description of access to services among the South Asian population living in the UK but also to explore the factors that explain access to services and help-seeking behaviours. Goodman et al. (2010) suggest that observed ethnic disparities should be the starting point of further investigations and that all research must account for factors such as socioeconomic status and perceived racial discrimination.

Much of the existing literature focuses on prevalence of mental disorders among people who have presented to services or those who have been admitted to hospital settings. This belies the vast majority of mental health problems that are treated in primary care settings. More

research is required, therefore in primary care and community settings to gain a more accurate representation of the communities that are being studied (Lloyd, 1998; 2006).

## **Aims and Objectives**

The aim of this study was to carry out an exploration of access to and experiences of services among people of South Asian origin living in the UK who were experiencing distress. In order to achieve this aim, the following objectives were set:

1. Describe the socio-demographic profile of the sample recruited to the study
2. Explore the prevalence of psychological distress in the sample recruited to the study.
3. Establish the proportion of those experiencing psychological distress in the sample who sought help.
4. Explore the experiences and perceptions of those in the sample who had accessed services.
5. Explore the associations between distress, acculturation and quality of life in the sample.
6. Explore the factors associated with seeking help from services.

## METHODS

### Design

A non-experimental research design was employed for this study, involving an anonymous survey using self-report questionnaires. The target population for the study was adults (aged 18 or over) of South Asian origin currently living in England. This research design was deemed the most feasible and practicable methodology to explore the research questions within the resources available. Furthermore, given the stigma associated with mental health problems, it was anticipated that an anonymous survey design would have a positive impact on the response rate. An anonymous survey design eliminates opportunity for interviewer bias, significantly reduces the likelihood of social desirability bias and increases the willingness of participants to disclose sensitive information, compared with face-to-face interviews (Bowling, 2005). Qualitative methodology was considered to improve understanding of factors associated with access to services, however, the decision was taken to use a quantitative methodology to explore with a larger sample the themes that have been identified in previous research.

Questionnaires have frequently been used to explore mental health in South Asian communities in the UK (Bhugra, Thompson & Piracha, et al., 2003; Bhui et al., 2004; Bhui et al., 2004; Commander et al. 1997<sup>a</sup>; 1997<sup>b</sup>; Mason, 2003). However, much of the research has explored prevalence or identification of mental disorders, rather than exploring access to services more specifically. A survey methodology, therefore, was considered an appropriate methodology to answer the research questions of the present study.

In a randomised trial, Scott, Jeon, Joyce, Humphreys, Kalb, Witt & Leahy (2011) compared online, simultaneous and sequential modes of distributing surveys among a population of general practitioners to explore the impact upon response rate. They found that a 'sequential' mode (online link followed up later with a letter including a paper version of the survey) yielded the highest response rate, followed by the simultaneous mode (an initial letter with both the online and paper copy options, with a later follow-up letter). Millar & Dillman (2011) also found that using more than one survey mode would yield a greater response rate. The 'sequential' follow-up was not possible for this study, however, the 'simultaneous' mode was used, providing participants with paper copies of the survey with a link to an online version. Although unsolicited online surveys tend to have a low response rate, making the survey available online provided potential access to a wider range of respondents (Barker, Pistrang & Elliott, 2002).

Consideration was given to the use of a postal questionnaire design, using GP surgery patient lists. Response rates to postal surveys are significantly improved by contact prior to and

following distribution of questionnaires (Edwards, Roberts, Clarke, DiGuseppi, Pratap, Wentz and Kwan, 2002; Nakash, Hutton, Jorstad-Stein, Gates & Lamb, 2006); however, this was not possible due to resource constraints. Furthermore, Edwards et al. (2002) found that questionnaires were less likely to be returned if the questionnaires related to sensitive topics. The cost of distributing questionnaires by post, with a projected 10% response rate to achieve the number of responses required for adequate statistical power, meant that the use of a postal survey was not feasible for this study.

Taking these factors into account, the researcher used an anonymous mixed-mode survey, using questionnaires available both in paper and online formats. To improve response rate, participants were recruited using opportunity and snowball sampling techniques from a range of settings (see 'Setting' and 'Participants and Recruitment' sections).

### ***Piloting the questionnaire***

The questionnaire was piloted with four people known to the researcher. Three completed the survey online, two in English and one in Bengali. The other person completed the paper version of the questionnaire.

The length of time taken to complete the questionnaires ranged from 8 to 20 minutes and, therefore, the information sheet was amended to reflect that the questionnaire would take approximately 20 minutes to complete. This was a reduction from the original 30 minutes anticipated to be required to complete the survey.

Other suggested amendments related to increasing the size of the font of the Bengali text on the online survey and providing more spaces for free text to explain responses, particularly those relating to physical and mental health problems and disability.

Upon reviewing the piloted responses of the online survey, the researcher was able to identify where technical errors in the display logic of the questions had occurred and these were amended prior to the survey being distributed live. One person commented that some of the language within the English version of the 28-item General Health Questionnaire (GHQ28) measure appeared dated; however, this was not changed, due both to copyright restrictions and to retain the reliability and validity of the measure.

Upon entering responses of anonymous participants into the dataset, the decision was taken to add two further demographic items: 'What is your sexuality?' and 'What is your current, or most recent occupation?' were added after the first four online responses and one paper survey had been returned. An error in the Self-Administered Questionnaire of Acculturation (SAQA) was also identified and rectified at this stage. These participants' responses to these specific items were, therefore, not included in the dataset.

## Setting

The settings from which participants were recruited fell into three categories: NHS primary care, community organisations and online networks. A community sample was targeted, as opposed to seeking a clinical sample of people known to have mental health problems, with the aim of gathering representative data from the target population.

### ***NHS Primary Care Setting***

Three GP surgeries were selected for recruitment sites: one in Luton and two in the London Borough of Tower Hamlets. These areas were selected due to their high proportion of people of South Asian origin who live in these areas compared with the national average for England (see 'Participants and Recruitment' section). Furthermore, both Luton and Tower Hamlets Clinical Commissioning Groups (CCG) developed Equality Objectives for the services they provide (Luton CCG, 2013; Tower Hamlets CCG, 2013), highlighting the need to tackle health inequalities and improve the mental health needs of the communities they serve.

Unfortunately, due to constraints on time, the third GP surgery, one based in London, was excluded from the study due to delay in approval through the NHS Research and Development procedure. The GP surgery in Luton was involved in the development of the Problem Checklist (PC30: Mason, 2003), therefore they were approached due to their expressed interest in this research.

### ***Community Organisations Setting***

One community organisation based in London agreed to support recruitment of their South Asian members to take part in the survey. The organisation provides social support for the older Bangladeshi community.

### ***Online Network Setting***

Five online community networks were identified and agreed for information about the study to be shared on their social media websites, including Facebook and LinkedIn. Two of the organisations were Muslim networks with a combined online membership of 6930. The remaining three networks were for Sikhs (2240 members), Hindus (1840 members) and people from India (290 members). Members of these networks were encouraged to share the link to the questionnaire to their family, friends and acquaintances. In addition to the online link being displayed on social media websites for these networks, an advert was regularly placed in the weekly newsletters for subscribers.

The researcher attended one event organised by one of the Muslim online networks in person to make an announcement about the research, distribute the surveys and answer questions of those who expressed an interest.



Although these networks were identified as being for people of either specific religions or nationalities, all had an inclusive membership policy resulting in a potentially diverse population within the membership. In addition, although all of the networks were based in London, they all attracted members from around the country, therefore the location of those who completed the survey was not known.

## Participants and Recruitment

The study aimed to recruit a minimum of 100 patients from a target population of over 150,000 people. An opportunity sample was gathered on the basis of participants' attendance at one of the participating GP surgeries for any reason (information, physical or mental health problem, in the role of carer for another person), attendance at a community organisation or membership of an online network. In addition, the study employed a snowball technique, encouraging those aware of the study, or those who participated, to invite their acquaintances also to take part.

The study aimed to be as inclusive as possible to increase the generalisability of the findings to the population. Furthermore, as the survey was anonymous, participants self-selected to take part in the study. The inclusion criteria for the study, therefore were:

1. Adult (18 years or over)
2. Self-identified as of South Asian origin
3. Ability to read and write in English, Urdu or Bengali
4. Current residence within the UK.

As the inclusion criteria required literacy in English, Urdu or Bengali, those with low levels of literacy would have been precluded from participating in the study.

Table 2 displays the proportions of people of Asian ethnicity in the localities of Luton and Tower Hamlets, compared with England in the Census (2011) data. The 'Total Asian' category includes those who identified as Indian, Pakistani, Bangladeshi or 'Other Asian' ethnicity. Luton and Tower Hamlets have particularly high proportions of people from Pakistan and Bangladesh respectively, as is depicted in Table 2 below.

*Table 2: Population of South Asian Ethnicity by Locality.*

Location	All Ethnicities, Total Pop <sup>n</sup> (N)	Total Asian (n)	Pakistani (n)	Bangladeshi (n)
England	53,012,456	7.0% (3,710,872)	2.1% (1,113,262)	0.8% (424,100)
Luton	203,201	29.2% (59,335)	14.4% (29,261)	6.7% (13,614)
Tower Hamlets	254,096	38.0% (96,556)	1.0% (2541)	32.0% (81,311)

Attempts were made to establish from the practice managers of the GP surgeries how many registered patients they had and the proportion of those who were of South Asian origin in the two GP surgeries involved in this study. Unfortunately, it was not possible to gather this information from the GP practices.

## Measures

The survey comprised of six separate questionnaires (see Appendices 2 to 7). These included pre-existing and validated measures, which had been used in previous research studies exploring psychological distress, acculturation and access to services in a variety of different ways. Other questionnaires included in the survey were prepared specifically for this research, but were informed by previous studies. The following questionnaires were selected to cover four factors relevant to the research questions:

1. *Demographic Data*: Personal demographic questionnaire
2. *Acculturation*: Self-Administered Questionnaire of Acculturation (SAQA)
3. *Psychological Distress*: World Health Organisation, Well-being Index (WHO5); 28-Item General Health Questionnaire (GHQ28); 30-Item Problems Checklist (PC30)
4. *Access to Services*: Questionnaire relating to access and experiences of services.

### ***Translation of Measures***

In addition to English, the survey was translated into Urdu and Bengali languages. Although there are many other South Asian languages, resources were not available to translate the survey into more than two languages for this research. Urdu and Bengali were selected due to the large proportion of people from Pakistan and Bangladesh in the target populations in Luton and Tower Hamlets respectively.

Some of the questionnaires had existing translations into these languages which had been validated in other research. In this instance, the existing translations were used. For the measures requiring translation, the translations were carried out by professional translators who were native speakers of the language. Their translations were then proof read for accuracy by a separate translator, who was also a native speaker of the language and who had not been involved in the original translation.

### ***Demographic Information***

With the exception of the specific inclusion criteria for the research, participants self-selected to take part in the study. Comprehensive demographic data was collected in order that a clear description of the sample could be achieved. In addition, the demographic factors that were collected have been found in previous research to influence behaviours related to seeking help for mental health problems (Biddle, Gunnell, Sharp & Donovan, 2004; Mojtabai, Olfson, Sampson, Jin, Druss, Wang, Wells, Pincus & Kessler, 2011).

The demographic questionnaire asked questions about the personal demographics of the participant, including: age, gender, nationality, length of time in the UK, ethnicity, sexuality, immigration status, marital status, number of dependents, employment status and occupation, level of education, disability and whether or not they felt they had physical or mental health problems. The Self-Administered Questionnaire of Acculturation (see below) encompassed demographic questions about language, religion and living arrangements. These questions were, therefore, eliminated from the demographic questionnaire to avoid duplication. Questions used tick-box responses with the option to provide further information.

Guidelines from the Office of National Statistics (ONS) were used for the phrasing of demographic questions, to ensure the demographic information was collected in a way that would be comparable to national data, such as the Census data (Office of National Statistics, 2011). The decision was taken to include all categories of ethnicity as defined by the Office of National Statistics, as opposed to just the Asian category, to provide an additional step ensuring that participants met inclusion criteria for the research.

The ONS Census (Office of National Statistics, 2011) team provided the researcher with their Urdu and Bengali versions of their 2011 Census questionnaire. Therefore, the ONS Census translations of ethnicity and gender were used in the demographic questionnaire. All other items in the demographic questionnaire were phrased differently to those within the Census and so were translated for the purposes of this study.

The National Statistics-Socioeconomic Classification (NS-SEC: Office of National Statistics, 2010) of each participant was derived using the occupation listed by the participants. This information was categorised using the eight classes of occupation outlined in the NS-SEC guidelines, based on the Standard Occupation Classification 2010 System (SOC, 2010).

### ***Acculturation***

The 28-item Self-Administered Questionnaire of Acculturation (SAQA: Palmer, Macfarlane, Afzal, Esmail, Silman & Lunt, 2007) was selected to measure the level of acculturation within the target sample of this study. There have been many measures of acculturation developed with specific immigrant populations, such as Mexican Americans, Asian Americans, Japanese, and Hispanic people. Much of the literature has also been developed in the context of immigrant populations acculturating with North American culture (Palmer, et al. 2007). However, the SAQA was developed to address the absence of a validated acculturation measure for South Asian people in the UK. In addition, it was validated in Urdu, Bengali, Gujarati and Punjabi as well as English. Unfortunately, attempts to contact the authors to retrieve the translated versions of the SAQA were unsuccessful and therefore the measure underwent full translation for the purposes of this study.

Measures of acculturation intend to capture the behavioural and attitudinal changes that take place when individuals from one culture relocate to be immersed in another culture (Cabassa, 2003). There are many different acculturation measures that are developed for use with specific immigrant populations. Limitations of a uni-dimensional model of acculturation, gave rise to the theory of a bi-dimensional model (Berry, 1997; Cabassa, 2003). Although the authors of the SAQA did not make specific reference to the literature pertaining to acculturation as a uni- versus bi-dimensional process, they referred to having developed the scale with a view to using a single composite score, suggesting a uni-dimensional approach. However, principal components analysis of the scale in the study, identified it to be more in keeping with the bi-dimensional theory, with the following scales emerging: behaviours associated with acculturation, attitudes associated with acculturation and behaviours associated with country of origin. The Vancouver Index of Acculturation (Ryder, Alden & Paulhus, 2000) was considered for use in this study, however, it was decided that some items may not translate into a British cultural context. For example, the statement 'I would be willing to marry a North American person', would not translate as well with 'British', because many people of South Asian origin or heritage are, and would describe themselves as, British. The decision was taken, therefore, to use a measure that was developed specifically for use with South Asian people in a British context.

### ***Psychological Distress***

Three measures were selected to assess the level of psychological wellbeing and distress in the sample. Cut-off scores are identified for each measure below. The decision was taken to use cut-off scores as opposed to continuous variables, to reflect the need for clinical utility of these measures in a primary care setting.

#### WHO5

The five-item World Health Organisation Wellbeing Index (WHO5: Bech, 1997) was selected as a measure of quality of life to assess the positive general wellbeing of the sample. It is a self-administered measure giving positively-worded statements relating to personal well-being. Responses are set over a 6-item scale, ranging from 5 (all of the time) to 0 (at no time).

The World Health Organization Wellbeing Index was initially developed as a 28-item measure of both positive and negative wellbeing. This instrument was reduced to the five-item measure being used in the present study and measures only positive well-being (Bech, 1997; 2004). Bech concluded that when assessing quality of life, it is important to avoid the use of symptom-focussed language.

The WHO5 has been developed and validated across a wide range of cultures and in different settings (Lloyd, Roy, Begum, Mughal & Barnett, 2012). The WHO5 has been translated into

31 languages, including English and Urdu, which are publicly available on the WHO5 website at the Psychiatric Research Unit in Denmark.

The remaining two measures of psychological distress used negative symptom-focussed language of psychological distress: Problems Checklist (PC30: Mason, 2003) and General Health Questionnaire (GHQ28: Goldberg & Hillier, 1979). Use of the GHQ28 and the PC30 simultaneously replicates the data obtained in the Mason (2003) study, enabling the data from this study to be explored comparative to previous research.

Henkel, Mergl & Kohnen, et al. (2004) carried out a review of the validity of brief screening measures for mental health in primary care settings comparing the PHQ-9 and the WHO5. Their findings recommended a cut off score of 13 or below, indicative of poor quality of life on the WHO5. This is the cut-off score that has been used in this study.

### GHQ28

The primary measure of distress selected was the 28-item General Health Questionnaire (GHQ28: Goldberg & Hillier, 1979). The GHQ28 is a widely used measure of distress and has been translated into many different languages, including Urdu. The General Health Questionnaire was developed by Goldberg (1972), initially as a 60-item self-administered measure to screen for symptoms of psychiatric disorders in community and non-mental health settings. It has since been developed into shorter versions with 30, 28 and 12 item measures. Responses are anchored over a four-item response scale, with varying semantic responses matched to the item statements. The responses correspond to a score that indicate symptom severity ranging from 0-3. As with the PC30, higher scores on the GHQ28 indicate greater levels of distress. The GHQ28 provides both an overall rating and four subscale ratings for completed measures. This is helpful for comparative purposes with other measures used in the present study.

The GHQ was originally developed in London for the purpose of use within the UK only. However, it has now been widely used and personal correspondence with the MAPI Trust, the holder of all official translations of the GHQ measures, revealed that it has been translated into over 40 different languages. It has been used in many validation studies and has been found to retain its robust properties following the process of translation (Goldberg, Gater, Sartorius, Ustun, Piccinelli, Gureje & Rutter, 1997).

The GHQ28 was translated into Urdu by Riaz & Reza (1998) for the purposes of evaluating the reliability of an Urdu version compared with the English version. The study by Riaz and Reza yielded favourable results for the GHQ28 in Urdu and this translation has now been accepted as the authorised Urdu version. A literature search revealed no further validation studies of the authorised Urdu translation of the GHQ28. Both the English and Urdu versions of the GHQ28 were obtained from the publishers, GL Assessment Limited and the MAPI

Trust. Permission was granted by the MAPI Trust for the GHQ28 to be translated into Bengali for the purposes of this study.

Goldberg et al (1997) carried out a validity study of the GHQ12 and the GHQ28 and recommended cut-off thresholds of 5 or 6 for use in general health care settings. As this sample is a community sample, the decision was taken to use scores of 5 or above as the cut-off indicative of psychological distress in this study.

### PC30

The second measure of distress was the PC30. This is a 30-item self-administered single scale with a 5-item response scale ranging from 0 (not at all) to 4 (extremely), with higher scores indicating greater levels of psychological distress (Mason, 2003). It was developed through focus groups with people of South Asian origin living in South East England, including those from Bangladesh, Pakistan and India. A 60-item measure was initially developed and validated in English, Urdu and Gujarati languages. From this study, 30 salient items were derived. The 30-item measure has not yet been validated with a different South Asian sample from that used in the original study, and it was, therefore, selected to provide the opportunity to further assess the validity, sensitivity and specificity of measuring psychological distress among the South Asian community.

The preliminary analysis of the PC30 by Mason (2003) recommended a cut-off threshold of 19 or above to be indicative of clinically significant distress. This was the threshold used for the sample in this study.

### ***Access to Mental Health Services***

The final section of the survey related to participants' access to, use of and satisfaction with services for help with any emotional problems. As the survey was designed for a general community sample, rather than a clinical sample, many of the questions in this section may not have been relevant to the participants. This section started with a statement explaining that it was about health services for any emotional problems or distress that the participants may have experienced.

This questionnaire was designed by the author specifically for use in this survey. The questionnaire consisted of 12 questions exploring whether or not participants had sought help from services, and if so, if they felt satisfied with the service they had received? The questionnaire also explored whether or not participants were using services currently or had used services in the past. The questionnaire also explored whether or not participants had wanted help from services but had not been offered it, or, conversely, if they had been offered services that they had not wanted to use. Finally, for those who had either used services currently or in the past, questions were asked about their level of satisfaction with the support they had received and whether they had found them helpful and appropriate for their needs.

This survey was intentionally designed to elicit qualitative data, in addition to 'yes or no' response options, whilst keeping the section brief to reduce the burden on participants of completing the survey (Bowling, 2005).

## Procedure

### ***Research Assistants***

Two research assistants were recruited on an honorary basis to collect data from the GP surgeries. The research assistants were students enrolled on the University of Hertfordshire MSc in Research in Clinical Psychology and were identified by the academic supervisor for this study.

The research students were granted access to recruit participants from the GP research sites once they had an honorary contract in place with the University of Hertfordshire and had a Letter of Access granted by the NHS Research and Development process. Both research assistants were existing contracted members of NHS staff, therefore 'Research Passports' were not required, but confirmation of NHS to NHS pre-engagement checks were completed in order that a Letter of Access could be granted.

The role of the research assistants was to attend the GP surgeries and give questionnaires to potential participants who came to the surgery. They were available to answer questions about the research or direct them to the principal researcher if further information was required. The research assistants collected completed questionnaires and provided surgeries with more blank questionnaires if they ran out.

The research assistants entered any completed questionnaires that they had collected into a separate dataset, with guidance from the principal researcher. The accuracy of the data entry was then checked by the principal researcher.

### ***Data Collection at GP Surgeries***

As patients and/or their families came into the GP reception area, reception staff gave any adult who they believed to be of South Asian appearance a copy of the survey with the information and debrief sheets and the return envelope. Potential participants were given copies to give to family and friends if they chose.

Those given the survey were informed that they may return it by freepost in the envelope provided if they took it home or they could leave it with reception or with a research assistant (if present), if they chose to complete it whilst at their surgery. They were also informed of the option to complete the survey online. Posters (Appendix 8) were distributed at the surgeries to draw attention to the study being carried out, with removable tabs of paper with the link to the online survey.

The researcher and/or research assistants attended the GP surgeries twice or three times per week, to collect completed questionnaires, deliver new questionnaires and to assist in recruitment and questionnaire completion, if required. At local community events and organisations, depending upon the arrangements made with the organisations, the researcher either attended specific events and distributed questionnaires to attendees, or paper questionnaires were left with the organisation who then distributed them to their members. All paper surveys were given with the option of returning them in the freepost envelopes.

Paper questionnaires that were distributed were coded to enable the response rate from each recruitment site to be calculated. Data entry was carried out on a weekly basis by the researcher and research assistants, following collection of surveys from the GP practices. The research assistants attended one GP surgery each and gave questionnaires to patients who attended the surgery whilst they were there. They collected completed questionnaires and entered data they had collected into an SPSS data file. Data was then checked for accuracy by the researcher.

### ***Data Collection for Online/Community***

Research assistants were not involved in the collection of data from the online networks. The researcher contacted online networks and provided a brief message and link to be distributed on the webpage of each network. This was followed up once per fortnight.

Only the researcher had access to the questionnaires completed online, which had automatically generated identification codes, to protect the anonymity of participants. Completed questionnaires were downloaded and entered into the database on a weekly basis by the researcher.

## **Ethical Considerations**

Ethical approval was granted for this study by the University of Hertfordshire, Health and Human Sciences Ethics Committee with Delegated Authority (ECDA) (Appendix 9). The study was then granted full ethical approval following review by the Proportionate Review Subcommittee of the National Research Ethics Service (NRES) Committee North West (Liverpool Central) (Appendix 10). Due to changes in the management of research in the NHS, Luton did not have an established Research and Development (R&D) approval procedure, therefore approval was granted from GP partners at the participating surgery. For the Tower Hamlets practices, the North Central London Research Consortium (Noclcr) was responsible for R&D approval. A Noclcr peer review recommended major revisions be made to the study (Appendix 11), which were responded to by the researcher (Appendix 12). Following the response, R&D approval was granted for the research to take place at the Tower Hamlets GP practices (Appendix 13).



No participants were approached or surveys distributed in the community or through GP surgeries until appropriate ethical approval had been granted by the University of Hertfordshire and the NRES, respectively. This study did not present any significant ethical concerns, however, several ethical issues were considered and are discussed below.

### ***Informed Consent***

Prior to completing the survey, participants were given an information sheet (Appendix 14). This informed potential participants of the aims of the study, what would be involved in participating in the study, and that their information would be anonymous and stored confidentially. Participants were also provided with the contact information of the researcher and the project supervisor and given instructions on how to withdraw from the study if they changed their mind after taking part.

As the survey was completed anonymously, it was not possible to assess participants' capacity to consent to taking part in the research. Tacit consent was assumed through completion and return of the questionnaire. To ensure that this was clear to participants, a statement was provided both at the beginning and end of the survey confirming that by completing and returning the questionnaire, they had consented to take part in the study. At the beginning of the survey, there was a tick box for them to indicate that they understood this.

### ***Confidentiality***

The confidentiality of all participants was ensured because all surveys were completed anonymously. Those who completed surveys at their GP surgeries were able to give their questionnaires directly to reception staff who kept a sealed box in a staff-only area of the surgery for the surveys to be stored in. All paper surveys were also distributed with postage paid, addressed envelopes so that participants could return their questionnaires directly to the researcher at the university if they wished. Neither online, nor paper versions of the questionnaires requested information about the participants' name, date of birth or address.

To ensure participants were still able to withdraw from the study, a numbered code was provided on both information and debrief sheets. This code corresponded to the number of the survey they completed. Participants were instructed to contact the research using the details provided and cite the survey code if they chose to withdraw from the research. They were advised that they would not be asked for their name, date of birth or address at any stage, nor would they be asked to give a reason for withdrawing from the research.

### ***Distress***

Questions within the survey related specifically to experiences of psychological distress, including questions about suicidal thoughts and thoughts of self-harm. It was acknowledged, therefore, that for some participants these questions could trigger feelings of distress. In addition, completing a survey relating to mental health problems, could highlight concerns for

themselves or someone they know. To manage this risk, all participants were given a debrief sheet (Appendix 15) with a comprehensive list of resources and relevant services from which they could seek support.

### ***Debriefing***

The nature of the study did not necessitate any information being withheld from participants at the outset. For this reason, formal debriefing following completion of the survey was unnecessary, beyond signposting to services that participants may have been previously unaware of.

## **Statistical Analysis**

Statistical analysis of the data was carried out using IBM SPSS Statistics for Windows (v21).

Descriptive statistics were used to describe the socio-demographic characteristics and levels of acculturation within the achieved sample. Cross-tabulation, using Pearson's Chi-square and Fisher's Exact Chi-Square coefficients explored variations in distress and well-being across different socio-demographic characteristics within the sample. Although distress is linear, the use dichotomous cut-offs for distress have more clinical utility and aid estimations of prevalence.

The distribution and prevalence of psychological distress, as measured by the GHQ28 and the PC30, and quality of life, as measured by the WHO5 were assessed within the sample. Cross-tabulation (Pearson & Fisher's Exact Chi-Square) was carried out to explore variations in distress across different socio-demographic characteristics within the sample.

Reliability of the distress measures used was evaluated and reported upon, using Cronbach's Alpha coefficients and Corrected Item Total Correlations (CITCs).

To explore the relationships with distress as a linear measure, parametric (t-test, ANOVA) and non-parametric (Mann-Whitney U, Kruksal Wallis) tests were carried out to compare means of groups according to distress, quality of life, acculturation and seeking access to services. Associations between distress measures and acculturation were carried out using Spearman's two-tailed correlation analysis. To evaluate differences between groups, effect sizes were calculated using the 'r' statistic, on t-tests and Mann-Whitney-U tests. The reported effect sizes were interpreted using the following guidelines for social sciences by Cohen (1992): 0.10 small effect, 0.30 medium effect, 0.50 large effect.

Access to services and perceived satisfaction with services if they have been received were explored using descriptive statistics and cross-tabulation (Pearson & Fisher's Exact Chi-Square).

Logistic regression was carried out to explore factors that may be predictive of distress, quality of life and access to services. For the purposes of carrying out regression analysis, a priori calculation of sample size was carried out to ascertain the minimum sample size required. Using guidance by Field (2013) and Cohen's (1992) effect size index for multiple correlation, a sample size of 77 would be adequate for a model of up to 10 predictors based on an alpha level of 0.05, a medium effect size of 0.15 and the desired statistical power of 0.8. The decision was taken to collect a sample size of at least 100 participants, in order to provide a high degree of precision ( $< \pm 7\%$  for proportions).

## RESULTS

A total of 103 participants responded to the survey. Of these, 65% (n=67) were recruited through online community networks and events (Online/Community) and the remainder recruited through GP surgeries (GP). 104 surveys were distributed from the GP sites and 36 were returned, which yielded a 35% response rate for surveys distributed in paper format. It is not possible to ascertain the response rate for the online survey. However, of those who followed the online link to the survey, but did not take part, there was a 53% drop-out rate (n=68).

### Objective 1: Socio-Demographic Profile of Sample

The mean age of the overall sample was 34.3 (SD=11.31, range 18-75, values missing for 13 participants) and the majority were female (59%, n=60) with one person identifying their gender as 'other'. A higher proportion of those from the Online/Community groups were women (61%, n=40), compared with those recruited through GP surgeries (56%, n=20).

A higher proportion of people in the Online/Community group were born in the UK (46%, n=31) compared with the GP group (34%, n=12). Of those not born in the UK, the mean length of time they had lived in the UK was 20.6 years (SD=13.94, range = 0.6 – 49) and their mean age when they moved to the UK was 16.9 years (SD=10.02, range= 1 – 43). There was no significant difference in the length of time participants had lived in the UK or their age when they moved to the UK, according to their location or gender.

#### *Personal and Social Circumstances*

All frequencies and percentages for reported demographic data are presented in Table 3.

85% (n=87) of the participants described their immigration status as either UK or EEA Nationals with 5% (n=5) being on a husband/wife sponsorship, 6% (n=6) had leave to remain (indefinite and discretionary) and 4% were on a work/study visa (n=4). One person did not disclose their immigration status.

The majority of participants in the sample were married (48%, n=49) followed by single 36% (n=37). Those who were either cohabiting or with a partner but not living together made up 12% (n=12), while 5% (n=5) were either separated or divorced. The majority of participants did not have dependents either under 18 (67%, n=67, missing=3) or over 18 (83%, n=76). The majority of the sample (94%, n=86) identified as heterosexual, 4% (n=4) identified as bisexual and 2% (n=2) as lesbian. Information relating to sexuality was missing for 11 participants.

The majority of the participants were of Muslim faith (68%, n=69), there was a much higher proportion of Muslim participants in the GP group (81%, n=29) than the Online/Community

group (61%, n=40). Hindus represented 14% (n=14) of the sample and 11% (n=11) were Sikh. However, there were no Sikh participants in the GP sample, therefore they accounted for 17% of the Online/Community sample. Differences in the religions of the samples from the two locations as seen in Table 3, were found to be significant using a Fisher's Exact Chi-Square test (Fisher's Exact  $X^2(5)=9.666$ ,  $p=.048$ ). As can be seen in Table 3, this finding is most likely accounted for by the differences in Muslim and Sikh participants at the two locations.

### ***Nationality, Ethnicity and Language***

The vast majority of questionnaires were completed in English (94%, n=97), with the remaining 6% (n=6) completed in Bengali. No questionnaires were returned in Urdu. The median number of South Asian languages that those who responded were able to understand, speak read or write was 2 (n = 41), with a range from 0 (n=1) to 4 (n=6). The most widely understood South Asian language amongst this sample was Urdu (57%, n=56), followed by Bengali (36%, n=37), Punjabi (34%, n=35), Sylheti (25%, n=26), Gujarati (14%, n=14), Hindi (9%, n=9), Telugu (3%, n=3), Nepalese (2%, n=2) and Kashmiri (1%, n=1).

The majority of participants identified their nationality as British or British/Asian (81%, n=76). 13% (n=12) identified their nationality as from a South Asian country and the remainder identified themselves as a non-British and non-South Asian nationality, for example, Dutch. Nine participants did not provide their nationality.

Table 3 indicates a much higher proportion of Pakistani participants in the GP sample, and a higher proportion of Indian participants in the Online/Community sample. This difference was confirmed to be significant using a Fisher's Exact chi-square test (Fisher's Exact  $X^2(3)=9.57$ ,  $p=.022$ ). The 'Other' category included Sri Lankan, Nepalese and Mixed White/Asian participants. No participants identified their ethnicity as Bhutanese.

### ***Education, Employment and Occupation***

As can be seen in Table 4 (page 45), those who participated in this study were highly educated and in occupations in higher socioeconomic classification categories. The figures from the GP sample were more evenly distributed. The sample itself, however, is unlikely to be representative of the wider South Asian community.

There was a significant difference in the level of education achieved by the participants recruited from the two locations (Fisher's Exact  $X^2(2)=7.76$ ,  $p=.023$ ), but no significant difference by gender (see Table 4). In both locations, the majority were university educated, however, this was a significantly higher proportion in the online/community group, whereas a higher proportion at the GP location were educated to secondary level or below.

Five participants had not received education to a level higher than primary school and were all born outside of the UK; however, no significant difference was identified in level of education according to whether or not participants were born in the UK. Information about educational level was missing for two participants.

*Table 3: Demographic Characteristics*

<b>Socio-Demographic Characteristics</b>	<b>Online/ Community</b> % (n)	<b>GP</b> % (n)	<b>Total</b> % (N)
<i>Nationality</i>			
British or British/South Asian	79.4 (50)	83.9 (26)	80.9 (76)
South Asian	17.5 (11)	3.2 (1)	12.8 (12)
Other (not British or South Asian)	3.2 (2)	12.9 (4)	6.4 (6)
<i>TOTAL</i>	<i>100 (63)</i>	<i>100 (31)</i>	<i>100 (94)</i>
<i>Ethnicity</i>			
Indian	35.8 (24)	16.7 (6)	29.1 (30)
Pakistani	17.9 (12)	41.7 (15)	26.2 (27)
Bangladeshi	31.3 (21)	36.1 (13)	33.0 (34)
Other	14.9 (10)	5.6 (2)	11.7 (12)
<i>TOTAL</i>	<i>100 (67)</i>	<i>100 (36)</i>	<i>100 (103)</i>
<i>Immigration Status</i>			
UK or EEA National	83.6 (56)	88.6 (31)	85.3 (87)
Leave to Remain	7.5 (5)	2.9 (1)	5.9 (6)
Work or Study Visa	4.5 (3)	2.9 (1)	3.9 (4)
Husband / Wife Sponsorship	4.5 (3)	5.7 (2)	4.9 (5)
<i>TOTAL</i>	<i>100 (67)</i>	<i>100 (35)</i>	<i>100 (102)</i>
<i>Religion</i>			
Muslim	60.6 (40)	80.6 (29)	67.6 (69)
Hindu	13.6 (9)	13.9 (5)	13.7 (14)
Sikh	16.7 (11)	0.0 (0)	10.8 (11)
Other (Buddhist & Christian)	4.5 (3)	0.0 (0)	3.0 (3)
Not religious	4.5 (3)	5.6 (2)	4.9 (5)
<i>TOTAL</i>	<i>100 (66)</i>	<i>100 (36)</i>	<i>100 (102)</i>
<i>Marital Status</i>			
Single	37.3 (25)	33.3 (12)	35.9 (37)
In a relationship	13.4 (9)	8.3 (3)	11.7 (12)
Separated, Divorced or Widowed	6.0 (4)	2.8 (1)	4.9 (5)
Married	43.3 (29)	55.6 (20)	47.6 (49)
<i>TOTAL</i>	<i>100 (67)</i>	<i>100 (36)</i>	<i>100 (103)</i>

Table 4: Demographic Characteristics by Location and Gender

Socio-demographic Characteristic	Online/Community			GP			Total		
	Male	% (n) Female	Total	Male	% (n) Female	Total	Male	% (N) Female	Total
<i>Education Level</i>									
Secondary and Below	12.5 (3)	9.8 (4)	12.1 (8)	12.5 (2)	47.4 (9)	31.4 (11)	12.5 (5)	21.7 (13)	18.0 (18)
Higher	12.5 (3)	22.0 (9)	18.2 (12)	37.5 (6)	15.8 (3)	25.7 (9)	22.5 (9)	20.0 (12)	21.0 (21)
University	75.0 (18)	68.3 (28)	69.7 (46)	50.0 (8)	36.8 (7)	42.9 (15)	65.0 (26)	58.3 (35)	60.4 (61)
<i>TOTAL</i>	<i>100 (24)</i>	<i>100 (41)</i>	<i>100 (66)</i>	<i>100 (16)</i>	<i>100 (19)</i>	<i>100 (35)</i>	<i>100 (40)</i>	<i>100 (59)</i>	<i>100 (101)</i>
<i>Employment Status</i>									
Full Time / Part-Time	52.0 (13)	61.0 (25)	57.6 (38)	68.8 (11)	31.6 (6)	48.6 (17)	58.5 (24)	51.7 (31)	54.5 (55)
Self-Employed / Other	28.0 (7)	2.4 (1)	12.1 (8)	18.8 (3)	1 (2.2)	11.4 (4)	24.4 (10)	3.3 (2)	11.9 (12)
Unemployed	0.0 (0)	12.2 (5)	7.6 (5)	6.3 (1)	42.1 (8)	25.7 (9)	2.4 (1)	21.7 (13)	13.9 (14)
Student	12.0 (3)	22.0 (9)	18.2 (12)	0.0 (0)	21.1 (4)	11.4 (4)	7.3 (3)	21.7 (13)	15.8 (16)
Retired	2 (8.0)	2.4 (1)	4.5 (3)	2.9 (1)	0.0 (0)	2.9 (1)	7.3 (3)	1.7 (1)	4.0 (4)
<i>TOTAL</i>	<i>100 (25)</i>	<i>100 (41)</i>	<i>100 (66)</i>	<i>100 (16)</i>	<i>100 (19)</i>	<i>100 (35)</i>	<i>100 (41)</i>	<i>100 (60)</i>	<i>100 (101)</i>
<i>NS-SEC Level</i>									
Higher Managerial, Administrative & Professional	63.2 (12)	50.0 (17)	54.7 (29)	44.4 (4)	13.3 (2)	25.0 (6)	57.1 (16)	38.8 (19)	45.5 (35)
Intermediate / Routine & Manual	21.1 (4)	20.6 (7)	20.8 (11)	44.4 (4)	6.7 (1)	20.8 (5)	28.6 (8)	16.3 (8)	20.8 (16)
Unemployed	0.0 (0)	2.9 (1)	1.9 (1)	11.1 (1)	40.0 (6)	29.2 (7)	3.6 (1)	14.3 (7)	10.4 (8)
Student & Homemaker	15.8 (3)	26.5 (9)	22.6 (12)	0.0 (0)	40.0 (6)	25.0 (6)	10.7 (3)	30.6 (15)	23.4 (18)
<i>TOTAL</i>	<i>100 (19)</i>	<i>100 (34)</i>	<i>100 (53)</i>	<i>100 (9)</i>	<i>100 (15)</i>	<i>100 (24)</i>	<i>100 (28)</i>	<i>100 (49)</i>	<i>100 (77)</i>

Participants were more likely to be in full-time employment in the online/community group, while a larger proportion was unemployed or working part-time in the GP group, although this was not a statistically significant difference. Employment status was provided by all but one of the participants, however, occupation information was missing for 25% (n=26) of the cases.

As the data presented in Table 4 suggests, those recruited from the online/community sample were significantly more likely to be in the 'higher managerial, administrative and professional category', while those from the GP sample were more likely to be in the 'unemployed' category (Fisher's Exact  $X^2(3)=13.87$ ,  $p=.002$ ).

Men were more likely to be in the 'higher managerial, administrative & professional' or 'intermediate, routine & manual' occupations categories (57%, n=16 and 29%, n=8, respectively) than women. While women were more likely to be in either in the 'unemployed' or 'student, homemaker' occupations categories (14%, n=7 and 31%, n=15, respectively); these differences were on the margin of significance (Fisher's Exact  $X^2(3)=7.40$ ,  $p=.056$ ). When grouped into categories for paid versus unpaid, women were significantly more likely to be in an unpaid category 45% (n=22) compared with men (14%, n=4) ( $X^2(1)=7.47$ ,  $p=.006$ ).

Significant differences were found in the employment status of male and female participants. A similar proportion were in either full-time or part-time employment (male: 59%, n=24; female: 52%, n=31), however, a significantly higher proportion of men were self-employed (24%, n=10 vs 3%, n=2) while a significantly higher proportion of women were unemployed (22%, n=13 vs 2%, n=1), (Fisher's Exact  $X^2(4)=21.06$ ,  $p<.001$ ).

### ***Health Status***

The findings relating to health status are shown in Table 5. Overall, 28% (n=26) reported physical health problems. The most common health complaint related to pain (58%, n=15). The health problems that were reported included: cardiac problems (6%, n=6), irritable bowel syndrome, asthma/breathing problems and allergies/eczema (all 5%, n=5). The remaining participants reported physical health problems (4%, n=4) including diabetes and 'menstrual problems'.

Of the overall sample, 9% (n=9) reported mental health problems, two thirds of whom (n=6, 6% of total sample) reported depression, and just over half (n=5, 5% of total sample) reported an anxiety disorder. One participant reported post-traumatic stress disorder (PTSD), while another reported bereavement.



Of the sample, 6% (n=6) reported having a disability, a third (n=2, 2% of total sample) reported their disability was due to their physical health problem and another third reported that it was due to problems with their mobility. One participant reported problems with their eyesight due to their age. One participant did not disclose what their specific disability was.

As shown in Table 5, no significant differences were found between genders according to health status.

*Table 5: Health Status by Gender*

<b>Health Status</b>	<b>Male % (n)</b>	<b>Female % (n)</b>	<b>Total % (N)</b>	<b><math>\chi^2</math></b>
<i>Physical Health Problem</i>				
Yes	22.0 (9)	28.3 (17)	25.7 (26)	$\chi^2(1)=.519, p=.471$
No	78.0 (32)	71.7 (43)	74.3 (75)	
<i>Mental Health Problem</i>				
Yes	7.3 (3)	9.8 (6)	8.8 (9)	Fisher's Exact $\chi^2(1)=.193, p=.737$
No	92.7 (38)	90.2 (55)	91.2 (93)	
<i>Disability</i>				
Yes	7.3 (3)	4.9 (3)	5.9 (6)	Fisher's Exact $\chi^2(1)=.255, p=.614$
No	92.7 (38)	95.1 (58)	94.1 (96)	

### **Socio-demographics and Acculturation**

The level of acculturation in the sample was measured using the Self-Administered Questionnaire of Acculturation (SAQA). Higher scores on Scales 1 and 2 are indicative of greater acculturation to British culture. Higher scores on Scale 3 are indicative of lower acculturation due to retention of behaviours associated with the country of origin.

Table 6 shows the internal scale consistency of the three subscales of the SAQA, using Cronbach's alpha ( $\alpha$ ). The Corrected Item-Total Correlations (CITC) values for Scale 1 ranged from 0.21 to 0.61, on Scale 2 the CITC values ranged from 0.19 to 0.66 and on Scale 3 CITCs ranged from 0.10 to 0.52. Removal of any of the items below 0.30, however, would not have a significant impact on the overall internal consistency for any of the SAQA Subscales. Therefore, for the purposes of this analysis, items were left in the subscales. See Appendix 16 for reliability tables for the SAQA and please refer to the Discussion section for further consideration of the reliability of the SAQA and other measures used in this study.

*Table 6: Cronbach's  $\alpha$  values for SAQA Subscales*

<b>SAQA Subscale</b>	<b>Cronbach's <math>\alpha</math> (n)</b>
Scale 1: Acculturation Behaviours	0.77 (91)
Scale 2: Acculturation Attitudes	0.78 (91)
Scale 3: Behaviours Associated with Country of Origin	0.67 (88)

Figure 1 demonstrates the distribution of the SAQA subscale scores and Table 5 demonstrates the distribution of scales of acculturation according to the different socio-demographic characteristics, described above.

As shown in Figure 1, overleaf, Scale 1 of the SAQA was significantly negatively skewed, which was corroborated by a Kolmogorov-Smirnov test ( $D(101)=.230, p<.001$ ). The data were normally distributed for Scales 2 and 3, although as can be seen in Figure 1, Scale 2 deviated slightly towards the lower end of the skew.

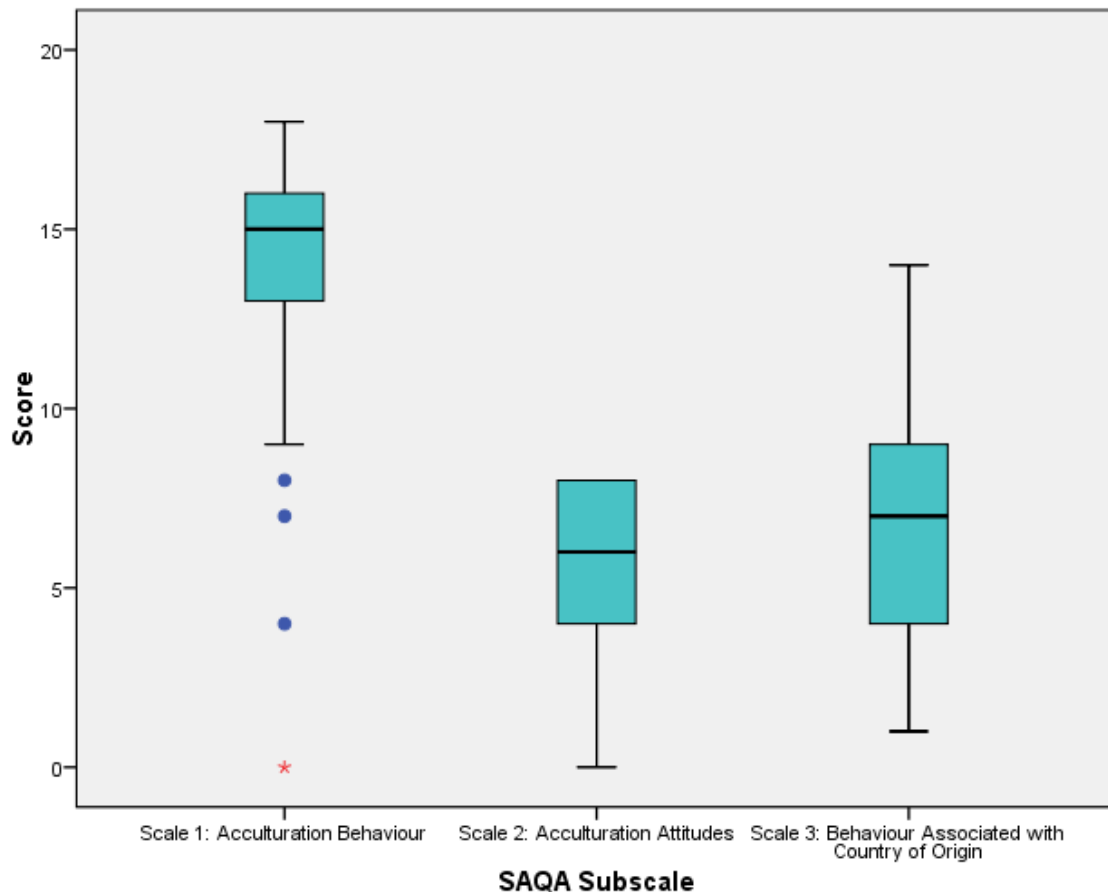


Figure 1: SAQA Subscale Scores

The extreme case identified in Figure 1 for Scale 1 of the SAQA was investigated and established not to be an erroneous response.

Table 7 summarises the distribution of acculturation scores across the three subscales of the SAQA according to different socio-demographic characteristics, which will now be described. Although Scales 2 and 3 are normally distributed, where groups contained less than 20 and a t-test or ANOVA identified significant variance between the means, these were followed by the appropriate non-parametric test (Mann Whitney U or Kruksal Wallis H, respectively) to control for Type I errors arising due to a small sample size. In these instances, non-parametric significance values are reported.

Table 7: Distribution of Acculturation Scores by Demographic Characteristics.

Socio-demographic Characteristic	Scale 1: Behaviours					Scale 2: Attitudes					Scale 3: Country of Origin				
	n	Mean (SD)	Mdn	Min/Max	Sig	n	Mean (SD)	Mdn	Min/Max	Sig	n	Mean (SD)	Mdn	Min/Max	Sig
<i>Location</i>															
Online/Community	66	14.39 (3.44)	15	0/18	*	59	5.68 (2.19)	6	0/8	ns	63	6.25 (3.25)	6	1/18	**
GP	35	13.09 (3.76)	14	0/18		32	5.81 (2.09)	6	2/8		34	8.12 (3.12)	8	1/14	
<i>Gender</i>															
Male	40	14.55 (3.09)	15	4/18	ns	37	6.03 (1.83)	6	2/8	ns	38	6.71 (2.78)	7	1/13	ns
Female	60	13.77 (3.46)	15	0/18		54	5.52 (2.33)	5	0/8		58	6.84 (3.36)	7	1/14	
<i>Born in the UK</i>															
Yes	43	15.44 (2.10)	16	8/18	**	42	5.86 (1.88)	6	2/8	ns	40	5.23 (2.56)	5.5	1/10	**
No	57	12.84 (4.09)	15	0/18		48	5.65 (2.09)	6	0/8		56	8.09 (3.32)	8	2/18	
<i>Ethnicity</i>															
Indian	29	14.55 (2.35)	15	9/18		27	5.44 (2.47)	7	0/8		27	6.44 (2.98)	6	1/13	
Pakistani	26	14.42 (2.73)	15	8/18	ns	24	5.79 (1.82)	6	3/8	ns	26	6.42 (3.16)	6	1/14	ns
Bangladeshi	34	12.88 (4.84)	15	0/18		30	5.83 (2.10)	6	2/8		32	8.03 (3.40)	7.5	2/18	
Other	12	14.42 (3.26)	15	7/17		10	6.00 (2.31)	6.5	1/8		12	6.00 (3.69)	6.5	1/12	
<i>Nationality</i>															
British or British/South Asian	74	14.66 (2.66)	15	7/18		67	5.84 (1.88)	6	2/8		70	6.56 (3.13)	7	1/14	
South Asian	12	13.67 (3.11)	15	7/17	ns	12	5.17 (2.98)	5.5	0/8	ns	12	6.25 (2.73)	6	2/10	ns
Other	6	13.67 (2.50)	14.5	9/16		5	4.60 (3.29)	4	1/8		6	8.17 (2.86)	8.5	5/11	
<i>Immigration Status</i>															
UK/EEA National	85	14.39 (3.30)	15	0/18	**	79	5.81 (2.08)	6	0/8	ns	82	6.60(3.08)	6.5	1/14	ns
Non-UK/EEA National	16	11.56 (4.24)	12.5	0/16		12	5.17 (2.55)	5.5	1/8		15	8.60 (4.07)	9	3/18	
<i>Marital Status</i>															
Single	36	14.50 (2.60)	15	7/18		35	6.11 (2.03)	7	1/8		35	5.94 (2.90)	6	1/11	
In a relationship	12	15.33 (2.35)	15.5	9/18	ns	11	5.18 (2.14)	5	1/8	ns	12	5.83 (3.01)	6.5	1/10	ns
Separated, Divorced or Widowed	5	12.40 (7.09)	15	0/18		3	7.67 (0.58)	8	7/8		5	9.20 (5.26)	8	4/18	
Married	48	13.33 (3.93)	15	0/18		42	5.40 (2.23)	6	0/8		45	7.69 (3.22)	8	2/14	

Table 7, continued.

Socio-demographic Characteristic	Acculturation Scale														
	Scale 1: Behaviours					Scale 2: Attitudes					Scale 3: Country of Origin				
	n	Mean (SD)	Mdn	Min/Max	Sig	n	Mean (SD)	Mdn	Min/Max	Sig	n	Mean (SD)	Mdn	Min/Max	Sig
<i>Religion</i>															
Muslim	69	13.45 (3.98)	15	0/18		59	5.78 (2.02)	6	1/8		65	7.31 (3.44)	7	1/18	
Hindu	14	14.07 (2.50)	15	9/17	ns	14	5.00 (2.69)	5	0/8	ns	14	5.71 (2.73)	5.5	1/10	ns
Sikh	11	15.27 (2.05)	16	12/18		11	5.45 (2.16)	6	2/8		11	7.09 (3.24)	7	2/13	
<i>Employment Status</i>															
Full Time / Part-Time	54	14.78 (2.63)	15	4/18		49	5.92 (2.04)	6	0/8		52	6.21 (2.84)	6	1/14	
Self-Employed / Other	12	15.42 (1.68)	15.5	12/18	**	12	6.67 (1.37)	7	4/8	ns	11	6.27 (2.65)	6	1/10	*
Unemployed or Retired	18	10.67 (4.47)	11	0/18		14	4.29 (2.53)	4	1/8		17	9.47 (4.05)	10	2/18	
Student	16	14.56 (2.50)	15	7/17		15	5.87 (2.10)	6	2/8		16	6.44 (2.76)	6.5	2/11	
<i>Education</i>															
Secondary or Below	19	9.74 (4.70)	10	0/16		13	4.69 (2.87)	4	1/8		18	9.94 (3.84)	10	4/18	
Higher	19	14.84 (2.46)	15	7/18	**	19	6.74 (1.15)	7	5/8	ns	18	6.22 (2.86)	7	1/10	**
University	61	15.16 (1.99)	15	8/18		57	5.54 (2.10)	6	0/8		59	6.05 (2.66)	6	1/13	
<i>NS-SEC</i>															
Higher Managerial, Admin. & Prof.	35	15.63 (1.72)	16	7/11		33	5.73 (1.84)	6	2/8		33	6.00 (2.61)	6	1/13	
Intermediate / Routine & Manual	16	14.25 (3.57)	15.5	4/18	**	15	5.73 (2.02)	6	1/8	ns	16	6.06 (2.79)	6	1/11	*
Unemployed	8	10.38 (3.89)	10.5	4/16		6	4.00 (2.61)	3.5	1/8		8	9.38 (2.39)	9.5	6/12	
Student & Homemaker	18	14.11 (2.83)	15	7/18		17	5.53 (2.21)	6	2/8		18	7.17 (3.38)	7	2/13	
<i>Paid Employment</i>															
Paid	66	14.89 (2.49)	15	4/18	**	61	6.07 (1.94)	7	0/8	ns	63	6.22 (2.79)	6	1/14	*
Unpaid	34	12.50 (4.13)	13.5	0/18		29	5.10 (2.41)	6	1/8		33	8.00 (3.76)	8	2/18	
<b>ALL PARTICIPANTS</b>	<b>101</b>	<b>13.94 (3.59)</b>	<b>15</b>	<b>0/18</b>		<b>91</b>	<b>5.73 (2.15)</b>	<b>6</b>	<b>0/8</b>		<b>97</b>	<b>6.91 (3.31)</b>	<b>7</b>	<b>1/18</b>	

ns = not significant, \* p<.05, \*\* p<.01

NB: Non-parametric tests were used for Scales 2 and 3 where n<20 for any of the sub-categories to control for Type I error.

A comparison of the means between the GP and community groups was carried out using a t-test (see Table 7). Those within the GP group were significantly more likely to have retained behaviours associated with their country of origin (Scale 3) than those in the Online/Community group ( $t=2.73$ ,  $df=95$ ,  $p=.007$ ,  $r=0.27$ ), suggesting a medium effect.

A comparison of means between levels of education, employment status and socioeconomic status was carried out using Kruksal Wallis (H) tests (see Table 7). Those with a lower level of education had a significantly lower mean score on Scale 1 of the SAQA for behaviours associated with greater acculturation ( $H(2)=24.49$ ,  $p<.001$ ) and higher scores on Scale 3 for behaviours associated with country of origin ( $H(2)=14.71$ ,  $p=.001$ ). Those who were employed or students had significantly higher scores on Scale 1 ( $H(3)=16.47$ ,  $p=.001$ ), while those who were unemployed or retired had lower scores for behaviour indicative of acculturation. This pattern was observed for Scale 3, behaviours associated with country of origin, which was higher among the unemployed and retired groups, again indicative of lower acculturation ( $H(3)=10.45$ ,  $p=.015$ ). When employment categories were grouped into paid and unpaid positions, those in an unpaid position had significantly lower scores on Scale 1 (Mann Whitney  $U=1522.00$ ,  $z=2.95$ ,  $p=.003$ ,  $r=.29$ ) and higher scores on Scale 3 ( $t=2.63$ ,  $df=94$ ,  $p=.010$ ). Those with lower socio-economic status had significantly lower scores on Scale 1 ( $H(3)=14.48$ ,  $p=.002$ ) and higher scores for Scale 3, behaviours associated with country of origin ( $H(3)=8.77$ ,  $p=.033$ ). These data suggest a considerable mean difference in acculturation scores according to socio-economic status. These findings suggest there may be a relationship between employment and education in the UK and acculturation to British society. Those who have limited education, who are unemployed, unpaid or from a lower socioeconomic status may have less exposure to and/or opportunity to interact with others from outside their immediate community or culture, or vice versa.

The data indicate that there may be differences in scores on the acculturation scales according to immigration status. However, the numbers were too small across five groups for any inferences to be drawn. When immigration status was grouped into a binary category, UK/EEA Nationals and Non-UK/EEA Nationals, UK/EEA Nationals had a significantly higher mean score for Scale 1 (Mann Whitney  $U=354.50$ ,  $z=-3.06$ ,  $p=.002$ ,  $r=-.30$ ). Similarly, those born in the UK had a significantly higher mean score on Scale 1 of the SAQA than those born outside of the UK (Mann Whitney  $U=1757.50$ ,  $z=3.75$ ,  $p<.001$ ,  $r=0.38$ ) and lower scores on Scale 3 ( $t=4.78$ ,  $df=94$ ,  $p<.001$ ,  $r=.44$ ). These results suggest that, as would be expected, those who are born in the UK or those with secure immigration status in the UK are considerably more likely to be acculturated to British culture, than those born elsewhere or with less secure immigration status. These findings may provide some evidence in support of the use of these scales, which will be discussed further in the 'Discussion' chapter.

## Objective 2: Distribution and Prevalence of Distress

### ***Distribution***

The following figures demonstrate the distribution of the total scores for each of the measures of distress and quality of life. Both the GHQ28 and PC30 were significantly positively skewed, which was corroborated by the Kolmogorov-Smirnov test (GHQ28:  $D(80)=.218, p<.001$ ; PC30:  $D(84)=.169, p<.001$ ). Figures 2 – 4 depict the distribution of scores on each of the measures in the sample using boxplots.

As with the SAQA, the reliability and internal consistency of the measures of distress used were calculated using the Cronbach's  $\alpha$ . The PC30 obtained a Cronbach's  $\alpha$  of 0.98, and the CITC values ranged from 0.63 to 0.85.

The reliability of the GHQ28 and WHO5 have been widely reported in published literature, therefore will not be reported in detail in this study, but they were consistent with previous research. Reliability tables for the PC30, GHQ28 and the WHO5 are available in Appendices 17 to 19 and further comment may be found in the Discussion section.

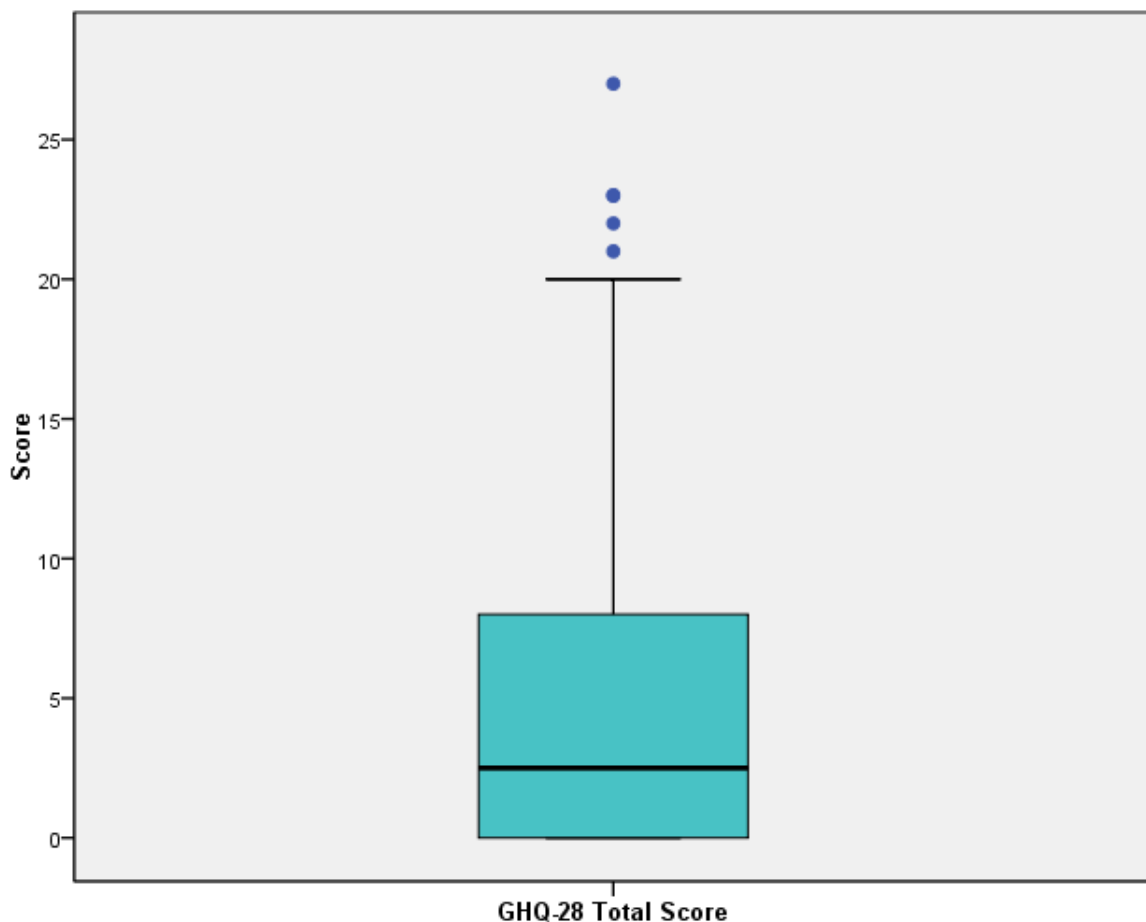


Figure 2: GHQ28 Total Scores

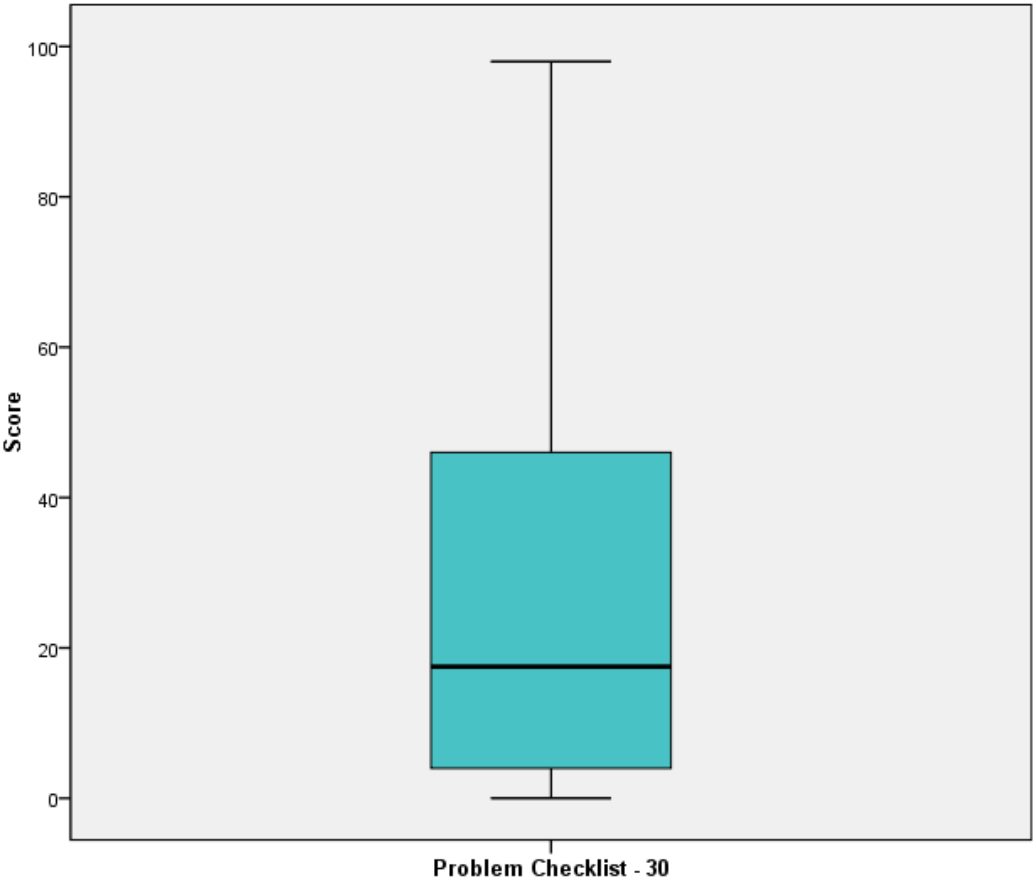


Figure 3: PC30 Total Scores

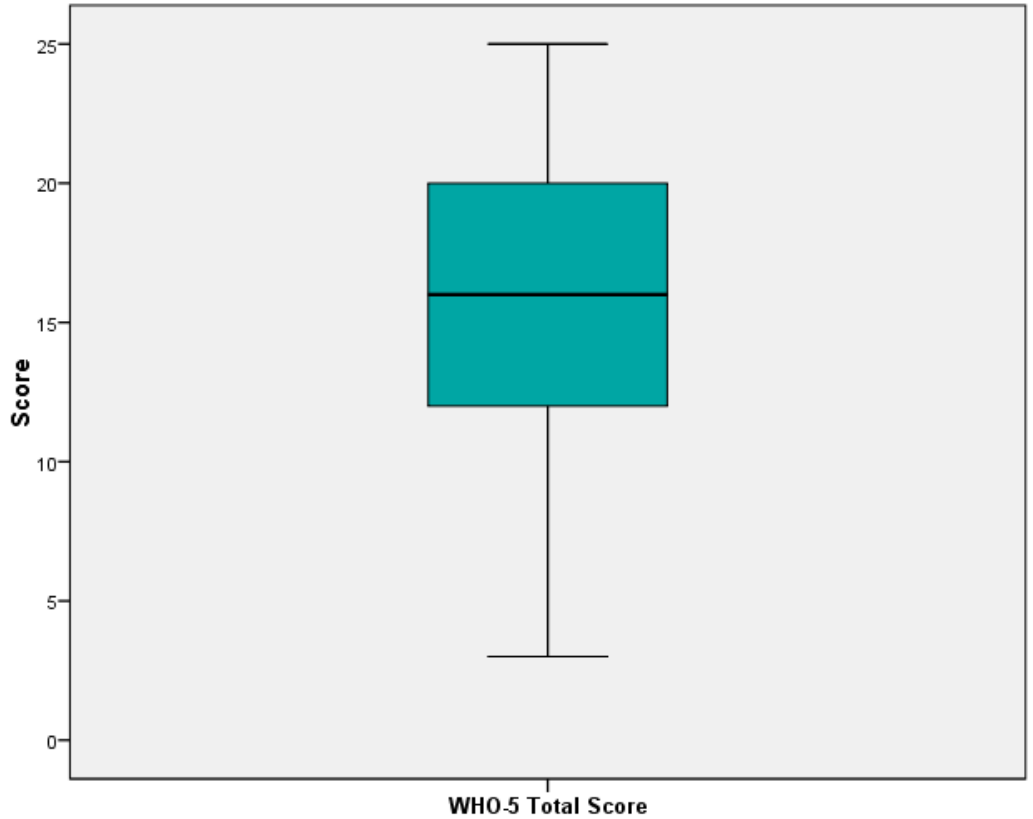


Figure 4: WHO5 Total Scores

In order to assess whether or not there was any significant variance across the different socio-demographic characteristics of the sample, a comparison of means analysis was carried out using Mann Whitney U and Kruksal Wallis (H) tests.

Table 8 depicts the distribution of distress and quality of life for each of the measures, across the range of socio-demographic features.

As can be seen in Table 8, the only significant differences in the mean scores on the distress measures according to socio-demographic characteristics was in employment on both the GHQ28 ( $H(3)=11.10, p=.011$ ) and the PC30 ( $H(3)=9.56, p=.023$ ), and socioeconomic status on GHQ28 scores ( $H(3)=8.56, p=.036$ ).

Close inspection of the results in Table 8, identified that those who were unemployed scored significantly higher on the measures of distress compared with the other employment status categories. Similarly those in the unemployed category for socioeconomic status also score significantly higher on the measures of distress than any other socioeconomic status category.



Table 8: Distribution of Distress and Quality of Life by Demographic Characteristics

Socio-demographic Characteristics	GHQ28					Psychometric Measure PC30					WHO5				
	n	Mean (SD)	Mdn	Min/Max	Sig	n	Mean (SD)	Mdn	Min/Max	Sig	n	Mean (SD)	Mdn	Min/Max	Sig
<i>Location</i>															
Online/Community	51	4.80 (6.63)	2	0/27	ns	56	25.02 (25.53)	13.5	0/95	ns	63	15.21 (5.67)	16	3/25	ns
GP	29	6.45 (7.44)	3	0/23		28	29.21 (28.39)	19.5	0/98		34	15.56 (5.05)	16	5/25	
<i>Gender</i>															
Male	31	4.97 (6.47)	2	0/23	ns	29	19.93 (21.91)	13	0/94	ns	38	15.58 (5.66)	13	3/25	ns
Female	48	5.46 (7.18)	3	0/27		54	29.19 (27.94)	22	0/98		59	15.17 (28.38)	15	3/25	
<i>Born in the UK</i>															
Yes	37	4.86 (6.75)	2	0/23	ns	39	28.41 (27.51)	19	0/98	ns	41	14.51 (5.05)	14	5/25	ns
No	42	5.95 (7.19)	3.5	0/27		45	24.69 (25.63)	17	0/95		55	15.89 (32.66)	17	3/25	
<i>Ethnicity</i>															
Indian	21	6.86 (7.03)	4	0/22	ns	25	28.12 (23.45)	26	1/94	ns	28	14.54 (5.12)	13.5	3/25	ns
Pakistani	22	5.73 (7.20)	3	0/23		22	36.50 (30.99)	38	0/98		26	14.31 (5.58)	14	5/25	
Bangladeshi	29	4.24 (6.09)	2	0/23		29	18.45 (20.72)	10	0/65		31	16.03 (5.47)	17	3/25	
Other	8	4.88 (9.20)	1	0/27		8	22.25 (34.38)	5.5	1/95		12	17.58 (5.45)	19	7/25	
<i>Nationality</i>															
British or British/South Asian	62	5.31 (6.56)	3	0/23	ns	62	27.18 (26.64)	18.5	0/98	ns	71	14.73 (5.32)	15	3/25	ns
South Asian	7	3.19 (8.45)	2	0/23		10	23.70 (21.87)	21	0/54		12	17.25 (5.31)	17	7/25	
Other	4	7.75 (12.97)	2	0/27		5	31.20 (40.95)	6	2/95		6	16.17 (4.62)	17.5	9/20	
<i>Immigration Status</i>															
UK/EEA National	70	5.57 (7.16)	3	0/27	ns	75	25.95 (26.73)	14	0/98	ns	82	15.00 (5.31)	16	3/25	ns
Non-UK/EEA National	10	4.20 (5.22)	2	0/16		9	30.33 (24.82)	27	0/65		15	17.13 (5.96)	18	4/25	
<i>Marital Status</i>															
Single	28	4.50 (6.55)	2.5	0/27	ns	29	22.34 (25.58)	11	0/95	ns	33	15.82 (5.08)	16	3/25	ns
In a relationship	9	7.78 (8.20)	3	0/20		10	32.90 (24.00)	26	5/72		11	15.00 (5.04)	14	8/25	
Separated, Divorced or Widowed	4	6.25 (7.76)	4.5	0/16		4	53.75 (36.34)	52	13/98		4	16.00 (8.41)	17	5/25	
Married	39	5.41 (6.96)	2	0/23		41	25.05 (25.75)	18	0/94		49	15.02 (5.57)	15	3/25	

Table 8, continued.

Socio-demographic Characteristic	Psychometric Measure														
	GHQ28					PC30					WHO5				
	n	Mean (SD)	Mdn	Min/ Max	Sig	n	Mean (SD)	Mdn	Min/ Max	Sig	n	Mean (SD)	Mdn	Min/ Max	Sig
<i>Religion</i>															
Muslim	56	5.45 (7.28)	2	0/27		59	26.76 (27.53)	18	0/98		66	15.24 (5.61)	16	3/25	
Hindu	9	8.33 (8.09)	9	0/22	ns	12	24.17 (19.05)	25.5	1/54	ns	13	14.85 (5.31)	13	6/25	ns
Sikh	9	3.56 (4.93)	1	0/15		9	30.44 (33.23)	14	1/94		10	14.90 (5.59)	14.5	3/25	
<i>Employment Status</i>															
Full Time / Part-Time	43	4.09 (5.76)	2	0/22		45	21.49 (22.69)	13	0/98		50	15.74 (5.58)	16.5	3/25	
Self-Employed / Other	10	7.20 (7.94)	5.5	0/23	*	9	28.44 (20.52)	30	1/55	*	12	13.42 (6.13)	12.5	6/25	ns
Unemployed or Retired	14	11.07 (9.10)	9.5	0/27		16	47.94 (33.24)	47.5	0/95		18	13.17 (4.94)	14	3/20	
Student	12	2.42 (2.39)	2.5	0/5		13	17.23 (20.93)	7	2/68		16	17.50 (3.86)	16.5	11/25	
<i>Education</i>															
Secondary or Below	15	9.93 (9.25)	7	0/27		14	40.36 (31.39)	36.5	0/95		18	14.78 (4.36)	14	9/25	
Higher	15	4.40 (4.79)	5	0/17	ns	18	21.78 (21.88)	11.5	0/68	ns	18	16.06 (5.32)	17	7/25	ns
University	50	4.34 (6.22)	2	0/23		50	25.24 (25.72)	15.5	0/98		59	15.07 (5.74)	16	3/25	
<i>NS-SEC</i>															
Higher Managerial, Admin. & Prof.	30	5.43 (6.20)	3	0/23		31	26.97 (24.29)	20	0/94		32	14.31 (5.85)	13.5	3/24	
Intermediate / Routine & Manual	11	4.45 (6.73)	2	0/18	*	14	20.29 (18.77)	22	0/54	ns	15	16.47 (6.13)	17	8/25	ns
Unemployed	6	15.00 (9.65)	15	2/27		6	52.33 (40.49)	62.5	0/95		8	13.63 (4.47)	15	6/18	
Student & Homemaker	15	3.8 (5.25)	4	0/21		15	25.67 (26.17)	14	3/87		18	16.44 (4.69)	16	7/25	
<i>Paid Employment</i>															
Paid	53	4.68 (6.27)	2	0/23	ns	54	22.65 (22.31)	15.5	0/98	ns	62	15.29 (5.72)	16	3/25	ns
Unpaid	26	7.08 (8.06)	5	0/27		26	34.17 (31.95)	25	0/95		34	15.21 (4.92)	15.5	3/25	
<b>ALL PARTICIPANTS</b>															

ns = not significant, \* p<.05,

### ***Prevalence of Psychological Distress***

The cut-off scores for the measures of distress were described in the Method chapter. Table 9 depicts the prevalence of psychological distress according to various socio-demographic characteristics. The generalizability of this data will be considered in the Discussion chapter.

One third of the sample (33%, n=27) scored above the cut-off threshold on the GHQ28 and half of the sample (49%, n=41) scored above the cut-off point on the PC30, indicative of psychological distress. There was no significant difference between locations of recruitment in the levels of distress. Both of these indications of distress are high prevalence rates for distress in this sample, compared with national estimates of the prevalence of 'common mental health disorders' in the community of 15% (Kendrick & Pilling, 2012) or 25% of having a diagnosable mental health problem in any given year (Singleton, Bumpstead, O'Brien, Lee & Meltzer, 2001). This will be discussed further in the Discussion chapter. Two fifths (39%, n=38) of the overall sample scored below the cut-off point on the WHO5, suggesting that they were experiencing a lower quality of life. Quality of life also did not differ significantly according to the location of recruitment.

As shown in Table 9, those reporting physical health problems were significantly more likely to score in the range for probable distress on the GHQ28 ( $X^2(1)=5.869$ ,  $p=.015$ ); however, no significant difference was observed with reporting of physical health problems and presence of distress on the PC30 or quality of life on the WHO5. There was no significant difference in the reported distress among those who reported having a mental health problem or a disability.

The final three characteristics in Table 9 (Feel Future is Secure, Fear of Racist Attacks, Fear of Discrimination) are selected questions from Scale 2 of the SAQA, that were identified as having clinical significance in the interpretation and understanding of distress within this sample. Those experiencing distress and a lower quality of life were significantly more likely to have reported fears of being discriminated against when applying for jobs because of ethnic origin (GHQ28:  $X^2(1)=3.98$ ,  $p=.046$ ; PC30:  $X^2(1)=12.35$ ,  $p<.001$ ; WHO5:  $X^2(1)=7.77$ ,  $p=.005$ ). Those above the threshold for distress on the PC30 were also significantly more likely to report feeling that their future was not secure (Fisher's Exact  $X^2(1)=4.64$ ,  $p=.045$ ), a finding which was also observed with low quality of life on the WHO5 ( $X^2(1)=4.04$ ,  $p=.045$ ) but not on the GHQ28.

The data indicates there may be more associations in the demographic characteristics than established through the statistical testing in this study. The reduction in sample size due to division into subgroups for the demographic variables, impacts on the ability to draw inferences from this data.

Table 9: Prevalence of Psychological Distress and Low Quality of Life

	GHQ28				PC30				WHO5			
	No Distress % (n)	Distress % (n)	TOTAL % (N)	Sig	No Distress % (n)	Distress % (n)	TOTAL % (N)	Sig	High QoL % (n)	Low QoL % (n)	TOTAL % (N)	Sig
<i>Location</i>												
Online/Community	72.5 (37)	27.5 (14)	100 (51)	ns	53.6 (30)	46.4 (26)	100 (56)	ns	60.3 (38)	39.7 (25)	100 (63)	ns
GP	56.7 (17)	43.3 (13)	100 (30)		46.4 (13)	53.6 (15)	100 (28)		21 (61.8)	38.2 (13)	100 (38)	
<i>Gender</i>												
Male	64.5 (20)	35.5 (11)	100 (31)	ns	58.6 (17)	41.4 (12)	100 (29)	ns	57.9 (22)	42.1 (16)	100 (38)	ns
Female	69.4 (34)	30.6 (15)	100 (49)		48.1 (26)	51.9 (28)	100 (40)		62.7 (37)	37.3 (22)	100 (59)	
<i>Born in UK</i>												
Yes	73.0 (27)	27.0 (10)	100 (37)	ns	48.7 (19)	51.3 (20)	100 (39)	ns	56.1 (23)	43.9 (18)	100 (41)	ns
No	60.5 (26)	17 (39.5)	100 (43)		53.3 (24)	46.7 (21)	100 (45)		63.6 (35)	36.4 (20)	100 (38)	
<i>Physical Health Problem</i>												
Yes	18.9 (10)	44.4 (12)	100 (22)	*	39.1 (9)	60.9 (14)	100 (23)	ns	22.4 (13)	34.2 (13)	100 (26)	ns
No	81.1 (43)	55.6 (15)	100 (58)		56.7 (34)	43.3 (26)	100 (60)		77.6 (45)	65.8 (25)	100 (70)	
<i>Mental Health Problem</i>												
Yes	7.4 (4)	7.4 (2)	100 (75)	ns	28.6 (2)	71.4 (5)	100 (7)	ns	5.1 (3)	13.2 (5)	100 (8)	ns
No	92.6 (50)	92.6 (25)	100 (6)		53.2 (41)	46.8 (36)	100 (77)		94.9 (56)	86.8 (33)	100 (89)	
<i>Disability</i>												
Yes	3.7 (2)	7.4 (2)	100 (4)	ns	20.0 (1)	80.0 (4)	100 (5)	ns	5.1 (3)	7.9 (3)	100 (6)	ns
No	96.3 (52)	92.6 (25)	100 (77)		53.2 (42)	46.8 (37)	100 (79)		94.9 (56)	92.1 (35)	100 (91)	
<i>Feel Future is Secure</i>												
Yes	79.2 (42)	77.8 (21)	100 (63)	ns	90.7 (39)	72.5 (29)	100 (68)	*	86.4 (51)	69.4 (25)	100 (76)	*
No	20.8 (11)	22.2 (6)	100 (17)		9.3 (4)	27.5 (11)	100 (15)		13.6 (8)	30.6 (11)	100 (19)	
<i>Fear of Racist Attacks</i>												
Yes	35.8 (19)	42.3 (11)	100 (30)	ns	30.2 (13)	48.7 (19)	100 (32)	ns	32.8 (19)	50.0 (18)	100 (37)	ns
No	64.2 (3\$)	57.7 (15)	100 (49)		69.8 (30)	51.3 (20)	100 (50)		67.2 (39)	50.0 (18)	100 (57)	
<i>Fear of Discrimination</i>												
Yes	37.7 (20)	61.5 (16)	100 (36)	*	23.3 (10)	61.5 (24)	100 (34)	**	29.3 (17)	58.3 (21)	100 (38)	**
No	62.3 (33)	38.5 (10)	100 (43)		76.7 (33)	38.5 (15)	100 (48)		70.7 (41)	41.7 (15)	100 (56)	
<b>TOTAL PREVALENCE</b>	<b>66.7 (54)</b>	<b>33.3 (27)</b>	<b>100 (81)</b>		<b>51.2 (43)</b>	<b>48.8 (41)</b>	<b>100 (84)</b>		<b>60.8 (59)</b>	<b>39.2 (38)</b>	<b>100 (97)</b>	

ns = not significant, \* p<.05, \*\*p<.01 NB: Where cell counts <5, Fisher's Exact X<sup>2</sup> is reported.

## Objective 3: Help-Seeking Behaviour

### *Help-Seeking*

When answering questions relating to help-seeking and experiences of services (see Objective 4), participants were reminded that the questions related to 'health services for any emotional problems or distress that [they] may have experienced'.

Overall, 46% (n=43) of the participants in the sample said they had sought help for their problems in the past. Half of the GP group (50%, n=16) and nearly half of the Online/Community group (44%, n=27) reported having sought help for their problems in the past. A higher proportion of women (52%, n=30) reported seeking help than men (34%, n=12), although this difference was not statistically significant. Responses were missing for 10 participants.

As shown in Table 10, those with a lower quality of life on the WHO5 were significantly more likely to have sought help at some point ( $X^2(1)=7.53$ ,  $p=.006$ ) and those above the threshold indicative of distress on the PC30 were also more likely to have sought help ( $X^2(1)=11.12$ ,  $p=.001$ ). However, there was no difference between those who met the threshold for significant distress on the GHQ28 and whether or not they had sought help.

A third of those who reported a low quality of life on the WHO5 (34%, n=11), a third of those experiencing distress on the PC30 (34%, n=13) and half of those experiencing distress on the GHQ28 (46%, n=12) reported that they had never sought help for their problems.

*Table 10: Help-Seeking by GHQ28, PC30 and WHO5 Thresholds*

	Sought Help			Sig
	Yes % (n)	No % (n)	Total % (n)	
<i>GHQ28</i>				
Distress	53.8 (14)	46.2 (12)	100 (26)	ns
No Distress	46.3 (25)	53.7 (29)	100 (54)	
<i>PC30</i>				
Distress	65.8 (25)	34.2 (13)	100 (38)	**
No Distress	28.6 (12)	71.4 (30)	100 (42)	
<i>WHO5</i>				
Low QoL	65.6 (21)	34.4 (11)	100 (32)	**
High QoL	35.6 (21)	64.4 (38)	100 (59)	
<b>TOTAL</b>	<b>45.7 (43)</b>	<b>54.3 (51)</b>	<b>100 (94)</b>	

ns = not significant, \*\* $p<.01$

### *Types of Services Sought and Used*

The median number of services that participants had sought help from and that they were currently using was one. Participants were more likely to have sought help from more services than they were currently receiving.

Of those who sought help, three quarters (74%, n=32) did so from their GP in the NHS. Of those who reported that they were currently using services, 81% (n=13) were doing so through their GP in the NHS. In seeking help from services, 62% (n=26) sought help from only an NHS service and 19% (n=8) sought help from either a non-NHS service or both NHS and non-NHS services.

Of those who were currently using services, 67% (n=9) were using only NHS services, while 27% (n=4) were using both NHS and non-NHS services and one participant (7%) was using a non-NHS service only. This suggests that although a relatively high proportion of people do not seek help from services, those who do, recognise the NHS as a source of help when experiencing distress.

The 'Other' services that participants specified included seeking support from friends (n=3), counselling provided through their employer (n=2), 'keeping busy' and drug replacement therapy (each, n=1). Of the two who reported they were currently using 'Other' services, one reported using a pharmacist and the other a community drug misuse service.

Table 11 demonstrates the types of services sought by participants and the current services they were using at the time of completing the questionnaire. Figure 5 displays the number of services participants sought and used.

*Table 11: Types of Services Sought and Used.*

Service Type	Services Sought (N=43) % (n)	Current Services (N=16) % (n)
GP in the NHS	74.4 (32)	81.3 (13)
Counselling or Group Support in the NHS	25.6 (11)	25.0 (4)
Counselling or Group Support in the Asian Community	11.6 (5)	6.3 (1)
NHS Mental Health Service	11.6 (5)	12.5 (2)
Private Mental Health Service	14.0 (6)	12.5 (2)
Support from Religious Leaders	7.0 (3)	6.3 (1)
Support from Social Services	7.0 (3)	0 (0)
Other	16.3 (7)	12.5 (2)

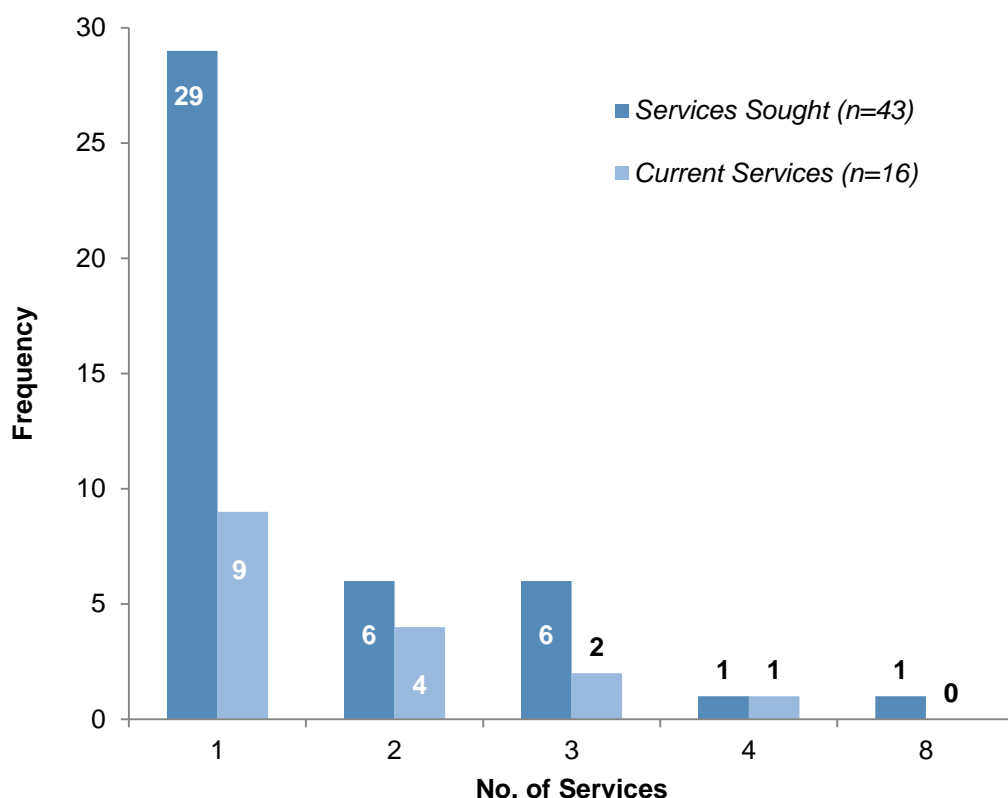


Figure 5: No. of Services Sought and Used

## Objective 4: Experiences of Services

This section explores participants' reported experiences of services from which they had sought help or had used. The results in this section are structured around the questions that were presented to the participants in the survey. Chi-squared ( $X^2$ ) tests were carried out to explore whether or not there were any significant differences in experiences of services according to different grouping variables. The following results are summarised in Table 12.

### ***If you sought help, did you feel that your problems were understood?***

More women felt that their problems had been understood (44%, n=18) compared with men (27%, n=7), whereas men were more likely to either feel that their problems had not been understood (39%, n=10) or that they did not know (35%, n=9). Those recruited through GP surgeries were more likely to feel that their problems had not been understood (50%, n=13) compared with those who had been recruited through Community/Online (26%, n=11) (see Table 12).

Those who scored in the range for distress on the GHQ28 and in the range suggesting a lower quality of life on the WHO5, were more likely to feel their problems had not been understood (50%, n=10 and 44%, n=11, respectively). Approximately a quarter (27%, n=18)

of those who had sought services did not know whether their problems had been understood. No statistically significant differences were observed between any of the groups.

Four participants provided further written information about why they felt their problems had been understood. One commented on the importance of being able to talk privately to a professional without emotional attachment to their situations. Another talked of seeking private therapy on the advice of a friend. One participant felt that although their problems had been understood, their problems had not resolved as they had been unable to find solutions. Finally, another reported that once they presented at A&E for their problems, they felt well understood by their psychiatrist but until that point, their GP who they had initially presented to had been 'utterly useless'.

Of those who felt their problems had not been understood, another four provided a written qualitative response. Three commented on the capability of 'doctors' to adequately understand or manage their emotional wellbeing. One described their doctor as a 'no gooder', while another felt that 'all the doctors offer are pills and I am sure there are other ways of dealing with loss'. One commented that doctors are not counsellors and are 'usually Asian that know your in-laws'. One commented on the therapy that they had been offered, and felt that it was not 'a very reflective or tangible approach'. Of the participants who had responded that they did not know if their problems were understood, two provided a written response. One reported a 'lack of cultural understanding', and the other stated that they were prescribed some medication at a difficult time due to their studies but that they had chosen not to take them.



Table 12: Experiences of Services by Location, Gender, Distress and Quality of Life.

	Experience of Services											
	Understood				Helpful				Appropriate			
	Yes % (n)	No % (n)	Don't Know % (n)	Sig	Yes % (n)	No % (n)	Don't Know % (n)	Sig	Yes % (n)	No % (n)	Don't Know % (n)	Sig
<i>Location</i>												
Community/Online	42.9 (18)	26.2 (11)	31.0 (13)	ns	54.3 (19)	22.9 (8)	22.9 (8)	ns	62.9 (22)	14.3 (5)	22.9 (8)	ns
GP	30.8 (8)	50.0 (13)	19.2 (2)		24.0 (6)	32.0 (8)	44.0 (11)		33.3 (8)	25.0 (6)	41.7 (10)	
<i>Gender</i>												
Male	26.9 (10)	38.5 (10)	34.6 (9)	ns	33.3 (8)	25.0 (6)	41.7 (10)	ns	45.8 (11)	16.7 (4)	37.5 (9)	ns
Female	43.9 (18)	34.1 (14)	22.0 (9)		45.7 (16)	28.6 (10)	25.7 (9)		52.9 (18)	20.6 (7)	26.5 (9)	
<i>GHQ Distress</i>												
Distress	30.0 (6)	50.0 (10)	20.0 (4)	ns	41.2 (7)	35.3 (6)	23.5 (4)	ns	50.0 (8)	25.0 (4)	25.0 (4)	ns
No Distress	42.5 (17)	30.0 (12)	27.5 (11)		43.2 (16)	21.6 (8)	35.1 (13)		50.0 (18)	16.7 (6)	33.3 (12)	
<i>PC30 Distress</i>												
Distress	37.9 (11)	41.4 (12)	20.7 (6)	ns	37.9 (11)	24.1 (7)	37.9 (11)	ns	44.4 (12)	14.8 (4)	40.7 (11)	ns
No Distress	38.5 (10)	26.9 (7)	34.6 (9)		47.6 (10)	19.0 (4)	33.3 (7)		59.1 (13)	18.2 (4)	22.7 (5)	
<i>WHO Quality of Life</i>												
Low Quality of Life	28.0 (7)	44.0 (11)	28.0 (7)	ns	36.4 (8)	27.3 (6)	36.4 (8)	ns	42.9 (9)	19.0 (4)	38.1 (8)	ns
High Quality of Life	42.9 (18)	31.0 (13)	26.2 (11)		45.7 (16)	28.6 (10)	25.7 (9)		57.1 (20)	20.0 (7)	22.9 (8)	
<b>TOTAL</b>	<b>38.2 (26)</b>	<b>35.3 (24)</b>	<b>26.5 (18)</b>		<b>41.7 (25)</b>	<b>26.7 (16)</b>	<b>31.7 (19)</b>		<b>50.8 (30)</b>	<b>18.6 (11)</b>	<b>30.5 (18)</b>	

### ***Did you find services helpful for your needs?***

Two fifths (42%, n=25) of the overall sample who had sought help from services, found them to have been helpful, although over a quarter (27%, n=16) found them to have been unhelpful. Those in the Community/Online group (54%, n=19) and women (46%, n=16) were more likely to have found the services they used helpful, while 44% (n=11) of the GP group and 42% (n=10) of men did not know if the services had been helpful for them or not (see Table 12).

Distress on the GHQ28 or PC30 and a lower quality of life on the WHO5 did not appear to be associated with participants' experiences of services as helpful or not. No significant differences were found between any of the groups and whether or not they found the services helpful.

Two participants who found the services they used helpful provided a written response. One participant commented that the therapy meant that it was 'easier to be open' and that the approach they had been offered was 'logical, rational and helped [them] through a difficult time'. The other commented that 'back then, it cleared my mind'. One participant, who did not find the service helpful, repeated her assertion that their doctors were 'no gooders'. Finally, one participant, who reported that they did not know if the services had been helpful, commented on the cultural aspects of help that is provided. They said that 'according to our culture, we depend [sic] to face problems of life ourselves and no not depend on sharing with public, but very near ones. If you cannot share with them, then the only way is left to fight'.

### ***Did you find services appropriate for your needs?***

Almost two thirds (63%, n=22) of the Community/Online group found the services to have been appropriate for their needs, compared with one third (33%, n=8) of the GP group. A similar proportion of male (46%, n=11) and female (53%, n=18) participants had found services appropriate for their needs, while more than a third (38%, n=9) of male participants did not know.

Half of participants both above (50%, n=8) and below (50%, n=18) the GHQ28 threshold for distress found services to have been appropriate for their needs; however, a quarter (25%, n=4) found that services had not been appropriate. Approximately one fifth of participants both above (20%, n=7) and below (19%, n=4) the threshold indicative of a low quality of life had not found services appropriate for their needs. Again, no significant differences were found between any of the groups in relation to their experience of services as appropriate for their needs.

One person provided a written response about services being inappropriate for their needs, commenting that the short term counselling offered to them would not help their 'long term' problem. They felt that none of the health services understood their problem and that '[clinicians] think they can just fix it and it will go away'.

### **Satisfaction with Services**

Of those who reported their level of satisfaction with their experience of services, having either sought or currently using them, 55% (n=22) reported that they were either slightly or very satisfied with the service they had received; 23% (n=9) were either slightly unsatisfied or not at all satisfied, see Figure 6.

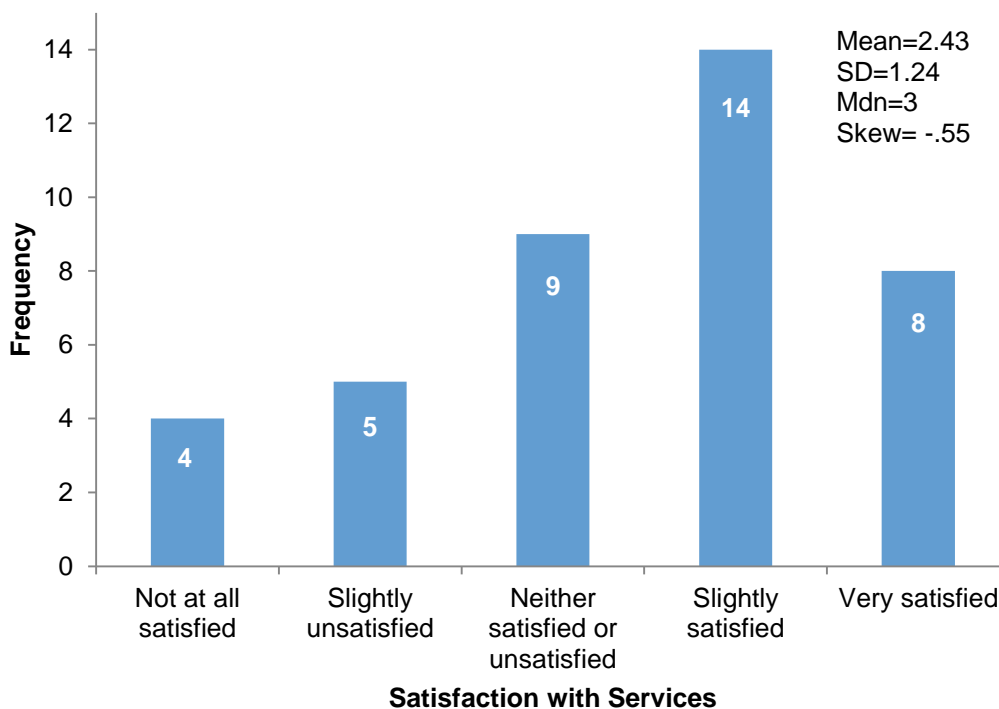


Figure 6: Satisfaction with Services

### **Preferred Service Type**

Of the 16% (n=11) of participants who chose not to use services that were offered to them, 36% (n=4) did not want to, 27% (n=3) felt it did not suit their lifestyle and 9% (n=1), each said it was not available to them, it was inappropriate for their religion, they did not want to burden their family, or the service they received was not helping. The remaining 58% (n=41) did not turn down any services offered to them, while 27% (n=19) said they did not know.

Almost one fifth (17%, n=14) reported that there were services that they wanted but were not offered, 32% (n=26) were not sure and 51% (n=42) said there were no services they wanted but were not offered. Six participants gave written responses about services they wanted:

- Domestic violence support (n=2)
- Pain management (n=2)
- Hypnotherapy (n=1)
- Muslim NHS therapist (n=1)
- To talk to someone (n=1)
- CBT on the computer (n=1)
- Centre of excellence for anxiety disorders (n=1)
- Advice to attend hospital straight away (n=1)
- Talking to others with similar experiences (n=1)
- Regular and free counselling. (n=1)

## **Objective 5: Associations between distress, acculturation and quality of life**

In preparation for building a model to predict help-seeking behaviour of the participants in the sample, associations between distress, acculturation and quality of life were explored.

### ***Distress and Quality of Life***

Spearman's rho correlation coefficients were calculated to explore the relationship between the distress and quality of life measures and acculturation. Where Spearman's rho coefficients have been used, bootstrapping confidence intervals at the 95% level have been reported.

There was a strong negative correlation between scores on the WHO5 and the PC30 ( $r_s = -.804$ , 95% CI [-0.87, -0.67],  $p < .001$ ) and the WHO5 and GHQ28 ( $r_s = -.707$ , 95% CI [-0.82, -0.53],  $p < .001$ ), see Figures 7 and 8. As would be expected, there was a significant positive correlation between the scores on the PC30 and the GHQ28 ( $r_s = .770$ , 95% CI [0.63, 0.86],  $p < .001$ ), see Figure 9.

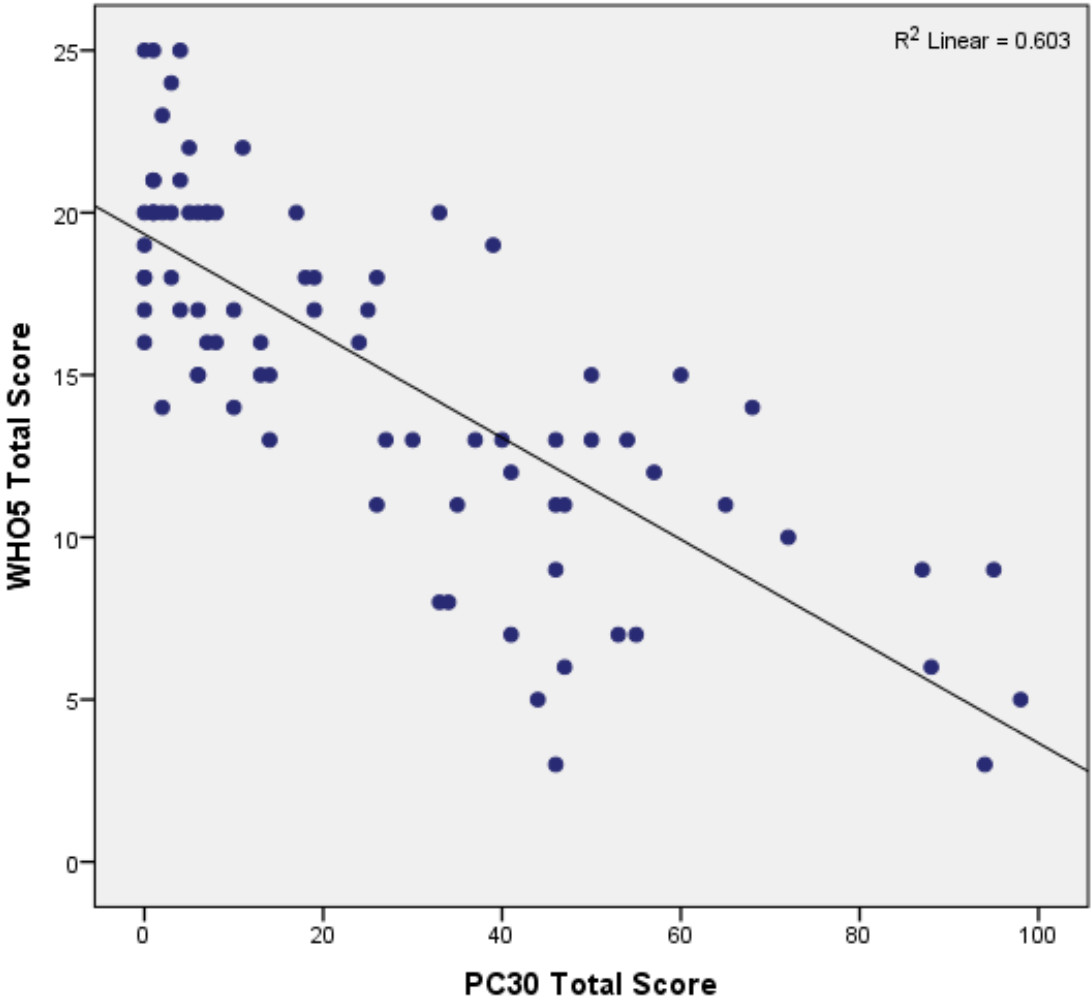


Figure 7: WHO5 and PC30 Total Scores

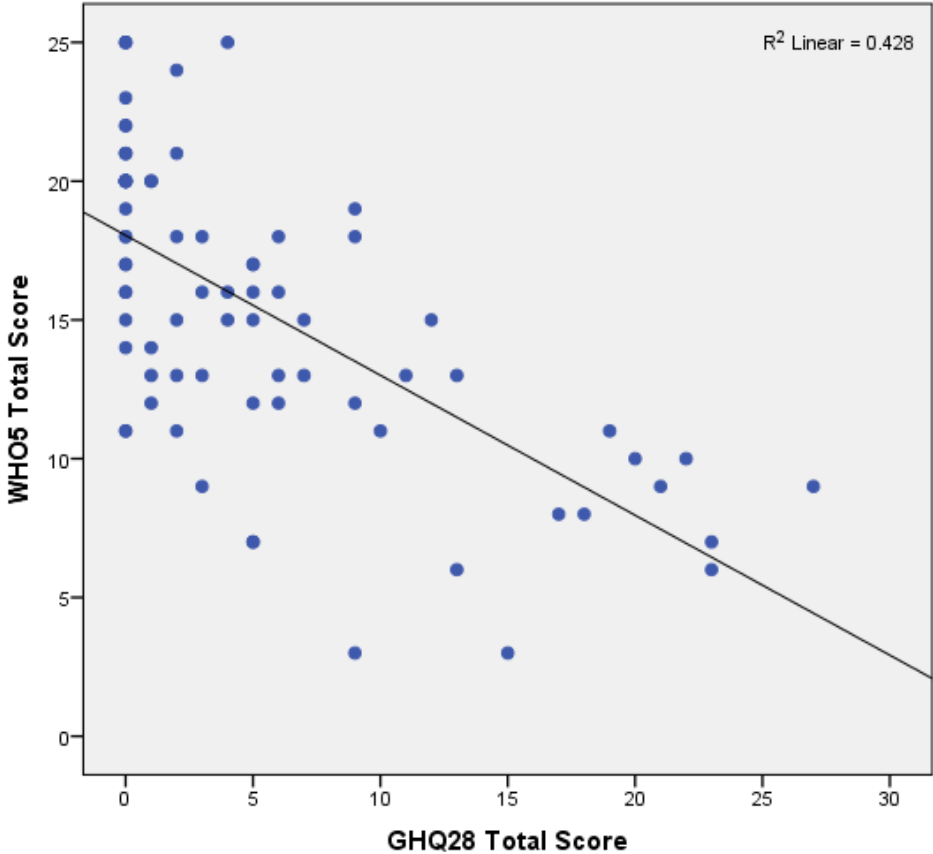


Figure 8: WHO5 and GHQ28 Total Scores

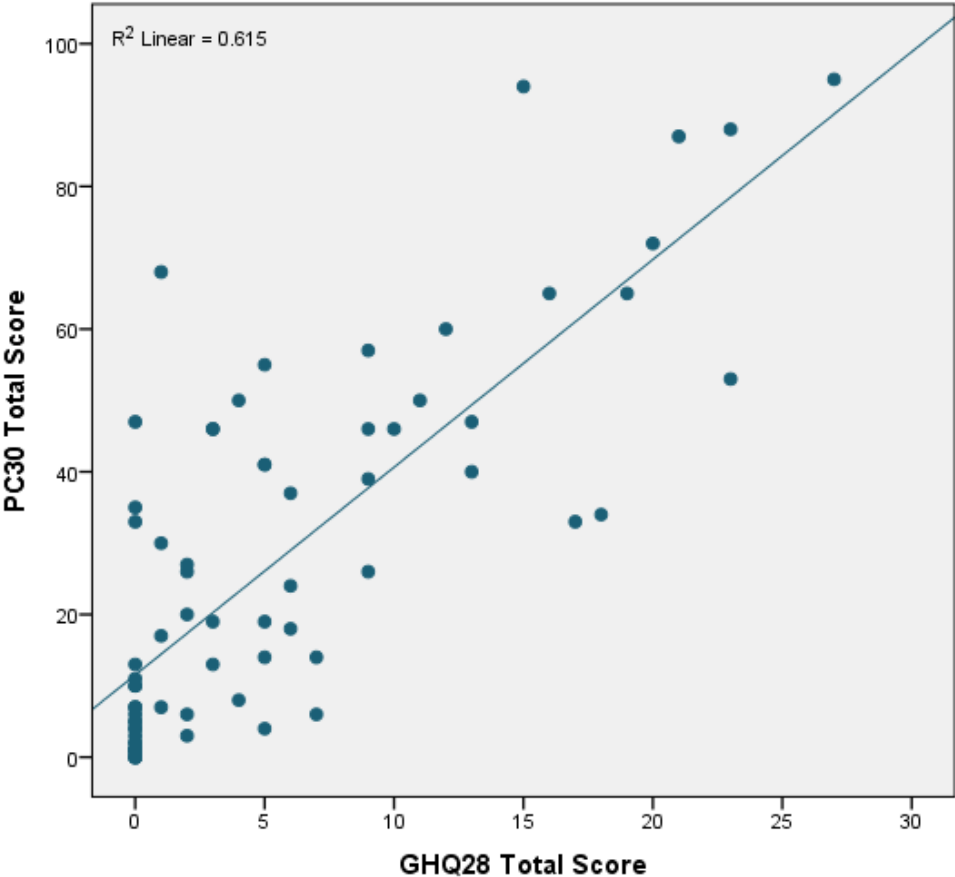


Figure 9: PC30 and GHQ28 Total Scores

Figures 10 and 11 display the percentages of those reporting their quality of life depending on whether or not their scores were above the threshold indicative of distress on the GHQ28 and the PC30. As is apparent from the figures, and corroborated by chi-square analysis, there are stark percentage differences in quality of life according to whether or not participants were also experiencing distress. On the GHQ28, 63% of those who had a low quality of life on the WHO5 were distressed compared with 37% of those reporting a low quality of life who were not distressed ( $X^2(1)=20.27, p<.001$ ).

The difference was much more acute with distress as measured by the PC30, where 97% of those who reported a low quality of life were above the threshold for distress, compared with only 3% who were not distressed ( $X^2(1)=44.93, p<.001$ ).

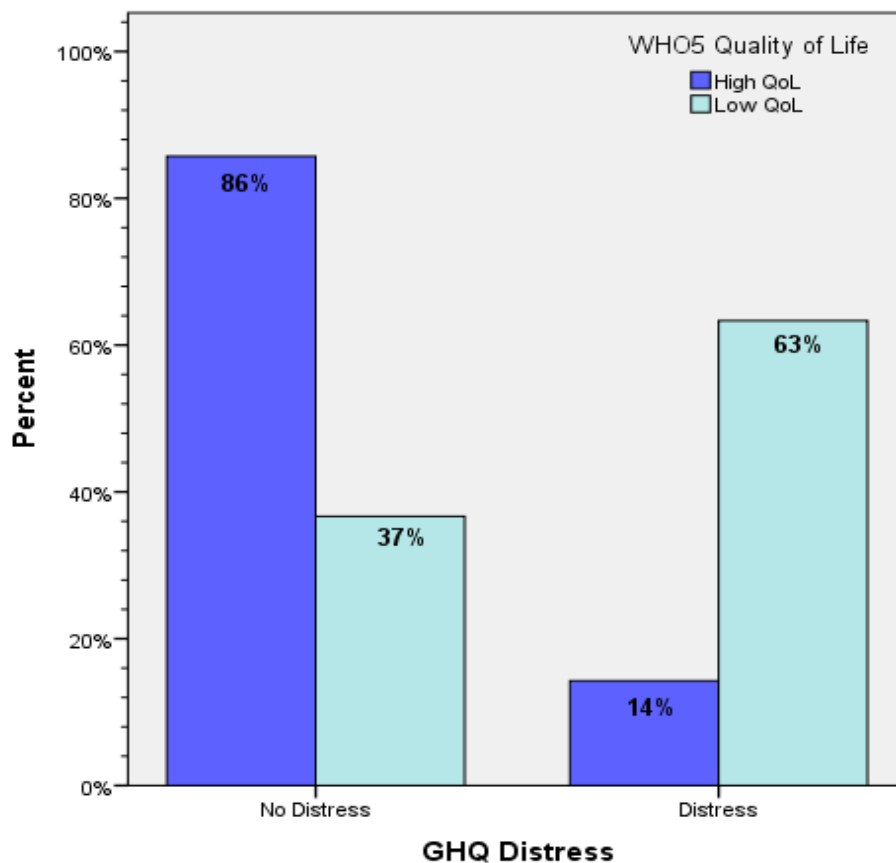


Figure 10: Percentages of GHQ28 Distress and WHO5 Quality of Life

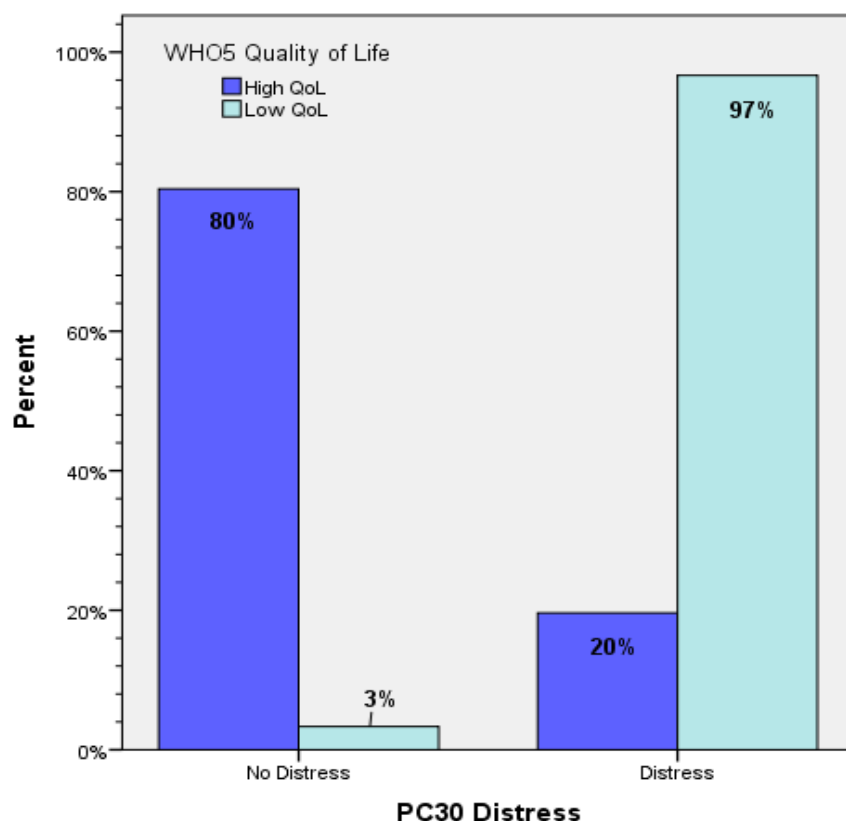


Figure 11: Percentages of PC30 Distress and WHO5 Quality of Life

### ***Distress and Acculturation***

Spearman's rho correlations were carried out to explore associations between acculturation and distress scores. These were further explored using Mann Whitney U tests to compare mean SAQA scores according to whether or not participants were above or below the distress or quality of life thresholds. Table 13 displays the mean scores on the different scales of the SAQA according to whether or not participants were above or below the thresholds for distress or low quality of life. Significant correlations are identified in Table 14.

Table 13: Mean SAQA Scores by Distress and Quality of Life

Distress & Quality of Life Measures	SAQA								
	Scale 1 – Behaviours			Scale 2 – Attitudes			Scale 3 – Country of Origin		
	<i>n</i>	Mean	(SD)	<i>n</i>	Mean	(SD)	<i>n</i>	Mean	(SD)
<i>GHQ28</i>									
Distress	27	13.0	(4.16)	23	5.17	(2.08)	26	7.54	(3.70)
No Distress	53	14.74	(3.12)	51	5.78	(2.04)	53	6.34	(3.16)
<i>PC30</i>									
Distress	40	13.61	(3.35)	37	4.73	(2.05)	39	7.33	(3.46)
No Distress	43	14.37	(3.90)	40	6.38	(2.08)	42	6.36	(3.11)
<i>WHO5</i>									
Low Quality of Life	37	13.92	(2.88)	34	5.00	(2.07)	34	6.50	(3.01)
High Quality of Life	59	14.08	(3.68)	52	6.17	(2.14)	58	6.98	(3.26)



There was a significant negative correlation between the GHQ28 and Scale 1 and Scale 2 of the SAQA. Closer inspection of the 95% confidence interval for the association between Scale 1 and the GHQ28, however, indicates that it may be a Type I error. Nonetheless, those below the threshold for distress, indicating no distress on the GHQ28, scored significantly higher on Scale 1 (Mann Whitney  $U=508.00$ ,  $z=-2.14$ ,  $p=.033$ ,  $r=-.24$ ), although this was a small effect.

The PC30 was significantly negatively correlated with Scales 1 and 2 and positively correlated with Scale 3 of the SAQA. Significant differences were found in the means of both Scale 1 (Mann Whitney  $U=646.50$ ,  $z=-1.97$ ,  $p=.048$ ,  $r=-.22$ ) and Scale 2 (Mann Whitney  $U=399.50$ ,  $z=-3.53$ ,  $p<.001$ ,  $r=-.40$ ) for the presence or absence of distress on the PC30.

Only Scale 2 of the SAQA was significantly positively correlated with quality of life on the WHO5. This finding was corroborated when comparing the means of those reporting a high quality of life, with those reporting a low quality of life (Mann Whitney  $U=575.50$ ,  $z=-2.78$ ,  $p=.006$ ,  $r=-.30$ ).

Table 14: Correlations between Acculturation, Distress and Quality of Life

SAQA	Distress & Quality of Life Measures								
	PC30			GHQ28			WHO5		
	$r_s$	$p$	95% CI	$r_s$	$p$	95% CI	$r_s$	$p$	95% CI
Scale 1 – Behaviours	-.296	.018	-.52, -.03	-.256	.042	-.49, .01			
Scale 2 – Attitudes	-.395	.001	-.61, -.12	-.288	.021	-.51, -.01	.320	.010	.09, .50
Scale 3 –Country of Origin	.268	.032	.02, .47						

## Objective 6: Factors Associated with Seeking Help

### Prediction Model on the Basis of Distress Cut-Off Scores

Although the measures provide linear scores of distress, use of cut-off scores, in practice have more clinical utility as screening measures for distress in busy primary care services. For this reason, a prediction model was built using dichotomous classification of the distress measures and evaluated using logistic regression.

A prediction model was built up in steps, using the distress and quality of life measures as dichotomous variables, either above or below their established thresholds for distress or low quality of life. In Step 1, the GHQ28, PC30 and WHO5 were all entered into the model. The PC30 was found to be the only predictor that remained highly associated with the outcome of seeking help from services. Those above the threshold for distress on the PC30 were four times as likely to have sought help from services (see Table 15). The WHO5 and the GHQ28 did not contribute reliably to the model (see Table 10, page 61, for contingency table).

The scales of the acculturation measures were entered into the model, however, none emerged as contributing significantly to the model and only the PC30 distress remained associated with seeking help from services.

When socio-demographic variables, including employment, education, religion, immigration status and age were put into the model, none increased the model fit. The only exception was gender. Although gender as a single variable is not predictive of seeking help from services, in Step 2, when added into the prediction model, it emerged as a reliable predictor of seeking help from services when combined with distress as measured by the PC30.

When added into the model at Step 3, experiencing physical health problems was found to also contribute to the predictive model of seeking help from services. See Table 15 for the three step prediction model of help-seeking.

It is important to acknowledge the effects of multicollinearity in these prediction models. The factors found to be associated with distress are not completely independent of each other, thus influencing their differentiating impact on seeking help from services.

Table 15: Logistic Regression. Factors associated with Seeking Help from Services

IV	Step 1 (Nagelkerke R <sup>2</sup> =0.06)				Step 2 (Nagelkerke R <sup>2</sup> =0.24)				Step 3 (Nagelkerke R <sup>2</sup> =0.28)			
	B	Wald	OR	95% CI	B	Wald	OR	95% CI	B	Wald	OR	95% CI
PC30 (Distress/No distress)	1.43	7.84**	4.17	1.54 – 11.31	1.49	8.81**	4.42	1.66 – 11.78	1.49	8.81**	4.42	1.66 – 11.78
Gender					1.09	4.32*	2.98	1.06 - 8.36	1.09	3.98*	2.98	1.02 – 8.69
Physical Health Problem									1.18	3.96*	3.27	1.02 – 10.50

\*\* p<0.01, \*p<0.05, DV = Sought Help from Services (yes/no), OR= Odds Ratio

## Summary

The main findings of the results of this study are summarised as follows:

- One third of the sample was above the threshold for distress on the GHQ28 and half of the sample was above the threshold for distress on the PC30. Two fifths scored in the range suggestive of a low quality of life.
- There were no significant differences in the distribution of distress according to the socio-demographic characteristics of this sample, with the exception of those who were unemployed reporting greater distress.
- Distress and quality of life were significantly associated with fears of discrimination.
- Almost half of the sample had sought help for their emotional problems in the past. Of those, two thirds sought help from an NHS service and three quarters approached their GP.
- There was a converse relationship between distress and acculturation in this sample; those scoring higher on behaviours and attitudes indicative of acculturation were experiencing lower levels of distress and had a higher quality of life.
- In this sample, seeking help from services is predicted by experiencing distress, being female and having a physical health problem.

## DISCUSSION

### Implications of the Findings

#### **Objective 1: Socio-demographic profile of the sample**

##### ***Education, Employment and Socioeconomic Status***

The socio-demographic profile of the sample indicated that a relatively young, highly educated and high socio-economic status sample was recruited to the study. The vast majority of the participants in this study were able to read and write in English, with only six questionnaires completed in Bengali. By virtue of taking part in this study, there was 100% literacy in the sample recruited. It is also interesting to note that there were no significant differences in the level of education or employment status according to gender in this sample. These findings suggest that the sample recruited is unlikely to be representative of the South Asian population living in the UK as a whole.

This research study attracted participants who, for the majority, by virtue of their education, socio-economic status and employment status, were less likely, to experience marginalisation and discrimination. Social class can be used in a way to capture issues of power associated with being labelled or perceived as being part of a social class (Spence, 2012). Nonetheless, as will be discussed further in the section pertaining to Objective 2, the sample reported high levels of psychological distress, a high proportion of whom had not sought help for their problems.

##### ***Health***

It was interesting to note the way participants reported their health status. When presented with a 'yes' or 'no' question about physical and mental health, there were very low rates of mental health but high levels of physical health problems, many of which related to pain or medically unexplained symptoms, such as irritable bowel syndrome or palpitations. Pain is associated with increased psychological distress (Njobvu, Hunt, Pope & Macfarlane, 1999) and some of the physical symptoms participants described have been argued to have psychological aetiology (Duddu, Husain & Dickens, 2008). Only 9% of the sample reported that they had a mental health problem, a significantly lower proportion than the national prevalence estimate of approximately 25% (Singleton et al., 2001) and the 33% - 50% of the recruited sample who reported experiencing distress.

There is a great stigma surrounding mental health problems within the South Asian population (Wynaden, Chapman & Orb et al., 2005; Loya, Reddy & Hinshaw, 2101; Shidhaye & Kermode, 2013). This may influence individuals' willingness to report mental health problems. In addition, when people consider what a 'mental health' problem is, they may conceptualise this as severe

mental health problems, such as psychosis. Many people who experience anxiety or depression, or distress more generally, would not consider themselves to be experiencing a mental health problem but perhaps more a socio-moral problem (Kirmayer, 2001<sup>b</sup>). This is important to hold in mind, as this is likely to have an impact on how people seek help, whether or not people know there is help available for less severe types of distress, how materials and information about services might be presented and the types of services that people would seek help from. For example, given the stigma around mental health, people might be more inclined to attend 'wellbeing' services, rather than mental health services.

### ***Acculturation***

Although there was a range of levels of acculturation as measured by the SAQA in this sample, by virtue of being able to participate in this study, participants were more likely to have higher levels of acculturation than some members of the community who were not reached in the recruitment for this study.

The majority of the sample was not born in the UK, however, the majority of those born outside the UK moved to the UK when they were in their teens. India, Pakistan and Bangladesh are in the top ten countries (first, third and sixth, respectively) where those resident but born outside of the UK were born (Office for National Statistics, 2011). The 2011 Census did not explore the immigration status of respondents, but it did explore the national identity of the UK population. In this study, the vast majority of participants had UK or EEA national status.

The data from this study identified that those born in the UK and who had UK/EEA national status achieved scores indicative of greater acculturation than those born outside of the UK or who did not have UK/EEA national immigration status, which would be expected. Furthermore, the data identified a considerable mean difference in acculturation scores according to socio-economic status and suggest there may be a relationship between being employed and having higher levels of education and being more acculturated to British society.

Clearly, the process by which a person becomes acculturated to a society is multi-faceted and complex. Theoretically the concept of acculturation is affected by individual, environmental and social characteristics (Lopez-Class, Castro & Ramirez, 2011; Salant & Lauderdale, 2009) as are employment, education and socioeconomic status. The data from this study do not allow for inferences about cause and effect to be made in relation to employment, education and social class and their relationship to acculturation. It may be that people are less acculturated because they are unemployed, from a lower class or uneducated, or conversely, they are unemployed, uneducated and have less social mobility because they have not acculturated to the dominant society in which they live.

Being unemployed, with low levels of education and lower socioeconomic status can reduce the exposure to and/or the opportunity to interact with others from outside one's immediate

community, or vice versa. In addition, those who are unemployed, have lower educational attainment and who are from a lower social class are more likely to experience discrimination and marginalisation, have poorer mental health outcomes and to feel disempowered (NIMHE, 2003; Paul & Moser, 2009; Williams, Yu & Jackson, 1997). It could be argued that this justifies and supports the need to provide more support to people within the community and support to learn English, which may empower them to gain employment and education and become more acculturated to British society, therefore reducing the negative impact of marginalisation and discrimination.

It is important to acknowledge the current and historical discourses within British media about immigration, social welfare and employment (Artaco, Benach, Borrell, & Cortès, 2004; Bhui et al., 2003). The process of 'othering' can reinforce perceptions of British society being dominant and those from other minority communities being subordinate (Johnson et al., 2004; Saeed, 2007). These discourses can feed racism and discrimination, which significantly hinder an individual's capacity to change their personal circumstances, or their sense of affiliation to the dominant society in which the discourses abound (Saeed, 2007). This study's findings of the association between acculturation and levels of distress should to be understood within this broader context.

Scale 2 of the SAQA has important items within the scale, but ones which may not necessarily be 'attitudes' indicative of greater acculturation. For example, the question 'do you fear racist attacks?', could be argued to be less an attitude than an experience of either perceived or actual racism. There are many factors that may influence a person's perception of racism, including the socio-demographic characteristics of their local and national environment, their religion and their current socio-geo-political contexts (Laird, Amer, Barnett & Barnes, 2007). There has been a reported rise in racism towards South Asian people and Islamophobia in the aftermath of the 9/11 terrorist attacks on New York in 2001 and the subsequent 'War on Terror' that has been waged (Abbas, 2004; Saeed, 2011). This is a very real and lived experience for many South Asian people living in the UK today, and may not be appropriately categorised as an 'attitude' of an individual. The implications for future research and further validation of the SAQA, will be discussed further in the 'Recommendations' section of this chapter.

## **Objective 2: Prevalence of distress**

As described in the 'Results' chapter, the prevalence of distress in the sample recruited to the study ranged from 33% on the GHQ28 and 49% on the PC30. Two fifths of the participants reported a low quality of life on the WHO5. There are many different estimates of the prevalence of mental health problems in the general UK population. Kendrick & Pilling (2012) estimated the prevalence of 'common mental health disorders' in the community at 15%. Common mental health disorders were described as anxiety or depression. The Mental Health Foundation reports that at least one in four British adults will experience a minimum of one

diagnosable mental health problem in any one year (Halliwell, Main & Richardson, 2007). They base their report on the findings of the Office of National Statistics' 2000 Psychiatric Morbidity study in the UK (Singleton, Bumpstead, O'Brien, Lee & Meltzer, 2001).

Reporting on prevalence in the UK is always challenging as both Singleton et al. (2001) and Halliwell, Main & Richardson (2007) acknowledge, due to the differences in measurement, indicators and reporting methods used. Burr & Chapman (2004) commented that varying estimations of the prevalence of mental disorders among people of south Asian origin may be due to the measures and/or diagnostic frameworks selected. It is important to note that in the present study, the aim was to measure self-reported 'distress' rather than specific diagnosable mental disorders as prevalence studies often set out to.

Notwithstanding, the prevalence of distress in this sample is comparatively high and there may be a number of explanations for this finding. Although the GHQ28 has been found to be related to common mental health diagnoses (Goldberg & Hillier, 1979; Goldberg et al. 1997), it is not a diagnostic measure, but a screening measure aimed at identifying those who *may* have a diagnosable mental health problem through more in depth assessment. Williams et al. (1997) found that the GHQ-12 may under-estimate distress in the South Asian population. The PC30 was developed specifically to identify 'distress' more generally, including distress arising from social and environmental circumstances, as opposed to solely emotional or psychological difficulties (Mason, 2003).

The studies that identified the current prevalence rates of 15% (Kendrick & Pilling, 2012) and 25% (Singleton et al. 2001), did so using structured clinical interviews administered by clinicians to identify and diagnose mental disorders. With this in mind, it would be expected that using the measures selected for this study a higher prevalence of general 'distress' would be identified. In this study, the lower scoring threshold for the GHQ28 subscales was selected, due to reported higher sensitivity (Goldberg & Hillier, 1979). However, Bhui, Bhugra & Goldberg (2000) found that the threshold for identifying distress on the GHQ-12 was higher among the Punjabi participants in their study than the White British participants. This could potentially be an explanatory factor for the very high prevalence rate of distress in the sample.

Comparison groups of people from other ethnic backgrounds were not recruited to this study, therefore it is not possible to consider whether there are ethnic differences in the prevalence of psychological distress in this study. However, previous research comparing Punjabi and English GP attenders identified no difference between the groups in the prevalence of anxiety or depression or somatic symptoms (Bhui, Bhugra, Goldberg, Dunn & Desai, 2001)

Validation of the PC30 remains in the early stages, and further validation and confirmation of appropriate cut-off scores is required. Exploration of the sensitivity and specificity of the PC30 are not within the scope and remit of this thesis but are the subject of planned further analysis,



pooling the data from this study with that of Mason (2003). This, along with assessment of the validity of the other measures used, will be discussed further in the 'Recommendations' section of this chapter.

Another contributory factor for the high prevalence rate may be the effects of an inherent self-selection bias in who would have chosen to complete a study that asked questions about psychological distress. Previous research has found that people are more likely to self-select to take part in a survey if they consider themselves to have some affiliation with the subject matter (Sibbald, Addington-Hall, Brenneman, & Freeling, 1994). Attempts were made to control for this, by ensuring the information sheet clearly stated that the survey, although about distress, was for anyone to complete. Nonetheless, self-selection bias is likely to have had some influence on the prevalence rate in this sample. It is also important to acknowledge that the socio-demographic profile of the sample suggests that it is unlikely to be representative of the South Asian population as a whole.

The three questions in Scale 2 of the SAQA - Feeling Future is Secure, Fear of Racist Attacks and Fears of Discrimination were considered to have clinical significance of their own accord in the interpretation and understanding of distress within the sample. Contrary to what may have been expected, fear of racist attacks was not associated with distress or a lower quality of life in this sample. However, it is important to consider the generalizability of this data, given the location of the study and the potential influence of an 'ethnic density effect' (Bécares, Nazroo & Stafford, 2009; Das-Munshi et al. 2010; Feng, Astell-Burt & Kolt, 2013). Luton and the London Borough of Tower Hamlets, where the GP participants were recruited, have large communities of South Asian people. In addition, the majority of the online community groups were based within London, which has a large South Asian population and the highest proportion of people from ethnic minorities in the UK. Therefore, those who took part in the survey may have been more protected from experiences of racism or those who had experienced it may not have had as acute an impact on their mental health, compared with those in other areas of the country who may have less protection from being part of a larger collective community.

Interestingly, those who feared discrimination in applying for jobs and felt that their future was not secure had significantly higher levels of distress and lower quality of life, on all measures. However, the wording of the question 'do you see your future as secure?' was ambiguous and its validity in the 'attitudes' scale of acculturation should be considered. Negative responses to this question contributed to a lower score of attitudes indicative of acculturation. Given the national context of austerity, however, concerns about the security of one's future is relevant to many people across all communities and ethnicities in the UK at present. It is likely that insecurity is more acutely felt by some communities than others, such as those from lower socioeconomic groups. Nonetheless, the reliability of this question in acculturation, phrased as it

is, should be examined. However, as a general concept, feeling secure about one's future is clearly inversely associated with experiences of distress and quality of life.

Previous research has indicated variations in experiences of mental health problems and distress according to age, gender and immigration status. However, these differences were not observed in this sample. This may be due to a relatively small sample size and the fact that the measurement of distress in the sample was not attuned to collect data on subtle nuances in demographic differences in distress. The only socio-demographic factor that was found to have significant variance in the level of distress was employment. Those who were unemployed had significantly higher levels of distress than those who were not. As previously stated, this finding supported the findings of existing research that has highlighted poorer mental health outcomes for those who are unemployed (Artacoz et al., 2004; Bhui et al., 2003). The results from this study cannot provide any information on cause or effect. It may be that those who have greater levels of distress are less likely to seek out employment, or, conversely, those who are unable to gain employment may then experience greater distress as a consequence.

The number of people who reported having a mental health problem in the questions about health status, was clearly disproportionate to the high levels of distress in the sample. This suggests that the term 'mental health' does not accurately capture the full range of problems that people experience. In terms of clinical practice, it is important to consider the language used by clinicians and services when discussing individuals' needs and preferences. Referring to mental health, at least at the early stages of engaging with a person, could in itself act as a barrier to people seeking help from, attending and/or engaging with services.

### **Objective 3: Help-Seeking Behaviour**

With a high prevalence of distress in the sample of participants, it may be anticipated that there would also be a high proportion who have sought help from services, or that those experiencing distress would be more likely to seek help from services. As expected, those who were experiencing distress, as measured by the PC30 and those reporting a lower quality of life, measured by the WHO5, were significantly more likely to have sought help for their problems. Interestingly, there was no statistically significant difference on the GHQ28 in help-seeking, regardless of the level of distress. Whilst it is encouraging that a higher proportion of those experiencing distress are likely to have sought help for their problems, a clinically significant minority of at least a third had not. This finding is consistent with previous research both in the general population in a predominantly white British region of Somerset (Oliver, Pearson, Coe & Gunnell, 2005) and among an ethnically diverse area of Birmingham (Commander, et al. 1997<sup>a</sup>), which suggests that this is not necessarily a problem specific to the South Asian population. The predominantly high level of education and higher socioeconomic status of this sample, may have meant they felt more enabled or empowered to seek help if they wanted to, than perhaps those who are more marginalised might. However, in the EMPIRIC study, four in

five (roughly 80%) of those who had a CIS-R score indicative of a possible mental health problem, had seen a doctor within the last 6 months (Sporston & Nazroo, 2002), which is higher than the proportion found in this study.

It is important not to make the assumption that access to NHS health services, as they are currently provided, would be beneficial for everyone. Perhaps services are not accessed as widely, because they do not fit with different conceptualisations of the causes and ways of managing mental health problems. In many parts of the world including South Asian countries, people having experiences that could be described as 'depression' or 'anxiety' do not view their problems as psychiatric and therefore are likely to reject psychological interventions that are based in culturally unfamiliar or discordant terms (Kirmayer, 2001<sup>b</sup>). Furthermore, Western or biological model approaches to service provision for psychological distress may be inappropriate or undesirable for people who may experience or make sense of their distress in psychosocial terms (Neale, Worrell & Randhawa, 2009; NSUN, 2014; Chowdhury, 2012).

For the majority of people who reported having sought help, the NHS was identified as a source of help for emotional problems. However, there was a significant proportion of people who reported having not sought help at all. Furthermore, there may be many people who recognise that they are experiencing distress and speak to their religious leaders, community leaders, friends, family or other sources of support, but do not consider this seeking help for their emotional problems. Many of the participants who sought help from NHS services, also sought help from other sources. Nonetheless, that the NHS is recognised as a provider of help for emotional problems among the majority of people who have sought help is significant and encouraging. This may provide an opportunity for consultation with experts by experience about how to widen the reach of the NHS to people who may need support but may not initiate contact or requests for support (Neale, Worrell & Randhawa, 2009; NSUN, 2014).

Findings of previous research that people of South Asian origin tend to seek help from non-health agencies or use self-help through prayer (Dein & Sembhi, 2001), were not replicated in this study. This may be due to unrepresentative sampling, or that those who reside in the UK are more likely to recognise the health services as sources help. Furthermore, health services are more accessible geographically in the UK than they are in rural areas of South Asian countries, where there may not be any health services for people to readily access, thus requiring them to find other means of help (Chowdhury, 2012).

#### **Objective 4: Experiences of Services**

The very low response rate to the questions about experiences of services for those who had used them has placed significant limitations on the capacity to draw any conclusions from this data. Many mental health services regularly use questionnaires for clients to evaluate their experience of the service they have received. It may be beneficial for services to give all

service users these brief questionnaires, in their language to be returned anonymously, following consultations with practitioners. This may gather a more routine and up to date litmus test of how different service users are experiencing the services they receive.

In all the questions relating to experiences of services, there were notable gender differences. Women were more likely to feel understood when they sought help than men. A higher proportion of men than women responded with 'don't know' to questions about their experiences of services. Given that very few people, male or female, provided a further qualitative response to explain their answer, it is not possible to ascertain what they were uncertain of or if this was a reflection of ambiguity and a lack of clarity in the phrasing of the question.

It is interesting that there was a discrepancy between the Online/Community group and the GP group in their perceptions of services. Although the trend did not reach statistical significance, a smaller proportion of the GP group responded positively about feeling understood or that the services they were offered were helpful or appropriate, than in the Community/Online group. Over a quarter of participants found the services they had used to have been unhelpful. Although a minority, this is still a significant proportion of people. Many further could not say either way if they had found the services helpful or not.

Those who were above the GHQ28 threshold for distress, were more likely to report that they had not felt understood than those who were below the threshold. It would seem that the GP was the first port of call for many of the participants and some were responding in relation to their experience of using GP services. Of the few qualitative responses that were provided, cultural appropriateness was mentioned by three participants but in different ways. This included one participant identifying concerns about confidentiality, due to their GP also being 'Asian' and therefore knowing their family and the community.

There were varying levels of satisfaction with the services that people had received, although of those who actively responded either positively or negatively, as opposed to neutral, a higher proportion were satisfied with the services that they had received.

One study comparing Punjabi and English GP attenders in London, found that English people seeking help for mental health problems were more likely to have their problems correctly identified by their GP than their Punjabi counterparts. The Punjabi GP attenders were more likely to be considered to have 'sub-clinical' problems or 'physical and somatic' symptoms (Bhui et al. 2001). Although this study was not carried out to assess the recognition of common mental disorders by GPs, the findings of Bhui et al. (2011) may provide some explanation for those who felt unsure if their problems were understood or who felt dissatisfied with the services they received. While the previous section noted that the majority recognised the NHS as a source of help, Bhui et al. (2001) have highlighted that individual needs of South Asian service

users not being recognised by clinicians remains a potential further barrier to accessing services.

Participants had difficulty identifying whether there were services that they would have wanted, if they felt they were offered what they were needed or if there were other services available that they might have needed but were not offered. There may be a reflection on the way in which the questions were phrased in the questionnaire and the positioning of these questions in the survey (discussed further in limitations) but it is important to consider that self-identification for the types of services that people want may not be easy or possible. To some extent, this question assumes that participants have some awareness of the types of services that are available. The number of people who said they did not know, suggests that there may be a general lack of awareness of different service types that people might access.

## **Objective 5: Associations between distress, acculturation and quality of life.**

### ***Distress and Acculturation***

Higher scores on both the PC30 and GHQ28 were significantly associated with lower acculturation scores on the SAQA. Higher acculturation scores on Scale 2 of the SAQA were also associated with higher scores for quality of life on the WHO5.

There remains a continuing paradox in the literature about acculturation and its relationship to mental health. Research has found acculturation to be both associated with improvements and deterioration in mental health (Rudmin, 2009). Hunt, Schneider & Comer (2004) explored the conceptualisation of acculturation in literature about the minority Hispanic population in the USA. Although their focus was on a different population, their conclusions about the study of acculturation remain relevant to this thesis. They found that reference in the literature to acculturation separated 'culture' from the wider social, environmental and economic challenges associated with immigration, poverty and limited second language skills. They also noted that debate around acculturation in health literature appeared to focus on the psychometric properties of measurement, as opposed to what the actual construct is that researchers are attempting to measure. Rudmin (2009) argued for the study of acculturation to be studied independently of health issues, which can confound the understanding of both constructs. He also argued that socioeconomic status and discrimination should be controlled in the study of acculturation.

There have been a range of findings from previous research, some of which have associated greater acculturation with poorer mental health outcomes, while others support the findings of this research (Salant & Lauderdale, 2003). Strong ethnic identity and lower levels of acculturation, have been found to be predictive of lower levels of psychological distress in another study (Burnett-Zeigler et al. 2013), although this was not carried out with South Asian people in a UK context. An explanation for the inconsistency in the literature about mental

health outcomes and their relationship to acculturation is the wide range of disparities in the measurement of acculturation and in the heterogeneity of the ethnic groups under study and the contexts in which they reside (Rogler, Cortes & Malgady, 1991; Lopez-Class, Castro & Ramirez, 2011). The resulting ambiguity, confusion and lack of clarity in the emerging research as a result have contributed to a sense of incoherence in the literature and directions of research (Hunt, Schneider & Comer, 2004).

Where acculturation has been associated with good mental health outcomes, an important factor appears to be marginalisation. Bhui et al. (2005) found in a study of mental health among adolescents in East London, that those who made culturally integrated friendship choices had lower levels of mental health problems than their counterparts who were more marginalised, who chose friends from neither their own or another culture. The concept of marginalisation being more associated with poor mental health outcomes is supported by the findings within this study that those who were unemployed had scores indicative of less acculturation and had higher scores for distress. Unemployment is associated with greater social isolation more generally and poorer mental health outcomes (Artacoz et al., 2004; Bhui et al., 2003). Some have argued that the underlying factor, however, is poverty (Gaille, Paugam & Jacobs, 2010). In a South Asian community, this may further compound issues of integrating into British culture or becoming more acculturated and thus render individuals as more marginalised. There is, however, an assumption within this argument that minority ethnic individuals have better mental health outcomes when they are acculturated to the dominant culture. This is flawed because it implies that this is the desired outcome, when for some it may not be. Again, it therefore seems important to establish the extent to which a person feels integrated into any culture, that they do not feel marginalised and within that have a sense of belonging.

The associated socio-demographic factors, as previously discussed, suggest the SAQA may be an over-simplified construct of acculturation as opposed to a more dimensional construct of acculturation, confusing confounding variables, such as discrimination, as contributory factors. It has been argued that applying a quantitative and positivistic approach to the phenomenon of acculturation is overly deterministic and simplifies a complex and multi-faceted process (Chirkov, 2009). It is argued by some that acculturation studies do not have an adequate grasp of culture within them (Triandis, 1997). The findings of this study support findings of previous research that greater acculturation is associated with lower distress, however, the mechanism by which this association is found and the development of the construct of acculturation as measured by the SAQA requires further research.

### ***Distress and Quality of Life***

The findings identified a difference in the reporting of a low quality of life and experiencing distress according depending on whether it was measured by the GHQ28 or the PC30. Almost

all (97%) of those who reported a low quality of life on the WHO5 were above the threshold for distress on the PC30.

While there are implications for assessing the specificity of the PC30 in further research, there is an implication that the PC30 may capture a concept of distress that lies between the GHQ28, which is focussed on psychological distress symptoms, and the WHO5 which is focussed on satisfaction with daily life. The PC30 was developed to capture more than just mental health distress, but social and familial distress also (Mason, 2003), so this finding is in line with what would be expected.

### **Objective 6: Factors associated with seeking help**

PC30 emerged as more predictive of help-seeking than the GHQ28 or the WHO5; however without a comparison group and a larger scale study, it is not possible to draw conclusions from this. This may be an indication that either PC30 could be more predictive of help-seeking behaviour in general or that it may be more sensitive to South Asian cultural understandings of distress. The answer to this question would lie in further research.

The findings of this study found that being a female with a physical health problem who is experiencing distress is the most significant predictor of seeking help from services. This is interesting when considering the findings of the EMPIRIC study, where South Asian women were the most likely to have consulted to a doctor in the last six months reporting a physical health problem, but the least likely to report emotional or stress-related problems (Sproston & Nazroo, 2002). In addition, Gilbert, Gilbert & Sanghera's (2004) found that shame among South Asian women was reported as one of the main barriers to seeking help for mental health problems. This stigma can be both within an individual's perception and in the wider society (Mojtabai, 2010). Stigma towards mental health problems was not explored in this study, but would be an important area for further research.

In light of these findings, one hypothesis may be that by seeking help through reporting of physical health problems, South Asian women may feel (consciously or subconsciously) that they are legitimising their help-seeking behaviour, whilst avoiding associated shame and stigma for mental health problems. The exploration of this hypothesis extends beyond the data from this sample, but is certainly a direction for further research.

An important factor that may have an impact on seeking help from services could be language and communication. Unfortunately, due to very few participants completing questionnaires in a non-English language, the impact of language on help-seeking could not be explored further in this study.

As discussed in the 'Results' chapter, the factors within the regression model predicting seeking help from services, cannot be considered to be entirely independent of each other.

Consequently, the power of their effects on seeking help from services was lost when added into the same model, due to the effects of multicollinearity.

## Limitations

The research support infrastructure in the NHS changed in April 2014 and this impacted on the process of gaining site-specific approval for the research to commence in the GP sites. In moving from Primary Care Trusts to Clinical Commissioning Groups, the landscape of primary care research was changed and resulted in a lack of standardisation from region to region. The consequence for this research was that significant delays in identifying the appropriate process and gaining local approval meant that a much smaller sample was recruited from GP surgeries. GP surgeries are likely to have had a more representative population than unsolicited online networks, and therefore the generalizability of this study was compromised.

This was a predominantly young sample with the vast majority UK or EEA national immigration status. The people in this sample had a disproportionately high level of education, fluency in English and were in predominantly in positions of employment that placed them within higher categories of socioeconomic status. This is likely to have significantly reduced the role of discrimination and marginalisation within this sample, which are known barriers to access general health services and mental health services more specifically. For these reasons, generalisations to the wider South Asian population in England must be made with caution.

Existing research identifies the importance of language and idioms of distress as factors that may influence access to health services (Sentell, Shumway & Snowden, 2007). However, it is clear from the sample that it would not have been possible to explore the impact of language, as all but six of the questionnaires were completed in English, despite other language versions being available. Problems with literacy remain a significant barrier not only to accessing health services but also to involvement in research aimed at exploring access to services. Although there are likely to be some first generation South Asian people living in the UK who are not literate, this number will be comparatively small. What is likely to present a larger barrier, however, is proficiency in English language (Sentell, Shumway & Snowden, 2007). Ability to communicate and articulate one's needs are particularly important in access to and experience of health services. Having difficulty in communicating one's needs, for whatever reason (including language proficiency, speech and language impairment, learning disability or neurodegenerative disease), hinders an individual's ability to advocate for themselves, which in turn may be associated with disempowerment, discrimination, marginalisation and social isolation. All of these are known associated risk factors for poor mental health outcomes (Bécares, Nazroo & Stafford, 2009; Greene, Way & Pahl, 2006; Williams, Neighbors & Jackson, 2002).



There is an inherent selection bias in recruiting participants for this study from a GP surgery. Those who were attending the surgery, by virtue of being there, are accessing a service. While many of those who attended the surgery may not have been there to seek help for psychological distress, those who consented to take part are more likely to have had some affiliation with the subject matter (Sibbald et al., 1994). This response bias also is likely to have applied to the unsolicited online survey.

It was initially proposed that GP surgery receptionists would distribute the questionnaires to all patients whom they believed to be of South Asian origin at the point of registration for their appointment. Practice managers at the GP surgeries agreed to this, however, subsequently, receptionists did not distribute any questionnaires. Instead, questionnaires were only distributed when research assistants attended the practice and gave them to participants. Neither the researcher nor research assistants were of South Asian origin, nor were able to speak any South Asian languages. Therefore, this may have resulted in a bias in terms of who was approached and who agreed to take part in the questionnaire. Those who did not understand English may have been less inclined to complete a questionnaire due to feeling less able or inclined to ask more about it. Relying on the presence of the researcher or research assistants therefore also meant it was not possible, due to constraints of time, to gather a larger sample from the GP surgeries.

A significant limitation of this study is that comparison groups were not used, for example White British or Black British sample. This would have provided an opportunity to assess whether the effects established in this study were due to differences within ethnicities, or the socio-demographic profile of different ethnic groups. It would not have been feasible for the scale and the timeframe for this research to recruit a comparison sample. However, this certainly provides an interesting consideration for future research.

Although there were clear justifications for defining the group 'South Asian' as the sample that was to be recruited to this study, it should be considered whether or not the term 'South Asian' is, in fact, appropriate at all for health research (Lloyd, 2006). As already described, there is such a wide range of ethnic and cultural identities encapsulated within the term 'South Asian' that it may be too broad, vague and heterogeneous to draw any accurate or specific conclusions from with a relatively small sample. Certainly some researchers have identified this as a concern for grouping wide ethnic groups into one study. For example, Bhui et al. (2004), decided to recruit a sample of Punjabi participants compared with White English, in light of inconsistent findings about the prevalence of depression in a South Asian population. The authors cited that Punjabis tend to retain a Punjabi identity, regardless of religious difference or citizenship of India or Pakistan. Within-group variations might be an interesting direction for research, but would require resources for a large-scale, funded multi-site study. It must be acknowledged that research in this field will always be complex due to the heterogeneity of the

ethnicities, cultures, religions and identities captured within the term 'South Asian' (Durà-Vilà & Hodes, 2012).

### **Structure and Content of Questionnaire**

The wording of the questions relating to access to services and use of services may have led some participants to answer erroneously to the questions. Although no concerns were highlighted during the piloting of the questionnaire, some response patterns suggested there may have been a misunderstanding of the questions. Furthermore, due to the length of the questionnaire, it is likely that many people were unable to sustain motivation or concentration to complete the written questions. It is clear that qualitative data would have enriched the findings of this study and had this met the challenges of feasibility required for a project of this limited scale, then further conclusions could perhaps have been drawn from the data.

Although the length of time in the UK and whether or not participants were born or migrated to the UK was established in the survey, there was no information to ascertain if they were second, third or fourth generation. It would have been interesting to explore to what extent, if any, the generation of living in the UK influenced their acculturation, help-seeking behaviour, and experiences and perceptions of the health services they had received.

Some of the questions of the PC30 and the GHQ28 will have asked very similar questions, which may have compromised the face validity of the questionnaire. Participants may have felt frustrated with having to answer what could have felt like duplicate questions, in an already long questionnaire. Certainly, several of those who did not complete the whole questionnaire stopped after either the first (WHO5) or second (PC30) distress measure.

Similarly, having the qualitative questions at the end of a long questionnaire may have deterred people from completing them, having already spent several minutes on the first section of the questionnaire. Those completing the questionnaire in GP surgeries, whilst waiting for appointments, may have felt rushed or aware that they would soon be called in for their appointment. On the other hand, careful consideration would need to be given to the placing of qualitative questions. Had they been right at the beginning of the questionnaire, the topic of the questionnaire may not have been as clear and could have been more confusing about what the questions were specifically related to.

### **Selected Measures**

The use of both the PC30 and the GHQ28 in this study may have frustrated the participants completing the questionnaire or had an impact on the face validity. However, there were clear justifications for doing so. This allowed data to be collected that may be pooled with that of previous research (Mason, 2003) to enable further validation of the PC30. In addition, the use

of an internationally established distress measure, alongside a newer measure provides clinical utility and relevance in the reporting of the research findings in the literature.

There has been criticism of the developing quantification of the construct of acculturation and the use of the SAQA in this study is no exception. Studies of acculturation tend to be confirmatory as opposed to exploratory and descriptive, which can close down adequate consideration of all the factors to consider in its study (Chirkov, 2009). This could also be said of the present study, where an empirical approach to understanding the construct of acculturation was selected. It was not the remit of this study to explore and describe the construct of acculturation. Nonetheless, the selection of this measure may have hindered the ability to draw conclusions about the impact of acculturation. This is clearly an area where further exploratory, descriptive ethnographic study would be beneficial.

## Recommendations

### Directions for Future Research

Future research would benefit from employing native-speakers of the languages and of both genders of those taking part in the study. Recruitment of comparison groups from different ethnicities, both minority and majority groups would be helpful in the interpretation of future research. Mixed-methods study to capture qualitative information about people's attitudes towards seeking help from and experiences of services would be beneficial. This would entail a large-scale study across many sites and would in all likelihood need to be a funded study. The extent of the research required extends beyond the scope of a doctoral thesis, but has highlighted necessary directions for future research.

This study highlighted the difficulties in recruiting marginalised and more hidden members of the population into research. This is an essential area for future research, as it is the experiences and perspectives of these people that are less heard and therefore accounted for in the design and delivery of mental health services.

This study highlighted the need for further assessment of appropriate preliminary cut-off scores of the PC30 to be explored. It is proposed that this research is carried out by pooling the data of this study with that of Mason (2003). The cut-off score of 19 yielded a high number of cases experiencing distress, which may suggest the specificity of the PC30 at this cut-off point is low. There was very high internal consistency between the items on the PC30. Future use of the measure may benefit from reverse-scoring some items, to control for acquiescence bias, where participants may have a tendency to either endorse or deny all of the questions.

The GHQ28 was selected for use in this study to gain comparable data to previous research, however, the utility of the subscales within the GHQ28 have not been explored within this study. Prady, Miles & Pickett, et al. (2013) found in little evidence to support the use of the GHQ28

subscales in clinical or epidemiological assessment of ethnically diverse populations of maternal women. This would be a useful area of further research, for which data is available from this study and that of Mason (2003).

Future research would benefit from exploring the role of stigma and izzat or different facets of shame on help-seeking behaviour. This was not covered within the remit of this particular study, but has been found to have a significant impact on attitude towards and help-seeking for mental health problems (Gilbert, Gilbert & Sanghera, 2004).

Cronbach's alpha supported the three factor structure of the SAQA as reported by Palmer et al. (2007). Further research to assess the content and construct validity of the measure would be beneficial. However, in addition to this, in depth, ethnographic and exploratory study of the construct of acculturation is required.

### **Implications for Mental Health Services**

The findings of this study suggest that identifying distress as a more general concept is clinically important in ensuring the wellbeing of the South Asian community. Using psychometric measures as screening tools for psychological distress, whether or not they are culturally specific or developed, are beneficial for identifying potential psychological problems, however, it is essential that in exploring their responses, clients' own understanding of their problems are elicited (Kirmayer, 2001<sup>b</sup>). Use of short, positively worded measures, such as the WHO5, may have clinical utility in busy GP practices. However, the use of a measure developed specifically with the South Asian population, such as the PC30 may also capture more subtle nuances in the cultural idioms of distress.

It is encouraging that a large proportion of people in the sample identified that the NHS is a source of help for emotional or psychological problems. However, previous research has suggested that there is poor recognition of mental health problems among South Asian people when they present to their GP (Bhui, et al., 2003). The implication is that if people are already seeking to access services, then focus should be on ensuring adequate recognition at primary care and increasing the cultural competence of primary care services, as this is likely to be the first interface for most people.

A particular finding of this study was the very small number of people who identified that they had a mental health problem, compared with the high prevalence of distress identified in the sample. It is important, therefore to consider how the very labelling of services might act as a barrier for some people accessing them. For example, if services were more integrated, for example providing physical and mental health care, then this may reduce some of the reluctance about attending a mental health service. Services could be referred to as 'wellbeing centres' for example. In addition, holistic and alternative therapies might be considered, including access to spiritual or religious services or employment of practitioners trained in

Ayurvedic therapies, for example. In addition, multi-agency integration of services, including social services, housing and employment centres may be beneficial, as distress could be due to social circumstances, such as housing or family problems.

Provision of training and mental health awareness to community members, cultural and religious leaders may help to improve access for the significant minority of people identified within this sample who do not seek help when they are experiencing distress. Where people are reluctant to go and seek help directly from mental health professionals, then this might be a means of improving the accessibility of help and support where required.

## CONCLUSION

The cultural context of an individual and their family influences how a problem is defined, understood and subsequently solved (Cauce et al, 2002; Hernandez et al., 2009). At every stage, therefore, it is clear that these will influence whether a person chooses to access services. In a British context, mental health services, by their very definition, are in place to treat problems as 'mental' problems, which are often understood from a medical perspective and therefore the solutions offered are predominantly medication and/or therapy. Considered from the perspective of a hugely diverse set of cultures within British society, it is clear that this is a very narrow framework.

This research identified that there are significant levels of psychological distress within the sample of South Asian people recruited to this study, yet there remains a significant proportion of the population whose perspectives and experiences were not captured by this research. Many of these people are precisely the people whose perspectives and experiences this type of research aims to capture: those who are more likely to be marginalised, disempowered and discriminated against due to their ethnicity, ability to communicate in the English language and exclusion from the workforce. It is therefore possible that there are higher levels of distress experienced in the wider South Asian population.

It is encouraging that the NHS is recognised by an ethnic minority population as a source of help for mental health problems, however, a significant minority of people did not have their needs met. Given that this research has suggested people do actively seek help for their problems in the NHS, the current ethnic inequity in mental health care may be influenced by stereotypes, lack of cultural competence and rigidity in the assessment and understanding of psychological distress across cultures. It is therefore important that when people of South Asian origin approach NHS services for help with psychological distress, that NHS clinicians at every level are equipped to recognise and provide culturally appropriate and effective support to meet the needs of the population they serve.

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## APPENDIX 1: Literature Search Terms

**DATES:** 1970 – present

**SOURCE:** Abstract, Keywords, Title

**DATABASES:** Campbell Collaboration, Cochrane Collaboration, OVID – MEDLINE, OVID – EMBASE, OVID – PsycINFO, Web of Science, PubMed, Scopus

*SEARCH 1: Literature about mental health services for ethnic minority people with mental health problems.*

<b>Services</b>	psycholog* OR primary care OR inpatient OR community OR CMHT OR GP OR general practi* OR support OR counsel* OR psychiatr* OR mental*
<b>Population</b>	South Asian OR Asian OR BME OR ethnic* OR minorit* OR cultur* OR India* OR Pakistan* OR Bengal* OR Gujarat* OR Bangladesh* OR Nepal* OR Punjab* OR Bhutan* OR Sri Lanka* OR Urdu* Mirpur* OR *Sylhet* OR Hindi* OR Hindu* OR Sikh* OR race OR racial*
<b>Condition</b>	distress OR mental health OR mental illness OR schizophr* OR psychos* OR psychology* OR problem* OR depress* OR anxi* OR psychiatr* OR somati*
<b>Type</b>	Review OR meta

*SEARCH 2: Literature about mental health services for ethnic minority people with mental health problems accessing services.*

<b>Services</b>	psycholog* OR primary care OR inpatient OR community OR CMHT OR GP OR general practi* OR support OR counsel* OR psychiatry* OR mental*
<b>Population</b>	South Asian OR Asian OR BME OR ethnic* OR minorit* OR cultur* OR India* OR Pakistan* OR Bengal* OR Gujarat* OR Bangladesh* OR Nepal* OR Punjab* OR Bhutan* OR Sri Lanka* OR Urdu* Mirpur* OR *Sylhet* OR Hindi* OR Hindu* OR Sikh* OR race OR racial*
<b>Condition</b>	distress OR mental health OR mental illness OR schizophr* OR psychos* OR psychology* OR problem* OR depress* OR anxi* OR psychiatr* OR somati*
<b>Access</b>	pathway* OR refer* OR access OR support OR help-seeking
<b>Type</b>	Review OR meta

*SEARCH 3: Literature about prevalence of mental health problems in ethnic minority people in the UK*

<b>Services</b>	psycholog* OR primary care OR inpatient OR community OR CMHT OR GP OR general practi* OR support OR counsel* OR psychiatry* OR mental*
<b>Population</b>	South Asian OR Asian OR BME OR ethnic* OR minorit* OR cultur* OR India* OR Pakistan* OR Bengal* OR Gujrat* OR Bangladesh* OR Nepal* OR Punjab* OR Bhutan* OR Sri Lanka* OR Urdu* Mirpur* OR *Sylhet* OR Hindi* OR Hindu* OR Sikh* OR race OR racial*
<b>Condition</b>	distress OR mental health OR mental illness OR schizophr* OR psychos* OR psychology* OR problem* OR depress* OR anxi* OR psychiatr* OR somati*
<b>Location</b>	England OR Scotland Or Wales OR Northern Ireland OR United Kingdom OR UK OR Britain OR Great Britain OR Brit* OR Engl* OR Scot* OR Welsh
<b>Epidemiology</b>	prevalence OR proportion OR percentage OR incidence
<b>Type</b>	Review OR meta

*SEARCH 4: Literature about prevalence of mental health problems in ethnic minority people in the UK accessing services.*

<b>Services</b>	psycholog* OR primary care OR inpatient OR community OR CMHT OR GP OR general practi* OR support OR counsel* OR psychiatry* OR mental*
<b>Population</b>	South Asian OR Asian OR BME OR ethnic* OR minorit* OR cultur* OR India* OR Pakistan* OR Bengal* OR Gujrat* OR Bangladesh* OR Nepal* OR Punjab* OR Bhutan* OR Sri Lanka* OR Urdu* Mirpur* OR *Sylhet* OR Hindi* OR Hindu* OR Sikh* or OR race OR racial*
<b>Condition</b>	distress OR mental health OR mental illness OR schizophr* OR psychos* OR psychology* OR problem* OR depress* OR anxi* OR psychiatr* OR somati*
<b>Access</b>	pathway* OR refer* OR access OR support OR help-seeking OR service provision
<b>Epidemiology</b>	prevalence OR proportion OR percentage OR incidence
<b>Location</b>	England OR Scotland Or Wales OR Northern Ireland OR United Kingdom OR UK OR Britain OR Great Britain OR Brit* OR Engl* OR Scot* OR Welsh
<b>Type</b>	Review OR meta

**APPENDIX 2: Questionnaire – Demographic Data**

SURVEY ID:
------------

Please do not write your name on this questionnaire and only write in WHITE boxes.

**I UNDERSTAND THAT BY COMPLETING THIS QUESTIONNAIRE, I CONSENT TO IT BEING USED FOR RESEARCH PURPOSES ONLY (please tick):**

<b>1. Age:</b>	<b>2. Gender:</b>	<b>3. Nationality:</b>
	<input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Other	
<b>4. How long have you lived in the UK?</b>	<input type="checkbox"/> Less than one year: <i>please state (months)</i> ..... <input type="checkbox"/> More than one year: <i>please state (years)</i> ..... <input type="checkbox"/> Since birth	
<b>5. What is your ethnic group?</b> <i>(Please tick <u>one</u> option that best describes your ethnic group or background)</i>	<p><b>White</b></p> <input type="checkbox"/> English / Welsh / Scottish / Northern Irish / British <input type="checkbox"/> Irish <input type="checkbox"/> Gypsy or Irish Traveller <input type="checkbox"/> Any other White background, <i>please describe</i> ..... ..... <p><b>Mixed / Multiple ethnic groups</b></p> <input type="checkbox"/> White and Black Caribbean <input type="checkbox"/> White and Black African <input type="checkbox"/> White and Asian <input type="checkbox"/> Any other Mixed / Multiple ethnic background, <i>please describe</i> ..... ..... <p><b>Asian / Asian British</b></p> <input type="checkbox"/> Indian <input type="checkbox"/> Pakistani <input type="checkbox"/> Bangladeshi <input type="checkbox"/> Chinese <input type="checkbox"/> Any other Asian background, <i>please describe</i> ..... ..... <p><b>Black / African / Caribbean / Black British</b></p> <input type="checkbox"/> African <input type="checkbox"/> Caribbean <input type="checkbox"/> Any other Black / African / Caribbean background, <i>please describe</i> ..... ..... <p><b>Other ethnic group</b></p> <input type="checkbox"/> Arab <input type="checkbox"/> Any other ethnic group, <i>please describe</i> ..... ..... .....	
<b>What is your sexuality?</b> <i>(Please tick <u>one</u> option)</i>	<input type="checkbox"/> Heterosexual / Straight <input type="checkbox"/> Gay <input type="checkbox"/> Lesbian <input type="checkbox"/> Bisexual <input type="checkbox"/> Other, <i>please describe</i> ..... .....	

<p><b>6. What is your current immigration status?</b>          (Please tick <u>one</u> option)</p>	<input type="checkbox"/> UK National <input type="checkbox"/> European Economic Area (EEA) National <input type="checkbox"/> Discretionary Leave to Remain <input type="checkbox"/> Indefinite Leave to Remain <input type="checkbox"/> Study Visa <input type="checkbox"/> Work Visa <input type="checkbox"/> Husband/Wife Sponsorship <input type="checkbox"/> Asylum Seeker awaiting decision <input type="checkbox"/> Refugee <input type="checkbox"/> Humanitarian Protection <input type="checkbox"/> Other, please describe.....	
<p><b>7. What is your marital status?</b>          (Please tick <u>one</u> option)</p>	<input type="checkbox"/> Single <input type="checkbox"/> With a partner (not living together) <input type="checkbox"/> Cohabiting / living with partner <input type="checkbox"/> Separated <input type="checkbox"/> Divorced <input type="checkbox"/> Widowed <input type="checkbox"/> Married <input type="checkbox"/> Other, please describe.....	
<p><b>8. Do you have any dependents under the age of 18?</b></p>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<p><b>If Yes, how many?</b></p>
<p><b>9. Do you have any dependents over the age of 18?</b></p>	<input type="checkbox"/> Yes <input type="checkbox"/> No	<p><b>If Yes, how many?</b></p>
<p><b>10. What is your employment status?</b>          (Please tick <u>one</u> option)</p>	<input type="checkbox"/> Full-time Employment <input type="checkbox"/> Part-time Employment <input type="checkbox"/> Self-Employed <input type="checkbox"/> Unemployed <input type="checkbox"/> Student <input type="checkbox"/> Retired <input type="checkbox"/> Other, please describe.....	
<p><b>10a. What is your current, or most recent occupation?</b></p>		
<p><b>11. What is your highest level of education?</b>          (Please tick <u>one</u> option)</p>	<input type="checkbox"/> No education <input type="checkbox"/> Primary education <input type="checkbox"/> Secondary education <input type="checkbox"/> Higher education <input type="checkbox"/> University education <input type="checkbox"/> Other, please describe.....	
<p><b>12. Do you have any physical health problems?</b>          If yes, please describe .....</p>		<input type="checkbox"/> Yes <input type="checkbox"/> No
<p><b>13. Do you have any mental health problems?</b>          If yes, please describe .....</p>		<input type="checkbox"/> Yes <input type="checkbox"/> No
<p><b>14. Do you have a disability?</b>          If yes, please describe .....</p>		<input type="checkbox"/> Yes <input type="checkbox"/> No

### APPENDIX 3: Questionnaire – Self-Administered Questionnaire of Acculturation (SAQA)

The following questions relate to languages and cultural aspects of the South Asian community.

15. Please indicate with a tick if you are able to understand, speak, read or write any of the languages below: <i>(tick all that apply)</i>				
	Understand	Speak	Read	Write
English				
Urdu				
Punjabi				
(Bengali) Bangla				
Sylheti				
Gujarati				
Other <i>(please specify):</i> .....				

16. What is the main language you use: <i>(tick all that apply)</i>				
	at home?	with friends?	with neighbours?	at work?
English				
Urdu				
Punjabi				
(Bengali) Bangla				
Sylheti				
Gujarati				
Other <i>(please specify):</i> .....				

<b>17. Which of the following best describes your religious affiliation?</b> <i>(Please tick <u>one</u> option)</i>	<input type="checkbox"/> Not religious <input type="checkbox"/> Christian <input type="checkbox"/> Muslim <input type="checkbox"/> Hindu <input type="checkbox"/> Sikh <input type="checkbox"/> Buddhist <input type="checkbox"/> Other (please describe).....
--	--

<b>18. Do you see Britain as your 'home'?</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No
---	--

<b>18a. If No, which country would you describe as your 'home'?</b> .....
.....

<b>19. Do you feel a part of British society?</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No
---	--

<b>20. Do you see your future as secure?</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No
--	--



21. Do you fear racist attacks?	<input type="checkbox"/> Yes <input type="checkbox"/> No
22. Do you fear being discriminated against if applying for jobs because of your ethnic origin?	<input type="checkbox"/> Yes <input type="checkbox"/> No
23. Do you fear being denied opportunities at work because of your ethnic origin?	<input type="checkbox"/> Yes <input type="checkbox"/> No
24. Do you fear a loss of cultural identity for yourself?	<input type="checkbox"/> Yes <input type="checkbox"/> No
25. Do you fear a loss of cultural identity for your children/future children?	<input type="checkbox"/> Yes <input type="checkbox"/> No
26. In the past year, have you celebrated any traditional South Asian cultural festivals?	<input type="checkbox"/> Yes <input type="checkbox"/> No
<p>27. In what languages are the television programmes/videos/films you usually watch and the radio stations you regularly listen to? (Please tick <u>one</u> box):</p> <p><input type="checkbox"/> Don't watch television/videos/films or listen to the radio.</p> <p><input type="checkbox"/> South Asian languages only.</p> <p><input type="checkbox"/> Mostly South Asian languages.</p> <p><input type="checkbox"/> South Asian and English languages equally.</p> <p><input type="checkbox"/> Mostly English language.</p> <p><input type="checkbox"/> Only English language.</p>	
<p>28. In what languages are the newspapers you regularly read? (Please tick <u>one</u> box):</p> <p><input type="checkbox"/> Don't read newspapers.</p> <p><input type="checkbox"/> South Asian languages only.</p> <p><input type="checkbox"/> Mostly South Asian languages.</p> <p><input type="checkbox"/> South Asian and English languages equally.</p> <p><input type="checkbox"/> Mostly English language.</p> <p><input type="checkbox"/> Only English language.</p>	
<p>29. What type of clothing do you wear at home?          (Please tick <u>one</u> option)</p>	<p><input type="checkbox"/> Traditional South Asian clothing.</p> <p><input type="checkbox"/> Western style clothing.</p> <p><input type="checkbox"/> Western and South Asian clothing equally.</p>
<p>30. What type of clothing do you wear <u>outside</u> the home?          (Please tick <u>one</u> option)</p>	<p><input type="checkbox"/> Traditional South Asian clothing.</p> <p><input type="checkbox"/> Western style clothing.</p> <p><input type="checkbox"/> Western and South Asian clothing equally.</p>
<p>31. Thinking about where you are living at the moment, please indicate below who you live with?          (Please tick <u>all</u> that apply)</p>	<p><input type="checkbox"/> I live alone</p> <p><input type="checkbox"/> I live with my parents</p> <p><input type="checkbox"/> I live with friends</p> <p><input type="checkbox"/> I live with my partner/spouse</p> <p><input type="checkbox"/> I live with my children</p> <p><input type="checkbox"/> I live with my in-laws</p> <p><input type="checkbox"/> I live with my grandparents</p> <p><input type="checkbox"/> I live with other members of my family (not listed above)</p>

#### APPENDIX 4: Questionnaire – WHO 5-item Wellbeing Index (WHO5)

This section is about how you have been feeling recently.

Please try to answer ALL the questions by ticking or circling the box for your answer.

---

Over the last two weeks:

1. I have felt cheerful and in good spirits.	<i>All of the time</i>	<i>Most of the time</i>	<i>More than half of the time</i>	<i>Less than half of the time</i>	<i>Some of the time</i>	<i>At no time</i>
2. I have felt calm and relaxed.	<i>All of the time</i>	<i>Most of the time</i>	<i>More than half of the time</i>	<i>Less than half of the time</i>	<i>Some of the time</i>	<i>At no time</i>
3. I have felt active and vigorous.	<i>All of the time</i>	<i>Most of the time</i>	<i>More than half of the time</i>	<i>Less than half of the time</i>	<i>Some of the time</i>	<i>At no time</i>
4. I woke up feeling fresh and rested.	<i>All of the time</i>	<i>Most of the time</i>	<i>More than half of the time</i>	<i>Less than half of the time</i>	<i>Some of the time</i>	<i>At no time</i>
5. My daily life has been filled with things that interest me.	<i>All of the time</i>	<i>Most of the time</i>	<i>More than half of the time</i>	<i>Less than half of the time</i>	<i>Some of the time</i>	<i>At no time</i>

**APPENDIX 5: Questionnaire – 30-item Problems Checklist (PC30)**

Over the past two weeks, how much have you been distressed by:

1. Getting angry for every little thing.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
2. Sadness and depression.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
3. Thinking about problems a lot.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
4. Crying inside.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
5. Not looking after yourself as you would usually do.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
6. Worries in the middle of the night.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
7. Feeling that there is no way out.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
8. Feeling guilty or regret.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
9. Losing interest in things.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
10. Boredom.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
11. Not wanting to face anybody.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
12. Feeling so angry like your mind would erupt.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
13. Eating yourself up from inside.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
14. Thinking it would have been better if you were not living.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
15. Fighting in the family.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>

16. Feeling you can't tell anyone about your problems.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
17. A thumping heart	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
18. Feeling unable to do things that you would normally be able to do.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
19. Finding it hard to express your heartache.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
20. Fear inside.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
21. Your mind going wrong.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
22. Feelings of insecurity.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
23. Fears.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
24. Crying.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
25. Anxiety and tension.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
26. Feeling that you want to break things.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
27. Feeling like an outsider.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
28. Thinking so much that it seems as if your brain is going to burst.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
29. Feeling alone and isolated.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>
30. Thinking it is not worth living.	<i>Not at all</i>	<i>A little</i>	<i>Moderately</i>	<i>A lot</i>	<i>Extremely</i>

## APPENDIX 6: 28-item General Health Questionnaire (GHQ28)

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Over the past few weeks, have you:

1. been feeling perfectly well and in good health?	<i>Better than usual</i>	<i>Same as usual</i>	<i>Worse than usual</i>	<i>Much worse than usual</i>
2. been feeling in need of a good tonic?	<i>Not at all</i>	<i>No more than usual</i>	<i>Rather more than usual</i>	<i>Much more than usual</i>
3. been feeling run down and out of sorts?	<i>Not at all</i>	<i>No more than usual</i>	<i>Rather more than usual</i>	<i>Much more than usual</i>
4. felt that you are ill?	<i>Not at all</i>	<i>No more than usual</i>	<i>Rather more than usual</i>	<i>Much more than usual</i>
5. been getting any pains in your head?	<i>Not at all</i>	<i>No more than usual</i>	<i>Rather more than usual</i>	<i>Much more than usual</i>
6. been getting a feeling of tightness or pressure in your head?	<i>Not at all</i>	<i>No more than usual</i>	<i>Rather more than usual</i>	<i>Much more than usual</i>
7. been having hot or cold spells?	<i>Not at all</i>	<i>No more than usual</i>	<i>Rather more than usual</i>	<i>Much more than usual</i>
8. lost much sleep over worry?	<i>Not at all</i>	<i>No more than usual</i>	<i>Rather more than usual</i>	<i>Much more than usual</i>
9. had difficulty staying asleep once you are off?	<i>Not at all</i>	<i>No more than usual</i>	<i>Rather more than usual</i>	<i>Much more than usual</i>
10. felt constantly under strain?	<i>Not at all</i>	<i>No more than usual</i>	<i>Rather more than usual</i>	<i>Much more than usual</i>
11. been getting edgy and bad-tempered?	<i>Not at all</i>	<i>No more than usual</i>	<i>Rather more than usual</i>	<i>Much more than usual</i>
12. been getting scared or panicky for no good reason?	<i>Not at all</i>	<i>No more than usual</i>	<i>Rather more than usual</i>	<i>Much more than usual</i>

13. found everything getting on top of you?	<i>Not at all</i>	<i>No more than usual</i>	<i>Rather more than usual</i>	<i>Much more than usual</i>
14. been feeling nervous and strung-up all the time?	<i>Not at all</i>	<i>No more than usual</i>	<i>Rather more than usual</i>	<i>Much more than usual</i>
15. been managing to keep yourself busy and occupied?	<i>More so than usual</i>	<i>Same as usual</i>	<i>Rather less than usual</i>	<i>Much less than usual</i>
16. been taking longer over the things you do?	<i>Quicker than usual</i>	<i>Same as usual</i>	<i>Longer than usual</i>	<i>Much longer than usual</i>
17. felt on the whole you were doing things well?	<i>Better than usual</i>	<i>About the same</i>	<i>Less well than usual</i>	<i>Much less well</i>
18. been satisfied with the way you've carried out your task?	<i>More satisfied</i>	<i>About the same</i>	<i>Less satisfied than usual</i>	<i>Much less satisfied</i>
19. felt that you are playing a useful part in things?	<i>More so than usual</i>	<i>Same as usual</i>	<i>Less useful than usual</i>	<i>Much less useful</i>
20. felt capable of making decisions about things?	<i>More so than usual</i>	<i>Same as usual</i>	<i>Less so than usual</i>	<i>Much less capable</i>
21. been able to enjoy your normal day-to-day activities?	<i>More so than usual</i>	<i>Same as usual</i>	<i>Less so than usual</i>	<i>Much less than usual</i>
22. been thinking of yourself as a worthless person?	<i>Not at all</i>	<i>No more than usual</i>	<i>Rather more than usual</i>	<i>Much more than usual</i>
23. felt that life is entirely hopeless?	<i>Not at all</i>	<i>No more than usual</i>	<i>Rather more than usual</i>	<i>Much more than usual</i>
24. felt that life isn't worth living?	<i>Not at all</i>	<i>No more than usual</i>	<i>Rather more than usual</i>	<i>Much more than usual</i>
25. thought of the possibility that you might make away with yourself?	<i>Definitely not</i>	<i>I don't think so</i>	<i>Has crossed my mind</i>	<i>Definitely have</i>
26. found at times you couldn't do anything because your nerves were too bad?	<i>Not at all</i>	<i>No more than usual</i>	<i>Rather more than usual</i>	<i>Much more than usual</i>
27. found yourself wishing you were dead and away from it all?	<i>Not at all</i>	<i>No more than usual</i>	<i>Rather more than usual</i>	<i>Much more than usual</i>
28. found that the idea of taking your own life kept coming into your mind?	<i>Definitely not</i>	<i>I don't think so</i>	<i>Has crossed my mind</i>	<i>Definitely has</i>

**APPENDIX 7: Questionnaire – Access to Services**

This section is about health services for any emotional problems or distress that you may have experienced.

<b>A1. Have you ever sought help for any of your problems?</b>		<input type="checkbox"/> Yes	<input type="checkbox"/> No	
<b>A2. Which service did you seek help from?</b> <i>(please tick all that apply)</i>	<input type="checkbox"/> GP in the NHS <input type="checkbox"/> NHS mental health service (e.g. Community Mental Health Team) <input type="checkbox"/> Counselling or therapy in the NHS <input type="checkbox"/> Group support in the NHS <input type="checkbox"/> Support from religious leaders (e.g. imam, priest) <input type="checkbox"/> Support from social services <input type="checkbox"/> Private mental health service <input type="checkbox"/> Group support within Asian community organisation <input type="checkbox"/> Counselling or therapy within Asian community organisation <input type="checkbox"/> Other.....			
<b>A3. If you did seek help, did you feel that your problems were understood?</b>		<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know
<i>Please explain your answer (optional):</i> .....				
<b>A4. Were any services offered to you that you decided not to use?</b>		<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know
<b>A5. If you answered yes, why did you chose not to use the service?</b> <i>(please tick all that apply)</i>	<input type="checkbox"/> It wasn't available to me <input type="checkbox"/> I didn't want to <input type="checkbox"/> It did not suit my lifestyle <input type="checkbox"/> It was not appropriate for my culture <input type="checkbox"/> It was not appropriate for my religion <input type="checkbox"/> Other.....			
<b>A6. Were there any services/help that you wanted, but were <u>not</u> offered?</b>		<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Don't know
<b>A6a. If you answered yes, what service or help would you have wanted?</b>	.....			
<b>A7. Are you currently using any services for help with any of the problems you feel you have?</b>		<input type="checkbox"/> Yes	<input type="checkbox"/> No	
<b>A8. What services are you currently using or have you used in the past?</b> <i>(please tick all that apply)</i>	<input type="checkbox"/> GP in the NHS <input type="checkbox"/> NHS mental health service (e.g. Community Mental Health Team) <input type="checkbox"/> Counselling or therapy in the NHS <input type="checkbox"/> Group support in the NHS <input type="checkbox"/> Support from religious leaders (e.g. imam, priest) <input type="checkbox"/> Support from social services <input type="checkbox"/> Private mental health service <input type="checkbox"/> Group support within Asian community organisation <input type="checkbox"/> Counselling or therapy within Asian community organisation <input type="checkbox"/> Other.....			

**A9. If you have used services, how satisfied you were with the service you used overall?**

*(please circle one answer)*

<i>Not at all satisfied</i>	<i>Slightly unsatisfied</i>	<i>Neither satisfied or unsatisfied</i>	<i>Slightly satisfied</i>	<i>Very satisfied</i>
-----------------------------	---------------------------------	---	-------------------------------	---------------------------

**A10. If you have used services, did you find them helpful for your needs?**

Yes       No       Don't know

*A10a. Please explain your answer (optional):*.....

**A11. If you have used services, did you find them appropriate for your needs?**

Yes       No       Don't know

*A11a. Please explain your answer (optional):*.....

**END OF QUESTIONS**

**Thank you for completing this questionnaire.**

**By returning this questionnaire, you consent for it to be used for research purposes.  
If you change your mind, you may withdraw your consent at any time by contacting  
the researcher.**



APPENDIX 8: Recruitment Poster



Are you aged 18 or over?  
Are you of South Asian origin or descent?  
(Pakistan, India, Bangladesh, Sri Lanka, Nepal or Bhutan)

If **YES**, then we would like your help.

We are doing an anonymous survey of adults of South Asian origin who are living in England to find out how they access services and support if they are experiencing distress.

You do not have to have any problems to take part; this survey is for ANY ADULT of South Asian origin.

The survey is available in English, Urdu and Bengali (Bangla).

Please take a copy of the survey from reception or complete it online at:

[https://qtrial.qualtrics.com/SE/?SID=SV\\_8uzeOM7JlxWY6Nf](https://qtrial.qualtrics.com/SE/?SID=SV_8uzeOM7JlxWY6Nf)

**TAKE THE SURVEY ONLINE AT:**  
[https://qtrial.qualtrics.com/SE/?SID=SV\\_8uzeOM7JlxWY6Nf](https://qtrial.qualtrics.com/SE/?SID=SV_8uzeOM7JlxWY6Nf)

**TAKE THE SURVEY ONLINE AT:**  
[https://qtrial.qualtrics.com/SE/?SID=SV\\_8uzeOM7JlxWY6Nf](https://qtrial.qualtrics.com/SE/?SID=SV_8uzeOM7JlxWY6Nf)

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[https://qtrial.qualtrics.com/SE/?SID=SV\\_8uzeOM7JlxWY6Nf](https://qtrial.qualtrics.com/SE/?SID=SV_8uzeOM7JlxWY6Nf)

**TAKE THE SURVEY ONLINE AT:**  
[https://qtrial.qualtrics.com/SE/?SID=SV\\_8uzeOM7JlxWY6Nf](https://qtrial.qualtrics.com/SE/?SID=SV_8uzeOM7JlxWY6Nf)

**TAKE THE SURVEY ONLINE AT:**  
[https://qtrial.qualtrics.com/SE/?SID=SV\\_8uzeOM7JlxWY6Nf](https://qtrial.qualtrics.com/SE/?SID=SV_8uzeOM7JlxWY6Nf)

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[https://qtrial.qualtrics.com/SE/?SID=SV\\_8uzeOM7JlxWY6Nf](https://qtrial.qualtrics.com/SE/?SID=SV_8uzeOM7JlxWY6Nf)

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**TAKE THE SURVEY ONLINE AT:**  
[https://qtrial.qualtrics.com/SE/?SID=SV\\_8uzeOM7JlxWY6Nf](https://qtrial.qualtrics.com/SE/?SID=SV_8uzeOM7JlxWY6Nf)

**TAKE THE SURVEY ONLINE AT:**  
[https://qtrial.qualtrics.com/SE/?SID=SV\\_8uzeOM7JlxWY6Nf](https://qtrial.qualtrics.com/SE/?SID=SV_8uzeOM7JlxWY6Nf)

## APPENDIX 9: University of Hertfordshire Ethics Committee (ECDA) Approval Letter

UNIVERSITY OF HERTFORDSHIRE  
HEALTH AND HUMAN SCIENCES

### MEMORANDUM

TO Sophie Milsom

CC [REDACTED]

FROM [REDACTED] Health and Human Sciences ECDA Chairman

DATE 3 February 2014

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Protocol number: LMS/PG/UH/00156

Title of study: Access to mental health services among the South Asian population in the UK: an exploration of clinically significant psychological distress using a culturally competent measure.

Your application for ethical approval has been accepted and approved by the ECDA for your school.

This approval is valid:

From: 3 February 2014

To: 16 May 2014

**Please note:**

**Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1. Should you amend any aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit form EC2. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.**

## APPENDIX 10: National Research Ethics Service (NRES) Approval Letter



### NRES Committee North West - Liverpool Central

HRA NRES Centre - Manchester  
3rd Floor  
Barlow House  
4 Minshull Street  
Manchester  
M1 3QZ

Telephone: 0161 625 7818  
Facsimile: 0161 625 7299

18 February 2014

Miss Sophia A I Milsom  
Trainee Clinical Psychologist

[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]

Dear Miss Milsom

**Study title:** Psychological distress and access to services among a community sample of the South Asian population in South East England.  
**REC reference:** 14/NW/0118  
**Protocol number:** LHS/PG/NHS/00152  
**IRAS project ID:** 147136

The Proportionate Review Sub-committee of the NRES Committee North West - Liverpool Central reviewed the above application on 19 February 2014.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager [REDACTED].

#### Ethical opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

#### Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

3

### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

**Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.**

Management permission (‘R&D approval’) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.crfforum.nhs.uk>.

Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites (‘participant identification centre’), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

### **Registration of Clinical Trials**

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett ([catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

### Approved documents

The documents reviewed and approved were:

Document	Version	Date
Advertisement	Poster	

Covering Letter		11 February 2014
Evidence of Insurance or Indemnity		18 July 2013
GP/Consultant Information Sheets		
Investigator CV	Milom	
Investigator CV	Mason	
Investigator CV	Wellsted	
Letter from Sponsor		20 January 2014
Other: Debrief Sheet	1	10 February 2014
Participant Information Sheet	3	10 February 2014
Protocol	2,4	08 February 2014
Questionnaire	2	18 December 2013
REC application	3,5	13 February 2014
References or other scientific critique report		29 November 2013

#### **Membership of the Proportionate Review Sub-Committee**

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

#### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### **After ethical review**

##### **Reporting requirements**

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

##### **Feedback**

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Information is available at National Research Ethics Service website > After Review

**14/NW/0118** Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hps.nhs.uk/hps-its/nres/>

With the Committee's best wishes for the success of this project.

Yours sincerely

A handwritten signature in black ink, appearing to be 'P. [redacted]', written over a black rectangular redaction box.

Chair

Email: [redacted]

Enclosures: *List of names and professions of members who took part in the review*

*"After ethical review – guidance for researchers"*

Copy to: [redacted]; University of Hertfordshire  
[redacted]

## APPENDIX 11: Noclor Peer Review

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123-125 Camden High Street  
3<sup>rd</sup> Floor Bedford House  
London  
NW1 7JR

Tel: 020 3317 3756  
[www.noclor.nhs.uk](http://www.noclor.nhs.uk)

27 May 2014

Miss Sophia Milsom  
Department of Clinical Psychology  
University of Hertfordshire  
Health Research Building,  
College Lane,  
Hatfield, AL10 9AB

Dear Sophia,

**RE: 147136 - Psychological distress and access to services among a community sample of the South Asian population in South East England**

The above research project has now been Peer Reviewed by Noclor. The recommendation from our reviewers on the study is that **major changes are required**.

Their comments are summarised as follows:

Although there have, in the past few decades been a number of studies carried out which demonstrate issues pertaining to lack of access to treatment for psychological distress amongst south Asians, the focus of this proposed research study is appropriate in view of changing demographic profiles of the South Asian Tower Hamlets population. However, there are some issues that need to be addressed in terms of methodology.

First, a questionnaire based survey may not be that helpful in establishing the validity of local categories of psychological distress. The semantic language (and metaphors) that will be used to enquire about psychological distress have not been described. Bengali and Bangla overlap but subjects are likely to be sensitive to the terms used. In addition, the Bangladeshi population may respond negatively to the use of the term Bengali. Also, the proposed sample does not seem to include the Sri Lankan population - this needs to be explained.

The term cultural validity and what it means is not explained. This concept is used in the protocol but not defined anywhere. Better explanation is required if it is to be used to enhance or culturally validate an existing instrument. This concept was used to assess musculoskeletal pain in Asian participants (*Palmer B, Macfarlane G, Afzal C, Esmail A, Silman AJ, Lunt M. (2007). Acculturation and the prevalence of pain amongst South Asian minority ethnic groups in the UK. Rheumatology (Oxford), 46(6), 1009-14. eScholarID:1d15654*) but there is on-going debate about the cultural validity of other instruments, especially those used in the socioepidemiological field (including the GHQ and WHO-5 (see Jenkins JH & Kamo M. 1992. *The meaning of expressed emotion: theoretical issues raised by cross-cultural research. Am J Psychiatry. Jan;149,1:9-21*). The instrument that the researchers propose to validate in this study (PC30) is unpublished.

There are also specific concerns about the process of translation of interview questions into local cultural idioms pertaining to psychological distress (?meetha dard, ?anpu, ?mushkil, ?sankat, ? dimakh ki taklif, ?soch-vichaar, ?ulzhan ?jinn ki taklif), psychological help and barriers to accessing this (?salaah mashwarah), racism, eurocentric theories of psychological help (including CBT and or psychotherapy). This process cannot be a simple forward and backward translation.

Rather than attempting to only use an existing (unpublished) measure, it may be better to consider including a separate validation component, perhaps including some focus interviews by researchers fluent in one or two of the local languages (Urdu/Bangla) with local NGOs, faith based organisations and *Imaams* (for the Muslim population) to agree a set of themes that arise and then develop a semi-structured questionnaire that assesses these. This could be completed alongside the PC30 to clarify whether the PC30 is fit for purpose.

An alternative would be to conduct a standard classic ethnographic study through participant observation over an extended period of time.

We do realise that these comments may be disappointing but they are offered in the spirit of constructive criticism and we hope they will be helpful to you in progressing your research.

Please could you address the points raised wither in a written document, sent by email, post or fax, together with the necessary amended study documents, making reference to the parts of the protocol that have been changed.

If you need any further information, please feel free to contact me on [REDACTED].

Yours sincerely,



[REDACTED]  
Research Facilitator  
Research & Development  
noclor | North Central London Research Consortium

[REDACTED]  
[REDACTED]



## APPENDIX 12: Response to Noclor Peer Review

**Department of Psychology**  
**University of Hertfordshire**  
College Lane  
Hatfield  
AL10 9AB  
Tel: XXXXXX  
Email: XXXXXX  
27<sup>th</sup> May 2014

Dear XXXXXXXXXXXXXXX,

### **RE: 147136 – Psychological distress and access to services among a community sample of the South Asian population in South East England.**

Thank you for providing the comments and recommendations of the peer review for this project. The peer reviewer is evidently knowledgeable in the area of psychological distress within the South Asian community and has provided helpful comments that will be considered in this research.

Please find our responses to each of the specific comments of the peer review below, along with general comments at the end. Where we have made changes, these have been highlighted in the relevant documents in yellow.

*“A questionnaire based survey may not be that helpful in establishing the validity of local categories of psychological distress. The semantic language (and metaphors) that will be used to enquire about psychological distress have not been described.”*

- Whilst we agree that a questionnaire-based survey would not be the best method to establish the validity of local categories of psychological distress, this is neither the stated aim nor research question for this project. As stated in the protocol under ‘Aims and Objectives’, the primary aims of the research are to explore the levels of distress, the proportion of those experiencing distress who have not accessed services, and, of those who have accessed services, what their experiences have been. The secondary aims of the research are to carry out a validation of a new measure developed with South Asian people (this will be discussed in more detail below).
- We feel the way this research will enquire about psychological distress is clearly laid out, as the (English version) of the research questionnaire was included with the submission for consideration. The questionnaire uses existing measures that have all been widely published and validated, with the exception of one which is the subject of validation in this project.
- We certainly agree with the peer reviewer that the semantic language and metaphors used in South Asian cultures is an area that must be given attention and consideration in any research of this type. This is discussed in the ‘Background’ section of the protocol and will be an area for much further, in-depth discussion in the interpretation of the results of the study and in the thesis.

*“Bengali and Bangla overlap but subjects are likely to be sensitive to the terms used. In addition, the Bangladeshi population may respond negatively to the use of the term Bengali”*

- Thank you for highlighting the variations in the language and terminology that people of Bangladeshi origin use. We agree and acknowledge that the Bangladeshi population is a heterogeneous group of people, with different cultural identities and that this diversity is further extended to a widely heterogeneous group represented by the term ‘South Asian’.

- We are unclear what changes the peer reviewer recommends in reference to this or which specific aspect of the protocol the reviewer is referring to, but the heterogeneity of the sample, and cultural identities of the populations represented by the sample, are topics that will be discussed and explored in greater detail in the thesis. The reviewer's comments are helpful in considering how these topics may be conceptualised in the thesis.
- The material available to participants does not make reference to 'Bengali', other than to say that this is the language that it is available in. In light of the reviewer's comments, where the term Bengali has been used in reference to language, this has been clarified with the term (Bangla) in the protocol, recruitment poster and participant information sheet.
- Having already collected data for this research within a community (non-NHS) sample, over a third of whom have identified their ethnicity as Bangladeshi, there has been no indication of any participant taking exception to the way in which either the language or ethnicity has been termed.

*"The proposed sample does not seem to include the Sri Lankan population – this needs to be explained"*

- We are unclear how this conclusion has been reached as our proposed sample does include the Sri Lankan population. The proposed sample is people of South Asian origin. Those taking part will 'self-identify' as South Asian, as they will complete the questionnaire anonymously. Furthermore, the recruitment poster, included in the submission of materials for consideration by Noclor, clearly states 'Sri Lanka' as one of the countries that fall into the South Asian category.

*"The term cultural validity and what it means is not explained. This concept is used in the protocol but not defined anywhere."*

- Having searched the term 'cultural validity', we are unable to find any use of this term in the protocol. We have referred to the need for 'more culturally appropriate services for recovery', in reference to research that has found mental health services in the UK remaining unresponsive to the expressed views of South Asian service users.
- We have referred to the term 'cultural competence' and 'culturally competent' measures (in reference to the PC30). This is a term frequently used in thinking about the skills of mental health professionals to adequately address the needs of a culturally diverse population (*Bhui, et al. (2007) Cultural competence in mental health care: a review of model evaluations. BMC Health Services Research, 7:15-25, Gurpinar-Morgan (2012) What is cultural competence and how might clinical psychology training equip psychologists to work with ethnic diversity? Clinical Psychology Forum, 230: 25-30*). Cultural competence may be defined as the incorporation of cultural beliefs, values and practices into the understanding of a person's presentation to prevent inappropriate diagnosis and inform collaborative understanding of problems and delivery of appropriate treatment interventions.
- Under the assumption that this is the term that the reviewer felt should be defined, this has been clarified further in the 'Background' section, where further information is provided on the development of the PC30.

*"Better explanation is required if it is to be used to enhance or culturally validate an existing instrument. This concept was used to assess musculoskeletal pain in Asian participants but there is ongoing debate about the cultural validity of other instruments, especially those used in the socioepidemiological field (including the GHQ and WHO-5). The instrument that the researchers propose to validate in this study (PC30) is unpublished."*

- We are grateful of the reviewer's comments on this and in highlighting specific literature pertaining to the ongoing debate. This is a debate that we are fully

engaged with, forms part of the rationale for this study and have commented on within the research protocol.

- The paper that the reviewer cited (Palmer et al. 2007) provided the development of a measure of acculturation for a population of South Asian people in the UK. We are aware of this research and have already included the measure from this paper as our selected measure of acculturation. Although there are many other measures of acculturation, this is the only one that was developed for use with a South Asian population in the UK.
- It is also acknowledged that there are limitations in the use of measures of psychological distress across cultures, particularly those developed to map onto psychiatric diagnostic criteria. The WHO-5 and GHQ-28 were selected as measures that have been extensively validated across many different cultures, in many different languages and are often the first port-of-call in screening for mental health problems in primary care. In the 'Background' section of the protocol, we discuss the limitations of existing measures of distress when used to screen for mental health problems in the South Asian community. The selection of the PC30 in the survey was due to it having been specifically developed with a diverse South Asian group, using focus groups and qualitatively analysing their expressions of psychological distress.
- As the secondary aims of the proposed study are to validate the PC30 as a measure that may be more sensitive in identifying psychological distress among South Asian people (having been developed using qualitative expressions of distress of South Asian people), the GHQ-28 and WHO-5 were selected to provide comparison data on measuring distress. This is standard practice in assessing the construct validity of any psychometric measure. They are both regularly used both clinically and in research, and therefore will be widely recognised in both academic and clinical literature, which will increase the clinical relevance and applicability of the research findings.

*“There are also specific concerns about the process of translation of interview questions into local cultural idioms pertaining to psychological distress, psychological help and barriers to accessing this, racism, Eurocentric theories of psychological help (including CBT and/or psychotherapy). This process cannot be a simple forward and backward translation.”*

- The proposed research does not involve interviews with participants, only the completion of anonymous questionnaires.
- We are grateful to the reviewer for highlighting the limitations of simple forward and backward translation of the terms used. Of the measures that have been selected, we have used the translations that have previously been validated within those populations where possible.
- The PC30 was developed using the language and cultural idioms described by the people within the qualitative focus groups, in their languages. The items of the PC30 were written in the three languages simultaneously by a writing team who included first-language speakers of each of the three languages. Items were not written in English and then translated.
- While we acknowledge that there will be, in any research across-cultures, limitations in translation of meanings, we feel that it is beyond the scope, aims and remit of this study to research this aspect.

*“Rather than attempting to only use an existing (unpublished) measure, it may be better to consider including a separate validation component, perhaps including some focus interviews by researchers fluent in one or two of the local languages (Urdu/Bangla) with local NGOs, faith based organisations and Imaams (for the Muslim population) to agree a set of themes that arise and then develop a semi-structured questionnaire that assesses these. This could be completed alongside the PC30 to clarify whether the PC30 is fit for purpose.”*

- We agree that this is an excellent process for the development of a measure of distress and is precisely the methodology used to develop the PC30. This has been clarified in the 'Background' section of the protocol.
- As this was the process for the development of the PC30, we feel that the secondary aims of this research provide the opportunity to continue the validation of this measure. The use of two separate samples (i.e. that of Mason, 2003 and the proposed sample of this study) provides the opportunity for both an exploratory and confirmatory factor analysis to be carried out.
- While we agree that qualitative information about cultural idioms of distress provide a much richer understanding of the individual experiences of distress, in busy primary care settings, it is vital that health professionals have resources available to them that can help to quickly identify those who may be warrant further, more in depth assessment of their psychological wellbeing.
- Given the literature (referred to in the protocol) suggesting that existing measures may underestimate distress due to language and constructs of distress, the development of a measure (PC30) specifically with a South Asian population, provides an opportunity for a more culturally sensitive measure. This research aims to explore this further.
- In addition, this is one, small aspect of this research. The primary aims of this research are to explore what factors may be associated with access (or non-access) to services for South Asian people and what their experiences have been.

*“An alternative would be to conduct a standard classic ethnographic study through participant observation over an extended period of time”.*

- We agree that this would be a fascinating piece of research, which would glean very important and rich qualitative data to further understand cultural idioms of distress. However, we do not consider that this methodology meets the research aims or questions for this project.
- This suggestion certainly provides a topic for consideration, when discussing directions for future research. This suggestion will be included in the discussion of the thesis.

### **General Comments**

We are grateful for the considered response of the reviewer, which has provided helpful areas for consideration in discussion of this research. We do feel, however, that the requirements for feasibility and availability of resources need to be taken into account in reviewing this project. As with any research, this project is not without its limitations, however we consider that this is the most appropriate and feasible design and methodology in the context of limited financial and time resources. This project is being conducted as part of a doctoral thesis and does not have funding for a longitudinal, ethnographic study, involving the employment of several interpreters.

We do not propose this project as an exhaustive exploration of all aspects pertaining to descriptions of psychological distress, acculturation and access to services, but as a contribution to the literature to aid further understanding of factors in this area. As a relatively small-scale piece of research, it is hoped that it will form the basis of a larger-scale research grant application in the future, in which mixed-methodologies may be employed and a deeper exploration of factors may be undertaken.

Whilst we are disappointed to note that the reviewer feels 'major changes are required' to this research project, having considered their recommendations, we feel that the reviewer has taken issue with specific parts of the project that do not relate to the overarching aims of this project. Moreover, they have highlighted problems in the existing literature and nosology that we agree with; these very issues inform the rationale for this research.

Due to this project having received approval by the NHS REC on the 19<sup>th</sup> February 2014 and being approved by R&D for GP sites in a different locality, this research has begun at other sites and with non-NHS participants. Therefore, we are somewhat restricted in the changes that we can make to the research design and measures, to avoid invalidating the research and participants' responses that have already been collected. However, we hope that the Chair of the Peer Review finds our responses to the peer reviewer's comments satisfactory. We consider that the inclusion of participants from the large Bangladeshi community in Tower Hamlets will provide an opportunity for their experiences and perspectives on their access to services to be heard and considered in this research.

Thank you for taking the time to consider this study and our response to the peer reviewer's recommendations. We look forward to hearing the outcome.

Yours sincerely,

Sophia Milsom  
*Trainee Clinical Psychologist*  
*Principle Researcher*

XXXXXXXXXX  
*Clinical Psychologist*  
*Research Supervisor*



**APPENDIX 13: Research and Development Approval – Tower Hamlets**



Badford House, 3rd Floor  
 125-133 Camden High Street  
 London, NW1 7JR  
 Tel: 020 3317 3045  
 Fax: 020 7885 5530/5785  
 www.noclor.nhs.uk

16 June 2014

Miss Sophia Milsom  
 Department of Clinical Psychology,  
 Health Research Building, University of Hertfordshire,  
 College Lane,  
 Hatfield,  
 AL10 9AB

Dear Miss Milsom,

<b>Study Title:</b> Psychological Distress and Access to Services Among a Community Sample of the South Asian Population in South East England <b>R&amp;D reference:</b> 147136 <b>REC reference:</b> 14/NA/0118		
This NHS Research Governance Assurance is based on the REC favourable opinion issued on <b>18 February 2014</b> and the most recent amendment submitted to the REC on <b>09 June 2014</b>		
Geographic area of Independent Practitioner and Name of Research Site	Name of current PILC	Date assurance issued
NHS Tower Hamlets CCG- [REDACTED]	[REDACTED]	16 June 2014
<b>If any information on this document is altered after the date of issue this document will be deemed INVALID</b>		

<b>Additional comments</b> Please note that this Assurance Letter is only limited to the Globe Town Surgery site. An additional assurance letter will be required for any other research sites.
<b>If any information on this document is altered after the date of issue, this document will be deemed INVALID</b>

This letter confirms that NHS Research Governance Assurance has been given for any site within the geographical area(s) identified above, which can act as research site(s) for the above study subject to the conditions listed on the following pages of this letter and the agreement of the relevant General Practice(s).

The study team are encouraged to gain written permission from each General Practice(s) site confirming their agreement to take part in this study. If evidence of this permission has not yet been provided to the R&D office, the study team are encouraged to ensure that each of the relevant General Practice(s) sites sign off a copy of the reply slip on the final page of this letter before returning the signed copy to us.

Please note that this letter only acts as assurance that the appropriate governance review has been conducted and that the General Practice(s) is ultimately responsible for the research activities that take place at this site. Specific details of the governance review can be provided upon request.



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London, NW1 7JR

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Please ensure that all members of the research team are aware of their responsibilities as researchers, which are stated in the subsequent pages of this letter. For further details on these responsibilities, please check the R&D handbook or noclor website: <http://www.noclor.nhs.uk>

We would like to wish you every success with your project.

Yours sincerely,

A handwritten signature in black ink, appearing to be "Sophia Milsom".

Research Operations Manager

Cc: [redacted] (Local Collaborator), [redacted] (Sponsor Contact)

## APPENDIX 14: Participant Information Sheet

SURVEY ID:

### INFORMATION SHEET

#### Access to services for South Asian people

##### **Aim of the study**

The aim of this research is to find out whether South Asian people in England have access to appropriate services and support if they are in distress or having problems in their general wellbeing. We also want to find out how satisfied people are with services.

##### **What is involved?**

We are looking for people to help us by completing a questionnaire. You do not have to be in distress or experiencing health problems to participate; this questionnaire is for any adult of South Asian origin.

The questionnaire will ask about your current circumstances, any general health complaints or problems, your wellbeing and ways you might have asked for help from health or other services. The questionnaire should take no longer than 20 minutes to complete.

You can do the questionnaire either on paper and leave it with your GP's reception, post it to the University of Hertfordshire in the attached envelope, or you can complete the questionnaire online at [https://qtrial.qualtrics.com/SE/?SID=SV\\_8uzeOM7JlxWY6Nf](https://qtrial.qualtrics.com/SE/?SID=SV_8uzeOM7JlxWY6Nf). You can invite your family and friends to take part either by taking copies for them or they can do it online. The questionnaire is available in English, Urdu and Bengali (Bangla).

##### **What are the risks of taking part?**

The questionnaire will ask about your problems and feelings, therefore, it is possible that you may find some questions upsetting. If this happens, you can seek support from your GP or any services listed at the end of the questionnaire, even if you do not take part in this study.

##### **What are the benefits of taking part?**

By taking part you will help us better recognise people's needs and problems. This will help health services to provide more appropriate services for South Asian people in future.

##### **Voluntary participation**

Taking part in this study is entirely voluntary. If you chose not to take part in the study your access to services will not be affected either now or in the future. If you agree to take part, but then change your mind, you can withdraw at any time by asking the researcher and giving the survey ID code at the top of this form.

##### **Confidentiality**

This questionnaire is anonymous so do not write your name. By completing this questionnaire and returning it you agree to take part. You will be asked to tick a box to confirm that you understand this. Questionnaires will only be seen by the researchers and will be stored securely. At no time will any information you give be shared in a way that means you can be identified.



**What will happen to the results of this study?**

This study will form part of the qualification of Doctorate in Clinical Psychology at the University of Hertfordshire. The study will be published, but will not mention individuals or specific answers. You can see the findings of the study by contacting the researcher.

**Who has reviewed this study?**

The project has been approved by the NHS Research Ethics Committee (protocol number: 14/NW/0118) and the Psychology Ethics Committee at the University of Hertfordshire (protocol number: LHS/PG/NHS/00152)

**Further Information & Researcher Contact**

For further information about this research please contact Miss Sophia Milsom, Trainee Clinical Psychologist (XXXXXXXXXXXXX) or the supervisor XXXXXXXXx, Clinical Psychologist (XXXXXXXXXx).

## APPENDIX 15: Participant Debrief Sheet

By returning your questionnaire, you have consented to take part in this research. If you change your mind about taking part you may withdraw by contacting the researcher, Sophia Milsom at XXXXX and quoting the following code:

SURVEY ID:

You will not be asked for your name and you will not have to provide a reason for withdrawing your questionnaire.

If you need support or advice for any issues raised in the questionnaire, the following services will be able to provide you with support and advice. You may also speak to your GP.

### General Advice

**Citizens Advice Bureau:** Free, confidential advice service on legal, financial and other matters.

0844 4111 444 [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

**Money Advice Service:** Free, independent advice on managing money.

0300 500 5000 [www.moneyadviceservice.org.uk](http://www.moneyadviceservice.org.uk)

### Health

**Samaritans:** 24-hour helpline for any person in emotional distress. 0845 790 9090

[www.samaritans.org](http://www.samaritans.org)

**Mind:** Provide helpline and services for people in mental distress. 0300 123 3393

[www.mind.org.uk](http://www.mind.org.uk)

Mind in Tower Hamlets & Newham - 020 7510 1081 / [info@mithn.org.uk](mailto:info@mithn.org.uk) [www.mithn.org.uk](http://www.mithn.org.uk)

**NHS Direct:** Health advice and reassurance, 24 hours a day. Freephone: 111

[www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)

**Relate:** Free advice and counselling for relationship and marriage problems.

0300 100 1234 [www.relate.org.uk](http://www.relate.org.uk)

### Safety

**NSPCC Child Protection Helpline:** Free, confidential service for anyone concerned about children at risk of harm. 0808 800 5000 [www.nspcc.org.uk](http://www.nspcc.org.uk)

**National Domestic Violence Helpline:** 24-hour free phone

0808 200 0247 [www.nationaldomesticviolencehelpline.org.uk](http://www.nationaldomesticviolencehelpline.org.uk)

**Victim Support:** Support and information to victims of crime (this is not the police).

0845 3030 900 [www.victimsupport.org.uk](http://www.victimsupport.org.uk)

**FMU The Forced Marriage Unit:** Confidential advice and assistance for those forced into marriage, at risk of being forced into marriage or worried about friends and relatives at risk. 020 7008 0151 (EMERGENCY - 020 7008 1500) [www.fco.gov.uk/forcedmarriage](http://www.fco.gov.uk/forcedmarriage)

## Housing

**Mungos:** Accommodation, support and emergency homeless services.

020 8762 5500 [www.mungos.org](http://www.mungos.org)

**Shelter:** Housing advice. 0808 800 4444 [www.shelter.org.uk](http://www.shelter.org.uk)

## Immigration/Asylum/Refugee

**Immigration Advice Service:** Legal support and advice relating to immigration and asylum.

0844 887 0111 / [info@iasservices.org.uk](mailto:info@iasservices.org.uk) [www.iasuk.org](http://www.iasuk.org)

**Refugee Council:** Support, advice and counselling for refugees.

020 7346 6777 [www.refugeecouncil.org.uk](http://www.refugeecouncil.org.uk)

## Lesbian, Gay, Bisexual & Transgender (LGBT)

**Broken Rainbow:** Support for all LGBT people across the UK.

0300 999 5428 / [help@brokenrainbow.org.uk](mailto:help@brokenrainbow.org.uk) [www.brokenrainbow.org.uk](http://www.brokenrainbow.org.uk)

**Himat:** For South Asian or Middle Eastern gay and bisexual men.

0207 791 2855 / [himat@positiveeast.org.uk](mailto:himat@positiveeast.org.uk)

**Imaan:** Support for LGBT Muslim people, families and friends. Safe space and support to address issues of common concern. 0203 3393 5188 / [info@imaan.org.uk](mailto:info@imaan.org.uk)

[www.imaan.org.uk](http://www.imaan.org.uk)

**Safra Project:** Supports LGBT Muslims. [info@safraproject.org](mailto:info@safraproject.org) [www.safraproject.org](http://www.safraproject.org)

## Men

**Mankind Initiative:** Support for male victims of domestic abuse and domestic violence.

01823 334244 [www.mankind.org.uk](http://www.mankind.org.uk)

**Men's Advice Line:** Advice and support for men experiencing domestic violence and abuse.

0808 801 0327 / [info@mensadvice.org.uk](mailto:info@mensadvice.org.uk) [www.mensadvice.org.uk](http://www.mensadvice.org.uk)

**Gemini Project:** Safe, emergency accommodation and support for men experiencing domestic abuse, including a helpline and support group. 0870 066 4233

## Women

**Against Forced Marriages:** Support for those in a forced marriage, worried that they or a friend might be at risk. 0800 141 2994 [www.againstforcedmarriages.org](http://www.againstforcedmarriages.org)

**Ashiana (Helpline):** Refuge and support for South Asian, Turkish and Iranian women aged 16-30, experiencing domestic violence, forced marriage and/or sexual abuse.

020 8539 9596 [www.ashiana.org.uk](http://www.ashiana.org.uk)

**Imkaan:** National Black, Minority Ethnic and Refugee (BMER) charity dedicated to addressing violence against women and girls. 0207 250 3933 [www.imkaan.org.uk](http://www.imkaan.org.uk)

**JAN Trust:** Prevent abuse and violence against women and girls including honour violence, domestic abuse, forced marriage and female genital mutilation. For Black, Asian, Minority Ethnic, Refugee (BAMER) and Muslim women. 0208 889 9433 [www.jantrust.org](http://www.jantrust.org)

**Jeena International:** Empowering women and young people to initiate personal and social change. Counselling and support. Provides safe homes for victims of domestic violence. 01753 424 240 / info@jeenainternational.org [www.jeenainternational.org](http://www.jeenainternational.org)

**Newham Asian Women's Project (London):** Provides advice and support for Asian women and children experiencing domestic violence specifically safety planning and advice, emergency refuge space and translation services. 0208 472 0528 [www.nawp.org](http://www.nawp.org)

**Roshni Asian Women's Aid:** Provides refuge for south Asian women and children experiencing domestic violence. 0115 924 2864 [www.womensaid.org.uk](http://www.womensaid.org.uk) (search for Roshni)

**The Sharan Project:** Confidential advice, befriending service and practical support for South Asian women, supporting independent living. 0844 504 3231 / info@sharan.org.uk [www.sharan.org.uk](http://www.sharan.org.uk)

**Solace Women's Aid (London):** For women and children affected by domestic and sexual violence. Range of services including emergency accommodation. 0808 802 5565 / info@solacewomensaid.org [www.solacewomensaid.org](http://www.solacewomensaid.org)

**Kiran Project:** Provides safe, temporary accommodation to Asian women and their children. 0208 558 1986 [www.kiranproject.org.uk](http://www.kiranproject.org.uk)

## APPENDIX 16: SAQA Reliability Table

Scale 1:

### Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.765	.791	9

### Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
ENGLISH	10.5055	7.897	.557	.382	.724
English at Home	13.6374	9.767	.205	.191	.772
English with Friends	13.4725	9.630	.418	.496	.755
English with Neighbours	13.4505	9.695	.434	.612	.755
English at Work	13.4945	9.519	.433	.494	.752
scale1tv	12.5714	7.759	.485	.355	.740
scale1news	11.9890	7.433	.527	.430	.733
Scale 1 - Clothes at Home	13.0000	7.667	.523	.546	.732
Scale 1 - Clothes Outside	12.7802	7.818	.611	.600	.715

Scale 2:

### Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.783	.778	8

### Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
ukhome	4.79	4.345	.187	.217	.795
britsoc	4.77	4.224	.395	.290	.778
futsec	4.93	3.640	.509	.344	.756
rev_racist	5.09	3.503	.478	.278	.762
rev_discrim	5.13	3.227	.637	.636	.731
rev_denyopp	5.07	3.240	.661	.654	.727
rev_cultidyoud	5.04	3.576	.455	.358	.766
rev_cultidch	5.25	3.302	.574	.472	.744

Scale 3:

**Reliability Statistics**

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.674	.711	10

**Item-Total Statistics**

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
festival	5.8977	9.978	.103	.044	.682
Non-English	3.7500	6.764	.328	.247	.699
Asian Language at Home	5.9318	9.214	.381	.225	.647
Asian Language with Friends	6.3182	8.748	.511	.480	.627
Asian Language with Neighbours	6.4773	9.172	.458	.365	.641
Asian Language at Work	6.5682	10.018	.165	.180	.674
scale3tv	6.2955	8.234	.518	.402	.615
scale3news	6.4773	8.735	.413	.351	.637
Scale 3 - Clothes at Home	6.0568	8.169	.384	.612	.640
Scale 3 - Clothes Outside	6.2614	8.517	.389	.592	.639

**APPENDIX 17: PC30 Reliability Table**

**Reliability Statistics**

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.978	.979	30

**Item-Total Statistics**

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
pc1	25.33	654.345	.741	.	.978
pc2	25.26	649.063	.781	.	.977
pc3	24.92	648.969	.720	.	.978
pc4	25.44	649.671	.788	.	.977
pc5	25.21	653.954	.759	.	.977
pc6	25.49	647.867	.837	.	.977
pc7	25.57	648.344	.839	.	.977
pc8	25.38	650.697	.722	.	.978
pc9	25.39	649.374	.801	.	.977
pc10	25.33	654.345	.681	.	.978
pc11	25.73	655.406	.800	.	.977
pc12	25.82	656.221	.846	.	.977
pc13	25.71	651.869	.832	.	.977
pc14	25.99	666.687	.633	.	.978
pc15	25.56	660.274	.635	.	.978
pc16	25.26	643.497	.789	.	.977
pc17	25.70	657.320	.731	.	.978
pc18	25.54	649.914	.803	.	.977
pc19	25.50	641.675	.844	.	.977
pc20	25.52	650.228	.809	.	.977
pc21	25.70	651.513	.841	.	.977
pc22	25.42	647.981	.810	.	.977
pc23	25.57	650.923	.844	.	.977
pc24	25.63	659.224	.752	.	.978
pc25	25.20	651.802	.758	.	.977
pc26	25.89	663.976	.669	.	.978
pc27	25.74	650.726	.791	.	.977
pc28	25.64	651.341	.730	.	.978
pc29	25.56	650.129	.772	.	.977
pc30	26.06	668.177	.694	.	.978

## APPENDIX 18: GHQ28 Reliability Table

### Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.943	.948	28

### Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
ghq1	21.05	193.073	.512	.	.942
ghq2	21.44	191.100	.486	.	.942
ghq3	21.07	183.944	.416	.	.947
ghq4	21.14	187.994	.555	.	.942
ghq5	21.32	183.396	.661	.	.940
ghq6	21.36	180.983	.736	.	.939
ghq7	21.46	186.701	.558	.	.942
ghq8	21.27	181.750	.751	.	.939
ghq9	21.21	181.168	.705	.	.940
ghq10	21.21	183.168	.740	.	.939
ghq11	21.33	184.500	.674	.	.940
ghq12	21.56	186.900	.682	.	.940
ghq13	21.46	186.151	.794	.	.939
ghq14	21.46	184.451	.772	.	.939
ghq15	21.26	192.044	.496	.	.942
ghq16	20.98	190.924	.598	.	.941
ghq17	21.04	191.911	.574	.	.942
ghq18	21.00	192.125	.541	.	.942
ghq19	20.94	190.859	.624	.	.941
ghq20	20.98	191.724	.553	.	.942
ghq21	21.02	190.049	.584	.	.941
ghq22	21.60	188.067	.584	.	.941
ghq23	21.73	186.275	.778	.	.939
ghq24	21.89	190.525	.666	.	.941
ghq25	21.79	192.393	.480	.	.942
ghq26	21.83	189.945	.656	.	.941
ghq27	21.99	195.612	.515	.	.942
ghq28	21.96	196.761	.326	.	.944



## APPENDIX 19: WHO5 Reliability Table

**Reliability Statistics**

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.895	.895	5

**Item-Total Statistics**

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
who1	12.00	20.083	.726	.558	.875
who2	12.20	19.742	.717	.591	.877
who3	12.24	20.183	.734	.568	.873
who4	12.67	17.432	.844	.746	.847
who5	12.22	19.567	.691	.580	.883