The experiences of young Somali adults with visible facial differences: Findings from a UK qualitative study

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Abstract

Background: The term visible difference refers to an appearance that is considered different to the societal ‘norm’, including skin conditions and scars. The psychosocial impact of living with a visible difference is well-documented in the literature, yet the experiences of ethnic minority groups are largely unknown. A limited amount of visible difference research, and further health research, indicates that these groups experience poorer outcomes. Specifically, Somali people constitute one of the largest diaspora groups in the United Kingdom (UK), and several socioeconomic indicators note increased disadvantage within this community compared to others. A small number of studies pertain to appearance among Somali people, yet no research specifically on visible difference is available. This study aimed to qualitatively explore the experiences of a group of young UK Somali adults with visible facial differences.

Method: A critical realist and contextualist theoretical lens was applied to this research. Remote semi-structured interviews were carried out on Microsoft Teams and Zoom, and data were analysed using Reflexive Thematic Analysis (RTA). Public Involvement with relevant stakeholders and community representatives informed and guided the design of this project. Eight participants took part, five men and three women, varying in age from 19 to 28 years (mean = 23.5). Visible differences included congenital conditions (n = 2), skin conditions (n = 2), and acquired facial scarring (n = 4).

Results: RTA identified three themes: Stigmatised Differences; Being ‘Other’; and Coping in Private. Stigmatised Differences related to participants’ accounts about the Somali community’s negative beliefs about the causes of visible differences, and the social and personal consequences these can have for Somali people who are personally affected. Here, participants also advocated for greater community awareness and education on this issue. Being ‘Other’ related to values, tied closely to culture, which participants drew on when conceptualising their lived experience. The data highlighted tensions for participants in managing modern and traditional values, including those related to gender and healthcare. Coping in Private related to coping mechanisms, and a preference for coping independently. If looking beyond the self for support, participants reported relying on family and friends, and dismissed the need for, or benefit of, external supports. However, participants recognised and discussed the benefits of peer support and community involvement in support-related efforts.

Conclusion: The findings of the current study highlight the experiences of young Somali adults with visible facial differences, a group that has historically been absent from the literature. These insights can inform future research with and support for this group. They particularly illustrate the need for an intersectional health psychology, which recognises how broader inequalities and discriminations serve as barriers to health and wellbeing, and the value of applying this approach to research, clinical practice, intervention, education, training and policy-making.

Introduction

1.1 Chapter Introduction

This chapter begins by introducing visible differences and discussing previous research on psychosocial outcomes for those with visible differences. Possible influential factors to adjustment and models of adjustment are also considered. Then, current evidence of efficacy for psychosocial interventions in visible differences is discussed. It is argued that appearance is important to health, and that appearance dissatisfaction can contribute to adverse health and psychosocial outcomes. Research suggesting that those with visible differences are at increased risk of appearance dissatisfaction is also referenced. Limitations of the current state of the visible difference knowledge base are discussed, including the prominent reliance on White Western research participants. The small amount of existing research with diverse groups indicates poorer psychosocial outcomes for minority individuals with visible differences. Possible reasons for such ethnic disparities are considered. Due to limitations within the visible different knowledge base, insights from the broader health literature base are drawn on. Reports of poorer health outcomes for ethnic minorities, and reasons for this, are discussed. It is argued that focusing on broad ethnic minority groups in research is ineffective and problematic, and thus the focus of the chapter shifts to the Somali community. The chapter introduces Somalia and the Somali diaspora and considers literature reporting poorer health and wellbeing among Somali migrants in the United Kingdom (UK). Possible explanations for this are considered. Finally, a case is made for the importance of adopting an intersectional perspective in health psychology. Health psychology should consider the multiple identity markers that can shape experiences and impact health-related outcomes, such as ethnicity. The chapter concludes by presenting a summary of the relevant literature, as well as this study’s research questions, aims and objectives.

1.2 An Introduction to Visible Differences

1.2.1 Defining Visible Differences

The term visible difference refers to a mark or condition resulting in an appearance that is notably different to societal ’norms’ and, importantly, is often regarded as ‘undesirable’ (Rumsey and Harcourt, 2012). Changing Faces, an authoritative UK charity that supports those affected by visible differences, report that one in five people self-identify as having a visible difference (Changing Faces, 2019). The term ‘disfigurement’ may be more commonly understood. This term has importance as those with “*severe disfigurement*” are protected from discrimination under the UK’s 2010 Equality Act. However, some within the community reject the term disfigurement due to its negative connotations, and visible difference is considered more acceptable by many. For example, it is used by the Centre for Appearance Research (CAR) who are the world leaders for appearance research. Thus, it will be adopted in this thesis.

A visible difference can result from a range of congenital (e.g., Cleft Lip and/or Palate (CL/P), birthmark) and acquired (e.g., psoriasis, alopecia) conditions, as well as trauma (e.g., burn injuries, scarring following accidents), or medical intervention (e.g., scarring and changes to the body following surgery, side effects of treatment (e.g., hair loss)). Irrespective of the cause, having a visible difference can present a range of social and psychological challenges for affected individuals (Rumsey and Harcourt, 2004). Interestingly, despite variations in causes, the psychosocial impact is reportedly largely similar across conditions (Rumsey, 2008). The psychosocial impact of visible differences is further discussed below.

1.2.2 Psychosocial Challenges

Those who look noticeably different can experience challenging interactions with others such as staring, intrusive questioning, social exclusion, teasing/bullying, and aggressive/anti-social behaviour (Creadore *et al.*, 2021; Reynolds and Harris, 2021; van den Elzen *et al.*, 2012; Magin *et al.*, 2008). Whilst experiences such as staring and unwanted questioning are not always inherently negative, for example they can arise from curiosity or concern, they can still prove challenging. Such attention can result in individuals feeling targeted and alienated, and for some people with visible differences, prior and anticipated social challenges over time can lead to fear of negative appearance evaluation by others and social avoidance (Rumsey, 2018).

In addition to social concerns, individuals may also experience difficulties pertaining to their psychological and emotional wellbeing (Rumsey and Harcourt, 2004). These include low self-esteem, symptoms of anxiety and depression, and overall reduced Quality of Life (QoL) - which can negatively impact areas such as employment, and interpersonal relationships. For example, in a UK-based qualitative study with adults with visible differences, Sharratt *et al*. (2018) found participants felt their appearance had a significant impact on their romantic relationships, including fearing being unattractive to others, feeling devalued, and anxiety about disclosing their difference to partners. The overall psychosocial impact of living with a visible difference has been demonstrated by reviews focused on a range of appearance-affecting conditions and injuries such as burns (Wisely *et al.*, 2007), CL/P (Stock and Feragen, 2016; Hunt *et al.*, 2005) and other craniofacial conditions (Feragen and Stock, 2017), alopecia (Liu, King and Craiglow, 2016; Rencz *et al.*, 2016), lymphoedema (Fu *et al.*, 2013) and cancer (Rezaei *et al.*, 2016).

Contemporary Western beauty ‘ideals’ are pervasive and prevalent across various areas of society, for example the media. Exposure to/endorsement of such unrealistic and unattainable ideals is shown to be detrimental to wellbeing among the general population (e.g., Avery *et al*., 2021). For those with visible differences, there is likely an even greater discrepancy between ideals and actual appearance, hence outcomes may be even more negatively impacted. Thus, individuals with visible differences may experience greater difficulties with negative body image and appearance-related distress. Body image relates to a person’s subjective feelings and thoughts about their body (Grogan, 2021). Whilst the physical appearance of the body is a key factor for body image, other aspects of embodiment – including how an individual uses their body to engage with the world, and whether they can appreciate what their body can *do* (body functionality) over how it looks – are also influential (Alleva and Tylka, 2021). Appearance-related distress may be understood as a broad term reflecting the various appearance-related challenges individuals experience, including low body-esteem, appearance-related social anxiety, and fixation on appearance. Similarly, Body Image Dissatisfaction (BID) is defined as negative perceptions towards one’s own body. Current literature provides evidence that visible differences and associated health conditions are an additional risk factor for BID (Teo *et al.*, 2016; Thomas-McClean, 2000). This is likely due to a combination of issues, including possible bodily changes because of illness or in response to treatment. For example, chemotherapy may lead to an impairment in body functionality and capacity to carry out daily activities, as well as changes to appearance (e.g., weight gain, hair loss). Beyond cancer, research into other appearance-altering conditions, such as burns (Pellard, 2006), and sclerosis (Ennis *et al.*, 2013), also cites the impact of these conditions on body image.

There are also additional challenges that those with a visible difference can face, including the burden of ongoing treatment and care, physical/medical complaints, and barriers to accessing treatment and support (e.g., financial, geographical, logistical; Li *et al*., 2019). For example, with respect to those with skin conditions, Rumsey (2018) outlines associated daily challenges including difficulties with clothing options, symptom management (e.g., itching), and limited lifestyle choices (e.g., avoidance of the sun or allergens). These challenges can contribute to poor functioning and wellbeing. Further, Evers *et al*. (2005) note that those with skin conditions may experience challenges such as sleep difficulties due to uncomfortable itching, which contributes to overall behavioural and cognitive impairment.

1.2.3 Factors Influencing Adjustment

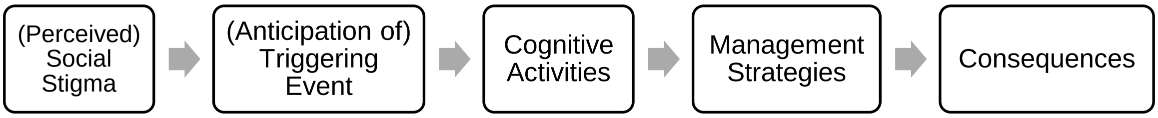
Psychosocial adjustment to visible differences is currently conceptualised as how an individual copes with having a visible difference. Experts in the field, Norman and Moss (2015), consider preoccupation with appearance, anxiety, depression, QoL, and social integration as ‘adjustment’. Moss and Rosser (2008) also note that adjustment to visible differences is a continuum and complex– whereby an individual may experience good and poor adjustment at different times.

Despite extensive evidence describing the psychosocial challenges many people with visible differences experience, there is also research to show considerable variation in coping between individuals. For some, the impact of living with a visible difference can be minimal and these individuals can adjust well – experiencing overall good social and psychological functioning as demonstrated by qualitative research in this area (Garbett, Harcourt and Buchanan, 2017). Egan *et al*. (2011) suggest that having a visible difference can in some cases contribute to enhanced wellbeing, with individuals thriving and experiencing a greater sense of resilience and resourcefulness. Egan and colleagues note that factors such as acceptance, positive relationships, and helpful coping strategies (e.g., optimism, active coping, spirituality) are likely instrumental to positive adjustment.

Research finds that the clinical severity of a visible difference does not necessarily predict poorer outcomes (Reid *et al.*, 2012; Ong *et al.*, 2007). That is, an individual with clinically more severe scarring (e.g., larger and covering a greater portion of the body) may report better adjustment than someone with less severe scarring. Similarly, demographic differences, such as age and gender, are not highly influential factors. The consensus remains that adjustment to visible differences is complex and multifaceted. However, questions related to which factors are influential to adjustment, and could be ameliorated through intervention, persist.

Various models of adjustment to visible difference have evolved. For example, body image models theorise that looking visibly different makes it more challenging to meet social norms of attractiveness (Cash and Grant, 1996). Other models focus on sociological factors (Goffman, 1968), social anxiety (Leary and Kowalski, 1997), and social skills (Rumsey, Bull and Gahagan, 1986). Sociological models emphasise the role of stigma, other models pose that social anxiety can lead to avoidant behaviours by those with visible differences, and social skills models propose training for affected individuals to manage stigma and related social challenges. An Integrated Model (Kent, 2000; Figure 1), combines concepts of body image, sociocultural stigma, social anxiety, social skills, and Cognitive Behavioural Therapy (CBT) to holistically capture the experiences of those with visible differences.

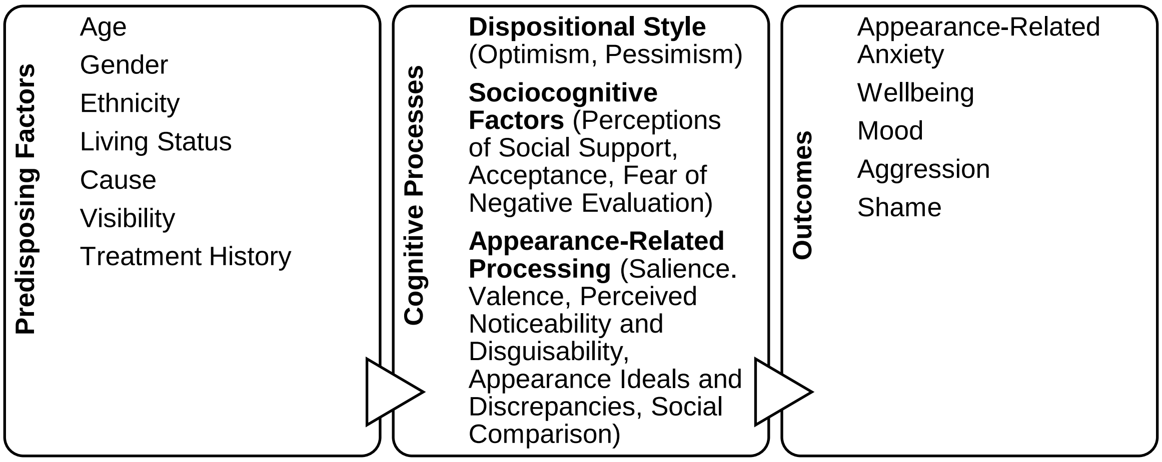
Figure 1. Kent's Integrated Framework



Re-produced from Kent (2000)

Leading researchers in the visible difference field, known as the Appearance Research Collaboration (ARC), also devised a framework intended to outline contributory factors for coping (Clarke *et al.*, 2013). The framework (Figure 2) was developed through consultation with experts, literature reviews, a collection of small-scale studies, and a large-scale survey study. It considers stable predisposing factors (e.g., gender, age, ethnicity), as well as malleable cognitive processes (e.g., optimism, perceived social support, significance of appearance in daily life), which are said to influence key psychosocial outcomes.

Figure 2. Appearance Research Collaboration (ARC) Framework



Re-produced from Clarke *et al.*, (2013)

1.2.4 Psychosocial Interventions

Systematic reviews have considered the effectiveness of different interventions for individuals with visible differences and found promising results for a combined cognitive-behavioural and social skills training approach (e.g., Norman and Moss, 2015). However, these reviews have also highlighted critiques of the current knowledge base, including a limited understanding about the optimal duration, intensity and setting of interventions (Norman and Moss, 2015).

Other research has also indicated the possible utility of Acceptance and Commitment Therapy (ACT) for this population (Zucchelli *et al.*, 2018). ACT is a third-wave behavioural therapy that aims to increase psychological flexibility and value-driven living. Unlike traditional CBT, ACT places emphasis on recognising and managing (rather than challenging or changing) negative thoughts, through mindfulness and cognitive defusion techniques (Hayes, Strosahl and Wilson, 2011).

Further, in addition to interventions for affected individuals, broader, societal-level interventions to reduce prejudice and stigma are warranted. These interventions serve to increase knowledge about and acceptance of visible differences in the general population and aim to reduce the social burden on those affected. A limited number of such initiatives have been developed and evaluated, yet due to the infancy of this research area, information about if and how these efforts are effective remains unclear (Stone and Fisher, 2020),

1.2.5 The Health Impact of Body Image Dissatisfaction

As noted, evidence finds that visible differences are an additional risk factor for BID (Teo *et al*., 2016; Thomas-McClean, 2000). BID can play a part in issues related to health including treatment decision-making and adherence (Hale, Radvanski and Hassett, 2015). BID has also been linked to other adverse health behaviours including smoking (Amos and Bostock, 2007; King *et al*., 2005); disordered eating (Stice, 2002; Cooley and Toray, 2001); and steroid use (Wright, Grogan and Hunter, 2000). Overall, body image is shown to correlate with multiple indicators of wellbeing, including social relationships, mental health, and life satisfaction/attainment (Jain and Tiwari, 2016).

The wealth of evidence pertaining to the negative impact of BID is such that various professionals including academics and public health experts have called for it to be recognised as a public health concern (Bucchianeri and Neumark-Sztainer, 2014). They have advocated for more initiatives that both promote and foster positive body image in the general population and address the psychosocial support needs (particularly BID) of those with visible differences (Williamson and Wallace, 2012). Specifically for health psychologists, appearance is imperative as it influences how people perceive others and themselves – impacting both psychosocial and health outcomes (Rumsey, 2008).

1.3 The Impact of Minority Status

1.3.1 Defining Key Terminology

It is important to precede this section by defining and selecting key terms of interest, including race, ethnicity, culture, and ‘minority’ status. Although historically used interchangeably owing to common elements across definitions, race and ethnicity are currently conceptualised as two separate issues. Race is defined by biological and physical characteristics (e.g., skin colour), whereas ethnicity is socially dependent. Such that scholars have called for researchers to avoid terms such as *race*, which can incorrectly signal biological differences (Khunti *et al.*, 2020). Instead, the term *ethnicity* is preferred, as it better allows for the consideration of social, cultural and religious elements which influence expression and identification. Within expressions of ethnicity, culture relates to general customs and beliefs shared by a group of people. UK Government guidance on 'writing about ethnicity', defines 'minorities' as those belonging to an ethnic category other than 'White British' (UK Government, 2021). These current guidelines on terminology will be adhered to throughout this thesis, unless citing older research that used other terms.

When referring the ethnic minorities, critics argue that broadly grouping individuals (e.g., Black and Minority Ethnic, 'BAME') is problematic and ineffective as minority communities may have more differences than similarities – or certain differences that warrant unique consideration. Minority individuals may also not identify or resonate with those broad terms (Khunti *et al.*, 2020; Milner and Jumbe, 2020). In line with this, in their final report on Covid-19 health inequalities, the British Government recommended that ethnic minority groups be referred to individually, rather than singularly (Race Disparity Unit and Cabinet Office, 2021). In research (Miranda *et al*., 2003) and healthcare (NHS Race & Health Observatory, 2021), it is more beneficial to focus on specific ethnic groups. This is because groups can be affected differently by various issues (e.g., socioeconomic inequalities, discrimination). As such, grouping terms such as 'BAME' will be avoided in this report, unless citing research that previously used these categorisations.

1.3.2 Minority Status and Appearance

Many scholars maintain that the concept of beauty is prescribed by social standards, which vary with time, place, culture and faith (Naqvi and Saul, 2012; Swami and Tovée, 2007; Poran, 2002). However, to date, most knowledge in the field of appearance and visible difference has been generated from research with relatively homogenous groups (i.e., White, Western people; Johnson *et al*., 2009). This generally tends to be the case in most psychological research, a phenomenon often referred to as WEIRD psychology (i.e., research samples largely derived from Western, Educated, Industrialised, Rich and Democratic societies; Henrich, Heine and Norenzayan, 2010). This gap in the literature is in part due to methodological limitations in accessing diverse samples - including inappropriate outcome measures, language barriers, and recruitment challenges (Naqvi and Saul, 2012). Thus, while the impacts of living with a visible difference are well documented for majority populations, because of this narrow sampling, less is known about how different (minority) groups view and experience altered appearances (Naqvi and Saul, 2012).

The relatively limited amount of research that has been conducted in this area suggests that minority groups in the UK with visible differences, particularly those from cultures which are significantly different to British culture, experience poorer outcomes. Specifically, research implies that minority groups view and experience appearance (and visible difference) differently, and often less favourably, to the White British majority. For example, in terms of attitudes to visible differences, research shows that compared to White British people, UK South Asians can have stronger negative views towards those who look different, which has adverse implications for affected individuals in the community (Hughes *et al.*, 2009). Similarly, Rumsey *et al*. (2004) found that 'non-White' respondents with a visible difference reported that their appearance caused more worry had a greater overall impact on QoL compared to White respondents. Further, Rumsey *et al*. found a significant difference in relation to perceived noticeability of the difference; 'non-White' respondents felt their condition was more noticeable than White respondents. Similarly, research in CL/P with South Asian (Reekie, 2011), non-Anglo (Hutchinson *et al.*, 2011) and a group of unspecified ethnicities (Stock, Feragen and Rumsey, 2016) found that ethnic minority adults reported poorer outcomes in comparison to ethnic majority adults. These included greater social stigma and lack of acceptance, psychosocial issues, and treatment dissatisfaction.

Cultural factors are likely to influence individual experiences. Rozario (2007) published a case study about a British Bangladeshi woman in the UK with neurofibromatosis and found key differences between her experiences, and those of European and American individuals with the condition. They argued that disparities were largely due to factors related to Bangladeshi culture, particularly in relation to gender, sexuality and marriage. For example, because of her condition, the individual was deemed unmarriageable, 'less of a woman', and excluded from cultural networks. Rozario posed that in Bangladeshi culture, appearance is closely related to social identity (particularly for women), which results in harsher treatment for those who do not fit the standard. Similarly, research exploring the lived experiences of UK South Asians with vitiligo found issues related to specific appearance-related cultural values and myths, particularly about the cause of condition (Thompson *et al.*, 2010). As in Rozario's study, this resulted in greater stigmatisation of those affected which extended to relationships, intimacy, and social support within the community. Thompson *et al*. also reported accounts of a loss of ethnic identity given the presentation of vitiligo on darker skin, which is more visible than that on lighter skin. In a similar study by about the experience of Chinese women living in the UK with skin conditions, Lam and Thompson (2021) highlighted themes including negative cultural views on appearance, and the women's internalisation of negative reactions from others. Combined, this contributed to shame and self-disgust. Ethnic minority women have also reported specific, and at times poorer, experiences following breast cancer diagnosis compared to White women. These include poorer body image and psychosocial functioning, reduced social support, and challenging healthcare experiences; such as the provision of appropriate wigs and prosthetics, and concerns related to gender of Health Professionals (HPs; Patel-Kerai *et al*., 2017; Patel-Kerai *et al*., 2015; Patel, 2014).

1.3.3 Minority Status and Health

Health disparities are well documented and in most Western healthcare systems minority groups are generally found to have poorer health-related experiences and outcomes. Differences between the health of minority and majority groups have previously been observed in a range of areas, including cardiac health (Ben-Shlomo, Naqvi and Baker, 2008), sexual health (Dougan *et al.*, 2005), cancer (Licqurish *et al.*, 2017; Glick *et al.*, 2012), mental health (Gajwani *et al.*, 2016), and more recently in relation to Covid-19 (Mamluk *et al.*, 2020). Previous research has also identified adverse health behaviours among minorities, including reduced physical activity (UK 'BAME' groups; Koshoedo *et al*., 2015) and increased smoking (UK ethnic minorities; Luthra, Nandi and Benzeval, 2020). As part of a review of health survey data, Smith, Kelly and Nazroo (2009) found that ethnic minorities in England reported poorer general health across generations, suggesting intergenerational adversity at play.

Nazroo (2014) argues that health variations between groups can be explained through genetic differences, migration effects, cultural factors, access to quality care, or socioeconomic variables (including discrimination and racism). However, the dominant perspective of academics is that differences are more likely due to extrinsic factors and inequalities (e.g., discrimination and racism) than innate variance between groups (e.g., genetics; Nazroo, 2014). Importantly, the relationship observed between ethnicity and health should be regarded as a product of systemic flaws that affect ethnic groups differently, as opposed to fundamental ethnic differences. As Wallis (2020) summates, the issue is *racism, not race.* Thus, disparities in health are most typically regarded as the consequence of a complex intersection of broader social and structural determinants which contribute to the observed inequality (Razai, Majeed and Esmail, 2021). Such determinants can include Socio Economic Status (SES), population diversity, and rates of health literacy.

Research consistently finds a relationship between minority status and low Socioeconomic Status (SES; Gazard *et al.*, 2015). In a recent report on the impact of Covid-19 on 'BAME' groups, based on literature reviews and stakeholder feedback, Public Health England (2020) deduced that the increased risk of Covid-19 transmission, morbidity, and mortality in these groups, was exacerbated by inequality related to housing, income, transportation, and occupation (SES factors). For example, individuals from minority groups were reported to be more likely to work in occupations with higher risk of Covid-19 exposure.

Issues related to ethnic density (geographical concentration of ethnic minorities) are another possible explanation for health inequality between ethnic groups (UK - Sotubo, 2021). Bécares, Nazroo and Stafford (2011) identified that UK ethnic minorities living in areas with decreased ethnic density were more likely to engage in unhealthy drinking behaviours, compared to those living in areas with increased ethnic density. The authors theorise that density is a proxy for discrimination – whereby less ethnically diverse spaces can lead to increased rates of bias and subsequent greater stress for affected groups, and this may contribute to unhealthy behaviours.

Health disparities may also be exacerbated by lower levels of health literacy. Health literacy relates to the skills that people require to understand, appraise, and apply health information, including reading and writing skills, and more complex communicative, interpersonal, problem-solving and critical thinking skills (Sørensen *et al.*, 2012). Lower health literacy contributes to the under-use of healthcare services, particularly preventative services, and overall poorer health outcomes (Berkman *et al.*, 2011; Benjamin, 2010). Research finds that minority groups are disproportionally affected by lower levels of health literacy (Kutner *et al.*, 2006). A possible cause is the difficulties migrants can face when navigating the transition to a new country – including learning a new language, culture, and health system (Wångdahl *et al.*, 2014).

Logistical barriers preventing minority groups receiving care are also widely reported, including limited finances, access, childcare and transport (Koshoedo *et al.*, 2015). Similarly, mistrust of HPs, often caused by previous negative experiences, is also common and shown to deter health-related help-seeking behaviours among ethnic minorities (Public Health England, 2020). A review of self-reported health among migrant and ethnic minority groups in Europe found that migrants and ethnic minorities felt more disadvantaged in comparison to majority groups, and tended to report greater barriers to accessing healthcare (Nielsen and Krasnik, 2010). Taking these findings together, it is unsurprising that ethnic minorities are also shown to seek health support and care at a reduced rate. For example, in a retrospective cohort study, Stagg *et al*. (2012) found a much-reduced level of registration with General Practitioners among migrants living in the UK.

1.4 The UK Somali Diaspora

1.4.1 A Brief Introduction to Somalia and Somali Migration to the UK

Somalia, a country in East-Africa, has a long history of conflict and unrest (war, poverty, famine; Gulleid, 2019). Consequently, Somalis constitute one of the largest diasporas in the world, estimated at over 1.2 million (Hammond *et al.*, 2011). The UK is said to have the biggest and most established community of Somali migrants in Europe (Hammond, 2013). Large communities have grown in major UK cities, including Bristol, Birmingham, Leeds, and London, with 78% of Somali people in the UK residing in London (ICAR Briefing, 2007). In the 2001 census, 43,000 Somali people were estimated to be living in the UK (Office for National Statistics, 2001), although this is likely to be an under-representation due to issues concerning the accuracy of ethnic minority group data. It has been suggested that within much of the published public data, Somali people are frequently incorporated into broader categories; often classed as Black African. As such, figures can be misleading and result in an under-detection of disparities and need (Brown and Langer, 2010). However, as per standard ethnic and cultural definitions (UK Government, 2021), Somali people are considered ethnically Black and culturally Somali. Islam is the dominant religion (Liberatore, 2017).

1.4.2 Somali Health and Wellbeing

Despite the significant Somali presence in the UK, limited research has investigated Somali experiences of health and wellbeing (Straus, McEwen and Hussein, 2009). From the available research, it appears that UK Somali people experience poorer health outcomes in relation to diabetes (Wieland *et al.*, 2012), childbirth (Straus, McEwen and Hussein, 2009), hepatitis B (Cochrane, Collins and Horwood, 2016), visual impairment (Higginbottom, Rivers and Story, 2014), and cancer (Abdullahi *et al.*, 2009). For example, research exploring experiences of autism in the UK Somali community has found that Somali people are at particular risk of having limited knowledge about autism (Fox *et al.*, 2017). Further, Fox *et al*. highlighted issues regarding language, namely a lack of appropriate vocabulary for describing autism in Somali. Combined, the authors argue that a lack of knowledge and appropriate language on autism creates increased stigma about the condition among the Somali community. In the field of tuberculosis, research also finds misconceptions about the disease, stigma, and subsequent increased social isolation for affected Somali people (Gerrish, Naisby and Ismail, 2012). Further research similarly shows that Somali individuals with tuberculosis may limit disclosure of the condition to minimise stigma (Gerrish, Naisby and Ismail, 2013).

Poorer mental health experiences and outcomes have also been demonstrated in the Somali community (McCrone *et al.*, 2005). In part this is argued to be due to limited knowledge and increased stigma (e.g., perceptions that mental illness is caused by spirit possession), logistical barriers to care, and mistrust of HPs (Linney *et al.*, 2020; Loewenthal *et al.*, 2012). In research about Somali women's maternity care, Konje and Konje (2021) report poorer outcomes and pose that language barriers are influential. Given their findings, the authors argue for the inclusion of robust translation services in maternity healthcare settings. In addition to language competency, the authors pose that HPs may not possess sufficient cultural competency to deliver appropriate care to Somali women. For example, an understanding of the importance of religion, or the preference for continuity of care. A qualitative study with US-based Somali refugees echoed these sentiments (Freeman *et al.*, 2013). They noted HPs can experience challenges Somali patients; owing to language barriers, difficulties associated with working with interpreters, and differences in religion and culture. They also argued that religion plays an important role in Somali refugees' healthcare decisions and behaviours, as religion informs how illness is understood. Somali refugees can view illness as 'God's will', which has important implications for perceptions of health motivations for improving health behaviours.

As with other ethnic minority groups (see section 1.3.3), issues related to health literacy and SES can also be applied to understanding the health experiences of Somali people. Research into health literacy has found Somali migrant communities at risk of lower levels of health literacy (Gele *et al.*, 2016). In a Norway-based study about Somali immigrant women, Gele *et al*. found that a large proportion of the sample were not health literate (i.e., could not obtain, understand and act upon health information), which impacted the women's health-related decision-making. More, in a UK-based study, McEwen, Straus and Croker (2009) found that Somali people were at risk of making unhealthy food choices (e.g., low fruit and vegetable consumption) owing to their reliance on traditional Somali foods and broader attitudes to diet, as well as limited knowledge on nutrition. Yet, health-related choices, such dietary, are also greatly influenced by access, and 'healthy' *choices* may not always be accessible. Ultimately, limited health literacy, combined with specifical cultural attitudes (e.g., on diet), can influence health-outcomes for Somalis.

Research from a range of SES domains which contribute to health and wellbeing - such as employment, education, and finances - suggests that Somalis in the UK occupy the lowest levels of the SES ladder. Jabłonowski, Mohamed and Sugulle (2013) note that compared with other migrant groups, The Somali community have one of the highest rates of unemployment, social/educational inequalities, and poverty. Specifically, unemployment and economic inactivity rates within the Somali community have been found to be amongst the highest in all ethnic minorities in the UK (Khan, 2008). Similarly, in terms of reliance on social security, the ratio of Somali-born benefit claimants is higher than any other UK ethnic minority group (Harris, 2004).

One explanation for the higher incidence of health and socioeconomic disadvantage within the Somali diaspora, is Somali people's distinct ethnic (Black) and religious (Muslim) differences compared to the UK majority population (White, Christian). In a study about migrant mental health, Warfa *et al*. (2012) found that Somali people in the UK feel particularly disadvantaged as they are not only migrants, but also Muslim and Black, making the process of integration particularly challenging. Similarly, Liberatore (2017) report that Somali people are among the most reprimanded migrant groups in Europe, and specifically in the UK, they are often discriminated against on the grounds of Female Genital Mutilation

(FGM)-related practices, misconceptions about gang violence, and perceived threats of Islamic radicalisation – ideas that collectively frame Somali people as a threat. Such examples of discrimination can cause stress, significantly compromise health, and contribute to disparities in outcomes (Krieger, 2014). Research has identified a link between discrimination and associated stress, and health-related behaviours (Paradies, 2006), and this relationship is outlined in the Minority Stress Model (MSM). Initially developed to elucidate the experiences of sexual minorities (Meyer, 2003), the MSM has since been extended to include other marginalised groups (e.g., ethnic minorities). The model poses that minority groups can face hostility and discrimination, leading to increased stressors which can negatively influence mental and physical health. The model acknowledges how multiple marginalised identity markers can combine to increase discrimination – causing a double or even triple jeopardy (Millar and Brooks, 2022).

Those working in relevant areas of health (including providers and researchers) recommend that the provision of community education and development of culturally sensitive services are necessary to ameliorate health experiences and outcomes for UK Somali people (Fox *et al.*, 2017; Gerrish, Naisby and Ismail, 2013; Abdullahi *et al.*, 2009). Suggestions for Somali community interventions include those that target low levels of health literacy (Gele *et al.*, 2016), reduce stigma about health conditions and disabilities (Linney *et al.*, 2020), and increase knowledge and understanding about positive health behaviours (e.g., diet; McEwen, Straus and Croker, 2009) and conditions (e.g., hepatitis B; Cochrane, Collins and Horwood, 2016). Researchers have also called for training to educate HPs to consider cultural issues which may impact healthcare, for example illustrating how religious factors can influence behaviour and the importance of continuity of care (Konje and Konje, 2021; Straus, McEwen and Hussein, 2009).

1.5 An Intersectional Health Psychology

An intersectional approach aims to consider the impact of multifaceted experiences and combined identities. These can be ascribed characteristics (e.g., ethnicity), but also achievements (e.g., employment). However most important is that they carry varying levels of power and privilege (Christensen and Jensen, 2012). Previous intersectional health research has noted the impact of multiple identity markers on health, including ethnicity, but also sexuality and gender identity (e.g., Johnson *et al*., 2016; Agénor *et al*., 2015)

The impact of different intersecting identities and experiences on health is an issue that health psychologists should prioritise in research and practice. It has been noted that health psychology to date has largely been rooted in Western views on wellbeing – consequently, traditionally health psychology has neglected those not native to such Western systems and who may have different understandings and experiences (Landrine and Klonoff, 1992). While there is increasing work focused on the experiences of more diverse groups, most work remains Euro-American, middle class and androcentric. Scholars advocate for a more diversified health psychology; one which considers factors such as ethnicity, disability, age, sexual orientation, gender identity, and poverty (Smith and Suls, 2004; Yali and Revenson, 2004). Health psychologists should continue to recognise how multiple intersections of identity influence all areas of life, including health, and thus need to be accounted for in research, clinical practice, intervention, education, training and policymaking. The appropriate consideration of intersectionality in practice may be referred to as *context competency* – which is not only essential for the efficacy of health psychology practice, but also the credibility of the discipline (Yali and Revenson, 2004). Particularly in recent years, some working in the field have felt the necessity to defend the discipline and ascertain its utility; for example, Hamlet *et al*.'s (2017) response to Hilton and Johnston's (2017) piece suggesting that health psychology as a discipline falls short in various areas (e.g., applied practice), and that an entirely new division of psychology, clinical health psychology, is indicated. Yet, by being flexible and adaptable to socio-cultural changes, and demonstrating commitment to diversifying the field (i.e., being *context competent*), Yali and Revenson argue that health psychology can continue to evolve with integrity and authority and retain a place within the various psychological divisions.

1.6 Chapter Summary and Research Aims

A visible difference can present a range of psychosocial challenges and is a risk factor for the development of appearance dissatisfaction. This can have an adverse impact on health behaviours and outcomes, and other areas of wellbeing. Scholars have called for this issue to be considered by those in public health, psychology, and all other relevant disciplines concerned with promoting health and wellbeing. Yet, the visible difference field, as with many other fields in psychology, has received criticism for largely focusing its efforts on a homogenous group (White, Western). This is problematic due to that fact that what is 'known' in this area, may not be true for all. The limited amount of visible difference research focusing on more diverse groups, suggests that minority individuals may experience poorer outcomes. The broader health literature also offers insights about how intersections of experiences and factors; including discrimination, structural racism, SES, low health literacy, limited access to health, previous negative health experiences, reduced knowledge off illness and disease and increased stigma, cultural beliefs and norms which may impact health/health behaviours; may be applied in understanding health disparities. The amalgamation of these factors presents a particular set of challenges which are worthy of further enquiry, and scholars in the field of visible difference have called for further research to explore such experiences.

Somali people constitute one of the largest diasporas in the world and there is a significant Somali presence in the UK. Literature indicates that in comparison to other diaspora groups and the majority group, Somali people in the UK experience poorer health outcomes, as well as greater socioeconomic disadvantage and discrimination. Taken together, this suggests that Somali people with appearance-altering health conditions may be at particular risk of psychosocial distress.

Whilst some health psychologists are working within an intersectional framework, the field more broadly should embrace this ethos to a greater degree. Health psychologists must consider different intersecting identity markers and their possible influence on health and wellbeing. In the case of visible differences, similar work with different communities is needed. In the context of increasingly diversifying communities and health disparities, this research is necessary and timely. The current study therefore asks: *What are the experiences of Somali people with visible facial differences?* To the researcher's knowledge, no such research has been conducted. Though research into the experiences and outcomes of Somali people in various health contexts exists (see section 1.4.2), none reflect on the influence of appearance– an element which the body image and visible difference literature clearly demonstrates is important for health and wellbeing. Insights into how individuals perceive their experiences is key when considering what influences adjustment and is a first step in evidence-based practice. This information will enable stakeholders to consider what kind of support, if any, is required and most suitable for Somali people with visible differences.

1.6.1 Aims and Objectives

The primary aim of the current study is to qualitatively explore the subjective experiences of UK-based (young) Somali adults with visible facial differences. Additionally, the research has the following objectives:

1. To study Somali cultural meanings and understanding of visible differences

2. To investigate how cultural meanings, understandings, and other factors and practices may influence the psychosocial experiences of Somali people affected by visible differences

3. To consider preferred coping strategies among Somali people with visible differences

4. To identify areas for improvement in health psychology, health care and research with Somali people with visible differences

Method: Theory, Design and Procedure

2.1 Chapter Introduction

This chapter begins by discussing theory including ontology and epistemology. Various aspects of the design are discussed, and justifications for choices are provided, including the broader choice of a qualitative design and interview method. The issues of translation and interpretation, and public involvement in research are considered in relation to this project. Sampling is discussed, including criteria and strategy. The procedure of the study is described and ethical considerations, as well as data processing issues are discussed. The chapter then focuses on analysis. Whilst Reflexive Thematic Analysis (RTA) was selected in the current project, other analytic approaches are discussed and justifications for choices are provided. Procedural steps of RTA, important theoretical reflections related to analysis, and issues on quality of qualitative research are also discussed. Finally, the characteristics of the sample are presented. Here, issues related to sample representativeness, size, and concepts of ‘power’ and data saturation are also considered.

2.2 Disclosing and Considering Positioning

Critical self-reflection is a crucial part of qualitative research. For the purposes of transparency, researchers are encouraged to explicitly discuss how their own values, presumptions and experiences may influence their choices, decisions, and actions regarding their research. Such pre-existing factors are said to inescapably influence all aspects of research; from initial interest to how the work is carried out, to how the findings are ultimately interpreted and presented (Harrison, MacGibbon and Morton, 2001). The following sections of the report disclose and reflect on the researcher’s personal and theoretical positions in relation to this project.

2.2.1 Personal Positioning

Since the inception of this study, and as it has progressed over the past two years, self-reflective journaling has been a facilitative strategy for personal introspection (Ortlipp, 2008). Through journaling, and more recently for the purposes of this write-up, revisiting the journals, I have identified and considered my own experiences and positions in relation to this work. The following offers a reflection of this self-examination, and considers, 1) my identity as a White Portuguese woman (and crucially, an outsider to the Somali community), 2) my professional role as a researcher and trainee health psychologist, and 3) my pre-existing knowledge and experience in health psychology and visible difference research, as well as in qualitative research methods.

I have been working in the field of visible difference since 2017 and whilst my passion for the area has grown, so has my disillusion regarding the field’s shortcomings. After reading countless variations of the phrase, *“further research with more diverse groups is warranted”* in research reports, and eventually writing similar sentiments myself – for example, in research related to parents of children with Cleft Lip and/or Palate (CL/P; Costa *et al.*, 2021a; Costa, White and Stock, 2020), children with CL/P (Costa *et al.*, 2021b), and adults with CL/P (Costa, Ardouin and Stock, 2022) – I stopped to ask when the field would actually move towards being more inclusive?

I have always been passionate about fairness. I am politically liberal, and supportive of immigration and multiculturalism. I value cultural diversity and celebrate the contributions that different communities make to society. This is reflected in much of my learning and work to date. As an undergraduate psychology student, when given the option, I chose to enrol on the following modules: Psychology of Appearance and Embodiment; Social Justice; Human Sexuality; and Gender, Psychology & Society – which further fuelled my fire about issues pertaining to equality. During the peak of societal attention towards 'Brexit', I wrote my Psychology BSc thesis on *Perceptions of immigration and immigrants in contemporary Britain.* In this qualitative project, I presented themes indicating evidence that elements within society can depict immigrants as a threat to 1) national security, 2) national identity, and 3) national resources, and argued that these narratives can work to justify and legitimise the harsh treatment of immigrants in the UK.

As a first-generation immigrant, I have been aware and possibly more mindful (as compared to my British peers) of being 'othered' (Schenk, 2021). For example, I can understand and relate to the feeling of being in a country where you do not speak the language, of taking different food for school lunches and having others comment on it, and of seeing my mum struggling to decipher and navigate public systems (e.g., healthcare). Despite this, as I become more educated on such matters, particularly on the concept of intersectionality, I began to appreciate how my outward presentation – of what some may call the "good immigrant" (Kwak, 2018; that is, as minimally different from the majority group as possible) – protects me from discrimination reserved for those who are more clearly 'other'. Indeed, as a White woman, with a good level of spoken English and no other physical characteristics that present me as 'other' (e.g., religious clothing), I am not typically viewed (and treated) by the majority group in the same way as other groups of migrants might be.

As a Health Psychology MSc student, I became particularly interested in reading about and discussing inequalities in this area (e.g., Brondolo, Lackey and Love, 2012; Gurung, 2018; Lyons and Chamberlain, 2006). As I entered the visible difference space, I noticed that these issues that plague (health) psychology, are also relevant here. In recognition of this, I felt stirred to do what I could with the resource that I had, to help the situation and move the field forward in what I believe to be a more positive direction. Clearly, going into this project, I had specific desires for what it would achieve, which were inextricably bound up with my own views and experiences.

Suffice to say my journey on this project has not been linear. Crucially, I am not Somali, and I also do not have a visible difference. As such, I am an outsider. This issue felt particularly pertinent given that the inception of this project coincided with the surge of the Black Lives Matter (BLM) movement following George Floyd's murder – leading me to think even more deeply about issues of privilege. Appendix 1 offers an extract of my reflective diary whereby I consider the BLM movement and my feelings towards this project. At the time, I questioned the ethics around me doing this research. *Is it right for me to do this research? If I do, am I just contributing to the problem?* After much reading, research, and debate, and following advice from my Director of Studies to write a 'pros and cons' list of carrying out this research (as well as considerations for how to counter-act the 'cons'), I ultimately chose to continue.

Broader debates exist about researching communities that one does not belong to, and possible challenges (Dwyer and Buckle, 2009; Irvine, Roberts and Bradbury-Jones, 2008; Brannick and Coghlan, 2007; section 2.6.2.1 for more information). While researcher-participant ethnic identity matching may not be feasible in most cases, the consensus is that researchers, particularly those working in communities which they do not belong to, should explicitly recognise, address and work to dismantle possible power dynamics, as these can ultimately harm minority communities in research (Muhammad *et al.*, 2015). Below, I reflect on how my identity as a young, White, non-Somali woman, and role as a researcher/trainee health psychologist from a well-established university, may have impacted the research.

My identity, and related interpersonal power dynamics, may have influenced the ways in which participants engaged in the research, and specifically, how they discussed topics such as healthcare and gender during the interview (and well as others that emerged within those, such as ethnicity and culture). Importantly, the nature of this project was particularly sensitive and could even be regarded as taboo by the wider Somali community. It is thus possible that my outsider position facilitated discussions – allowing participants to open-up about a sensitive topic to an individual that is external to their close community. For example, discussions about community stigma were possibly easier in this context. On the other hand, it is also possible that me being an outsider hindered rapport, and participants' levels of comfortability sharing certain issues. Further, participants knew that I am a young, White, non-Somali woman, who worked as a researcher/trainee psychologist. Participants may have regarded me as a HP and felt less able to share certain experiences of healthcare. More, it is possible that participants, knowing that I was racially White and ethnically non-Somali, felt less willing to share further culturally laden accounts of experiences. Similarly, my gender may have also made male participants less willing to share openly. Overall, the influence of factors such as race and gender of the researcher/participant are said to be complex and unpredictable but ultimately influential (Archer, 2002).

Overall, as much as I intended to amplify participants' voices, and believe I have done all I could to ensure their stories are reported accurately and sensitivity, I am mindful that I approached this topic with a research rather than lived-experience perspective. Being familiar with the visible difference literature, and qualitative methods more broadly, I had ideas going into the project about what issues may come up. Hence, the process of 'giving voice' to participants also involved adding my own 'voice' to the equation, in the form of my existing pre-conceptions (Fine, 1992). In interpreting the data of this project, I have also been mindful about how mine and participants' cultural differences may influence my interpretations. For example, in research about UK Black families' perceptions of barriers to healthy lifestyles, Ochieng (2013) found that much of what was judged 'healthy' was based on Eurocentric systems.

At this stage, after having carried out the work and completed my thesis, I am happy with my decision to pursue this research and feel confident that I have done as much as I could to ensure the project was robust, and that I mitigated the impact of being an outsider to the community as much as possible (e.g., Public Involvement – see section 2.5). I am also grateful for how forthcoming participants were in interviews, how valuable their insights were - and hope that their stories can contribute towards improvements in this area. Finally, I hope that I have made my subjectivities as clear as possible in this reflection, so that readers may interpret this thesis with these in mind.

2.2.2 Theoretical Positioning

Theory is said to be ‘the oxygen’ for research – key to all related practice (Braun and Clarke, 2022, pg. 156). Imperatively, whether acknowledged or otherwise, theory is influential to methodological choices. This is considered further in relation to the current project throughout this report, for example on the specific issue of sampling (see section 2.10.2), and below, ontology and epistemology are specifically defined and discussed.

Ontology is the philosophical study of reality and what constitutes a fact. It explores whether reality exists and is independent of human understanding, or if reality is a mere reflection of human perspective. The ontological spectrum may be understood as realism at one end, through critical realism, to relativism at the other (Braun and Clarke, 2013). Realism poses that there is a reality, that can be simply observed through research. Opposingly, relativism rejects this and argues for multiple constructed realities (dependent on time and context). Between these two poles sits critical realism, which posits that realities exist and can be ‘known’ – although importantly critical realism acknowledges that these realities are socially dependent.

Epistemology is the study of knowledge; questioning what can be known and how. The epistemological spectrum may be understood as positivism at one end, through contextualism, to constructionism at the other (Braun and Clarke, 2013). These different epistemological approaches make an important distinction between *discovery* and *creation* of knowledge. Positivism proposes that knowledge can be discovered (through research), whereas constructionism argues that knowledge is constantly created through discourse and social systems. Hence, in constructionism, there is no truth to be found, rather, there are socially situated knowledges to be explored. Contextualism, which sits between these two poles, seeks to find context-dependent knowledge/truth.

The researcher’s worldview and philosophical perspectives on research, as well as the aims of the study, were influential to theoretical decisions. As the current project aims to explore experiences, meanings and realities in the context of broader socio-cultural factors, critical realism was deemed the most fitting ontological framework to guide the research. Further, the researcher understands ‘truth’ to be contextually situated, yet in this research still aims to unpack the ways in which participants (in a given context) make sense of experiences. As such, contextualism was deemed the most fitting epistemological framework.

2.3 Design and Materials

2.3.1 Qualitative Design

A qualitative design was selected for several reasons. First, this topic area has not been explored among the Somali population and as such a qualitative approach is the most optimal way to gain a better understanding of the subject matter. Qualitative methods allow in-depth insight into experiences, meanings, perspectives, attitudes, beliefs, and concepts of normative behaviour, and enable researchers to fill gaps in existing knowledge (Braun and Clarke, 2013). Further, the Somali community perspective has historically been missing from appearance research, and a qualitative approach is likely the most effective way to amplify previously underrepresented experiences. It would not be appropriate in this case to use a quantitative survey made up of measures informed by the knowledge obtained through research with White Western groups. Naqvi and Saul (2012) highlight that the lack of ethnically/culturally diverse appearance research is in part caused by a lack of appropriate outcome measures. The use of a qualitative design thus avoids this issue.

Alternative qualitative approaches were considered, including interactive methods (e.g., focus groups, interviews) and non-interactive/participant-led methods (e.g., qualitative surveys, story completion tasks). Ultimately, it was felt that an interactive method would allow for the generation of more rich and in-depth data owing to the potential for the researcher to ask follow-up questions. Both focus groups and interviews were considered. Interviews involve a conversation between participant and researcher (and any other relevant third party e.g., interpreter), and can be unstructured, structured, or semi-structured; allowing the researcher to select their level of involvement in the discussion (Gill *et al.*, 2008). Focus groups are similar but involve collecting data from multiple participants through a group discussion (Gill *et al.*, 2008). Although particularly suitable for research on group norms and values, focus groups can be unsuitable for research involving individuals who are uneasy with one another, or research pertaining to taboo topics, as both factors can impede disclosure (Morgan *et al.*, 1998). Given existing evidence that health-related stigma is prevalent among Somali communities (e.g., Linney *et al*., 2020; Fox *et al*., 2017; Gerrish, Naisby and Ismail, 2012; Loewenthal *et al*., 2012), and the potential sensitivity of the topic of appearance, the researcher was concerned that participants may feel hesitant to share experiences with others from their community. The use of interpreters in focus groups (recruited to increase accessibility, see section 2.4) may post additional pragmatic challenges. Interviews were therefore selected as most appropriate.

2.3.2 Semi-Structured Interview Method

Qualitative interviews can be structured, semi-structured, or entirely unstructured. Semi-structured interviewing is commonly used in health research as it allows for flexibility and balance between supporting/focussing the discussion on relevant area and giving participants freedom to explore their unique experiences (Galletta, 2013; DiCicco-Bloom and Crabtree, 2006). As such, this approach was selected for the current study.

More creative strategies can also be applied to the original ‘semi-structured interview’, for example, narrative interviews. Narrative or life-story interviews involve participants sharing their story, often leading to participants/researchers shifting from an interviewer-interviewee dynamic, to a narrator-listener one. Given that the current project aims to amplify participants’ experiences, this approach was considered. Narrative interviews have been previously applied in health and wellbeing research (Anderson and Kirkpatrick, 2016). However, this approach increases participant preparation, which may pose accessibility concerns. For example, ahead of a narrative interview, participants are required to think of chapters that depict their story. This requires mastery of English (Anderson and Kirkpatrick, 2016). Given that English proficiency could be an issue for some participants in the current study, to reduce barriers to participation, this method was not selected.

An interview schedule was developed (Appendix 2), based on the researcher's own experience and understanding of the topic area, discussions with supervisors and colleagues (experts in field), input from Public Involvement (PI) representatives (see section 2.5), and the limited available literature pertaining to the experiences of UK minority groups with visible differences. Reflexive Thematic Analysis was selected as the method for data analysis (see section 2.9). As such, guidance from Braun and Clarke (2013) about how to develop robust interview schedules was followed. Thus, when devising the interview schedule, the researcher asked herself important questions such as: *What am I aiming to find out from this question? Does the question tackle my research aim(s)? Are there problematic assumptions embedded in the question? Is this question likely to be meaningful to participants, and how will they feel about being asked it?* For the last question in particular, insight from PI representatives (both from the visible difference and Somali community) was imperative, and the interview schedule was adjusted to reflect their feedback (see section 2.5). During interviews, the researcher followed the semi-structured interview guide, and asked follow-up questions as needed to expand on some of the responses (e.g., Interviewer: *Can you tell me about X*; Participant: *X was hard*; Interviewer: *What exactly about X was hard? How did that make you feel?*).

2.4 Translation and Interpretation

Language has been previously identified as a barrier to minority group engagement in appearance research (Naqvi and Saul, 2012). In other areas of research the provision of interpretation services has facilitated minority group involvement (e.g., Irvine, Roberts and Bradbury-Jones, 2008). In health, provision of professional interpreters is shown to improve health access, care, and clinical outcomes for patients with Limited English Proficiency (LEP; Karliner *et al*., 2007). Given this study's emphasis on maximising accessibility, and the possibility of participants having LEP, participant-facing materials were translated to Somali (Appendix 3b, 4b and 14b).

The provision of interpreters during interviews to facilitate engagement was also considered. There are concerns about using interpreters in research, including the impact of inaccurate translations and poor interviewer-interpreter alliance, which can negatively influence interviewer-interviewee relationship, and risk of interpreters 'taking over' the interview (Gill *et al*., 2013). For example, Patel-Kerai *et al*. (2015) carried out a qualitative study to explore Gujarati-speaking Indian women's experience of breast cancer diagnosis and treatment. As the lead author understood Gujarati, they were able to identify inaccurate interpretations.

Despite these potential limitations, two interpreters were recruited and offered to participants to increase accessibility, and steps were taken to minimise potential challenges. Interpreters were provided with a full brief about the aims of the study and given the opportunity to ask questions through telephone, Microsoft Teams or Zoom. During this meeting, the importance of confidentiality and accurate translations was reinforced, and the interview schedule was shared. Details of how the interpretation would be carried out were also discussed. For example, it was agreed that first- (I, we) rather than third- (he, she, they) person language would be used to encourage interpreters to translate verbatim without modification. It was also agreed that the interview would take a back-and-forth approach (i.e., interviewer asks question to interpreter, who asks question to interviewee, and then translates back to interviewer) rather than be entirely led by the interpreter (i.e., interpreter carries out interview independently). Although this option makes interviews longer, it allows the researcher the opportunity to ask for clarification or pose follow-up questions.

Following consultation with Somali PI representatives (see section 2.5), other more culturally nuanced issues around interpreters arose. Somali women may feel uncomfortable speaking about sensitive topics with Somali men - and vice versa. Further, as Somali communities are close, interviewees and interpreters may know each other which could raise concerns regarding anonymity. This is also reflected in broader health research with Somali individuals in the UK (Loewenthal *et al*., 2012). As such two interpreters were recruited, one male and one female. Participants were able to choose whether to have an interpreter and their gender. This option was communicated to prospective participants in participant-facing materials and initial communications with researcher, so they could give fully informed consent. All participants declined the offer to have an interpreter present during interviews (discussed further in section 4.3.2).

2.5 Public Involvement

2.5.1 Introduction

Public Involvement (PI) is defined as research carried out with or by members of the public, rather than to or for them. It is central to health research; reflected in the development of best practice guidelines/frameworks, and the demand of many research funders to see evidence of PI. It actively seeks to engage members of relevant communities in research to varying degrees and has the potential to improve the entire research process, including relevance, impact and integrity and the experience of those involved (Dawson *et al.*, 2020; Brett *et al.*, 2014).

A community participatory approach was adopted in the current research, which involves a partnership between researcher(s) and community members, with all parties contributing to the decision-making process. For this project, this was particularly imperative given that the researcher is an outsider from the group of interest (see section 2.6.2.1). As such, the aims of PI in the current study were to obtain the perspectives of relevant community representatives to inform and guide the research process.

2.5.2 Best Practice

The National Institute for Health and Care Research (NIHR; 2016) published six standards for researchers conducting PI in UK-based research:

1. Working together - value contributions from all parties involved, and build mutually respectful working relationships
2. Communication - use plain and accessible language, and communicate well with representative(s)
3. Inclusive opportunities - ensure that PI opportunities are accessible
4. Impact - identify and share insights about what PI efforts achieve
5. Governance - involve representatives in research governance, including management and decision-making

6. Support and learning - offer, promote and support learning opportunities that build confidence and skills of representative(s)

As part of each standard, the NIHR pose questions for researchers to ensure that their work meets these criteria. Best practice PI guidelines were adhered to throughout this project, and the table presented in Appendix 5, provides information on how this project complied with NIHR standards.

2.5.2.1 Public Involvement During Covid-19

This project was carried out during the peak of Covid-19 (2020, 2021), and the impact of the pandemic should be fully considered. Importantly, since the development of the NIHR guidelines, Covid-19 has altered how research is carried out. Thus, the NIHR (2021) updated advice about co-production during Covid-19. These include strategies for ensuring that PI is as accessible and safe as possible (e.g., safeguarding representatives when working remotely). Similarly, other authoritative bodies have also published guidance to promote accessibility and facilitate remote involvement in PI during Covid-19. For example, the National Co-ordinating Centre for Public Engagement (2020) published advice about how to run online meetings effectively with representatives. The researcher followed current advice during this project. For instance, providing flexibility about the choice of online platforms alongside providing about how to use platforms.

2.5.2.2 Involving Underserved Groups

The NIHR (2020) define the term ‘underserved’ as groups who are less included in research, have a higher healthcare burden, and respond to/engage with health services differently. Importantly, the term underserved does not place fault on groups members for research inequities (e.g., lack of inclusion), as may be suggested by other terms like underrepresented. Guidelines have been published specifically on diversifying PI efforts to ensure they are accessible for underserved groups (INVOLVE, 2012). This issue is particularly pertinent given that, as with other minority groups, the Somali community has historically been disengaged from research (UyBico, Pavel and Gross, 2007). Previously identified barriers to minority group engagement in PI include negative attitudes about research, limited relevant knowledge and information, financial restrictions and inequitable power dynamics between researchers and representatives (Ocloo *et al.*, 2021). Steps were taken to minimize the impact of these barriers (see Appendix 5). For example, communicating with representatives to increase their knowledge and reduce misunderstandings related to PI, as well as providing financial compensation for their time (see section 2.5.3.2).

2.5.3 Design

2.5.3.1 Representatives

Three PI representatives from the Somali community were engaged to provide advice. Whilst none had visible differences, they could all draw on cultural knowledge to comment on the appropriateness of this research for the Somali community. The group were two women and one man and, as their ages spanned from mid-20s to late-40’s, could provide inter-generational insights. In addition, one White British PI representative from the visible difference community also provided advice. Though not Somali, their lived experience allowed them to comment on the appropriateness of this research for the visible difference community.

Other relevant individuals were also consulted. This included two individuals with experience of research with the Somali community. One had extensive contacts with the local Somali community due to previous activism work and sat on relevant groups and boards. The other was the Head of Equality Diversity and Inclusion at the North Bristol NHS Trust.

Individuals were identified and engaged through recommendations from supervisors and relevant organisations (see Appendix 6).

Finally, the relevant experience of supervisors was also drawn upon. Two supervisors are expert in health psychology and visible difference (Professor of Appearance and Health Psychology; Associate Professor in Applied Health Research), and one is expert in health and related (in)equality (Director of the NHS Race and Health Observatory).

2.5.3.2 Procedure

First, communication between researcher and representatives was established, and key information about the project was discussed. Generally, representatives were contacted via email. After expressing an interest to be involved, they were invited to join a one-to-one meeting (via Zoom, Microsoft Teams, or telephone) to discuss the project in more depth and provide feedback on research materials (Appendix 7; meeting guide and plan). Ahead of this meeting, representatives were sent a ‘PI Resource Pack’ which contained draft study materials, including the participant information sheet and consent form, recruitment plan, study advert, and interview schedule (Appendix 8). Representatives were invited to review these in advance of the meeting and note initial thoughts and questions for discussion.

The researcher kept an ‘impact log’ of interactions with PI representatives (see Appendix 9 for example). This log detailed: information about each meeting, such as date, type of meeting, attendees; a summary of discussion points; any impact/outcomes following discussion; and other relevant information. To ensure transparency and collaboration, both of which are features deemed important in quality PI (NIHR, 2016), this document was shared with representatives who were invited to edit if necessary.

Throughout the project, PI representatives were updated on progress and consulted when advice was required (e.g., on recruiting older participants). Two representatives also carried out interpretation/translation work (see section 2.4), and at the end of the study all were provided with an infographic of the findings (Appendix 10).

In recognition of representatives’ contributions, and common barriers to involvement (e.g., financial), the NIHR recommend reimbursement of expenses and/or payment to promote accessibility, inclusivity, and illustrate the value of PI (NIHR, 2022). While no known expenses were incurred by representatives in this study, they were offered an honorarium payment. The NIHR suggest £25 for tasks/activities lasting approximately one hour; £50 for two hours; and £75 for half a day. Representatives carried out tasks that equated to around half a day’s worth of work for this project. However, as the project had limited funds and institutional barriers which limit paying external parties, participants were offered £20 online shopping voucher as a thank you. Whilst not in line with for recommended honorarium payment amounts, it was hoped that this token would serve to recognise contributors' time and effort, particularly during the earlier phase of the research which required more input (e.g., detailed feedback on research materials).

2.5.4 Evaluation and Reflection

There is growing literature on the importance of evaluating PI, and frameworks for doing so have been published (Gibson, Welsman and Britten, 2017; Pollard *et al.*, 2015). Evaluating PI can provide insight into what is (in)effective, and thus facilitate planning for future research. Given that Somali people have historically been disengaged with research, evaluating PI was particularly important. Representatives were invited to provide feedback about their involvement with the project through an online survey (Appendix 11), which three of the four representatives completed. When asked about reasons for contributing, representatives cited a desire to help others and learn something new, as well as an interest in the project more broadly. Representatives reported that these objectives were achieved; they positively influenced the study, enjoyed sharing information, had a positive experience with the researcher (e.g., feedback well received, ongoing commitment to building trust with community); and were generally enthusiastic/curious about the study (Appendix 12).

It is also important that researchers reflect on their own PI work to learn and improve from experiences (NIHR, 2016). As such, after each interaction with a PI representative, the researcher kept a 'personal reflections' log (see Appendix 13). For example, after meeting the first PI representative and noticing their uncertainty about the purpose of the meeting and objectives of PI more broadly, the researcher provided more information about PI and what to expect to the remaining representatives ahead of the initial meeting. This addition proved effective for increasing representatives' knowledge.

2.6 Sampling and Recruitment

2.6.1 Sampling Criteria

People of Somali heritage, over the age of 18, currently living in the UK, that have any form of visible facial difference, were invited to take part in this study. The focus on *visible facial differences* reflected PI feedback that this term is more inclusive, clear, and accessible than other terms, such as scarring, thus reducing the risk of misunderstanding the study's aim. For example, historically the UK Somali community has been subject to criticism around FGM which has led to alienation and animosity between communities. A Bristol University study found that FGM-safeguarding policies have offended and subsequently damaged relations between the local Somali and wider communities (Karlsen *et al.*, 2019). As such, it was felt that approaching the Somali community about experiences of differences more broadly (not confined to the face) may lead to misinterpretation of project objectives (i.e., FGM-related), and subsequently damage researcher-community relations. The term *visible facial differences* removed this possibility. In addition, it concentrates on the face and thus focuses on the aspect of looking noticeably different to others.

2.6.2 Recruitment

2.6.2.1 Doing Research as an ‘Outsider’

The researcher expected that recruitment would be challenging. The Somali community, as with many other ethnic and cultural minority communities, has historically under-engaged with research activities, in part due to typical research recruitment efforts and practices being exclusionary and ineffective at reaching wider audiences (UyBico, Pavel and Gross, 2007). Additionally, the researcher is not of Somali heritage, which posed concerns about the community’s willingness to engage. Evidence suggests that research involving individuals from minority groups can be particularly challenging when the researcher and participants do not share the same background (Dwyer and Buckle, 2009; Irvine, Roberts and Bradbury-Jones, 2008). The researcher’s ‘outsider’ status could induce a level of reticence, making it difficult to access participants and build rapport (Berger, 2015; Brannick and Coghlan, 2007). Alternatively, some argue that being an outsider may have a positive impact in that an external perspective enables more ‘objective’ and critical practice (Dwyer and Buckle, 2009; Brannick and Coghlan, 2007). However, this notion does not align with qualitative research, where the aspiration of achieving ‘objectivity’ is largely discredited (as it is contrary to underpinning philosophies and methodologies; Braun and Clarke, 2021). Nonetheless, the issue of rapport building is particularly relevant for this project, given that qualitative research involves more intimate contact between researcher and participant (Dwyer and Buckle, 2009).

Despite potential recruitment challenges, measures to ensure that research is more accessible and acceptable, to ultimately facilitate recruitment, were applied to the current project. For example, in line with advice on how to sensitively carry out research with other communities (Ross, 2017; Muhammad *et al.*, 2015), the researcher arranged an initial meeting with interested participants and used this opportunity to introduce herself and discuss relevant issues. During this meeting, the researcher drew attention to her outsider status, and invited prospective participants to ask questions, share concerns, or discuss anything else related to the project.

2.6.2.2 Recruitment Strategy

As per NIHR (2020) criteria (see section 2.5.2.2), Somalis can be considered ‘underserved’ in research. In a review of interventions to recruit such groups into research, UyBico, Pavel and Gross (2007) classified efforts into four categories: social marketing (mass mailing, mass telephone class, targeted media), community outreach (religious spaces, community leaders, organisations, house to house/door to door/face to face contact, community events), referrals (friends, family, other study participants), and health system recruitment (health professionals, medical records). UyBico and colleagues concluded that due to a lack of methodological rigour and inconsistent reporting of recruitment strategies, the evidence-base for increasing minority enrolment remains weak. Nonetheless they recommended a combination of efforts. Recruitment for this study was therefore multi-faceted, but for various reasons did not recruit through the NHS. For example, evidence from previous health research has found that minority groups and particularly Somalis, in comparison to majority groups, are more disengaged from and distrustful of healthcare services (Linney *et al.*, 2020; Freeman *et al.*, 2013; Loewenthal *et al.*, 2012). As such, there was concern that recruitment through the NHS would be ineffective at targeting individuals poorly engaged with services. It was important that this research included those accessing limited to no support and treatment, and thus likely most vulnerable to poor outcomes. Indeed, it has been argued that focusing on 'traditional' recruitment sites for health research (hospitals, healthcare institutes, academic research groups), can overlook the most marginalised groups, such that recruitment should aim to reach communities on a more personal level (Simon and Mosavel, 2010).

As per UyBico and colleagues' classifications, recruitment strategies were considered in relation to social marketing, community outreach, and personal referrals. Below recruitment is summarised into these three domains, and Appendix 6 provides a full breakdown of recruitment efforts.

1. Social marketing: The researcher collaborated with the University of the West of England's (UWE) press office to develop a press release, which was made available to national and international media outlets. A targeted and strategic approach was also utilized to connect with media outlets most popular among the Bristol Somali community. This included radio stations such as BCfm, dedicated to representing Bristol's underserved members and groups (see BCfm's Somali Show and Somali Ladies for relevant examples). As a result of the press release, in June 2021, the researcher was invited to speak on BBC Radio Bristol's breakfast show to discuss this project (available online [from 51.40 – 56.35]). Following this interview, the researcher was also invited to contribute towards a BBC news website article about the project. The article also included the perspective of Nura Aabe; the founder of Autism Independence whose work centres around raising awareness of autism in Somali community (available online). Additionally, the study was publicised via Reddit. Relevant sub-Reddits (forums), such as *r/somalia* (16,900 members), were approached and where possible, information about the study was shared on their platforms.
2. Community outreach: Research finds that recruitment through relevant community groups, organisations and charities can be one of the most successful recruitment methods for reaching the "hard to reach" (Rockliffe *et al.*, 2018). Local and national organisations connected to the Somali community were therefore approached (see Appendix 6 for list of organisations). With the aim of reaching the broader visible difference community, the project was also advertised through the Centre for Appearance Research (CAR) via their social media platforms (Instagram, Facebook, Twitter), website, and participant pool (a registry of interested research participants). The Appearance Collective charities (a group of charities dedicated to supporting people with visible differences) also helped recruitment by publicising the project through their various platforms. Appearance Collective charities include the Cleft Lip and Palate Association, Headlines Craniofacial Support, and Changing Faces (see Appendix 6 for list of charities).
3. Referrals: The researcher made connections with individuals who were recommended by others working in the area. Participants who took part in the study were also invited to communicate the opportunity to anyone they knew who may be eligible for/interested in taking part (i.e., snowball sampling).

At the end of the project, an infographic with a summary of results was also sent to groups that supported recruitment (Appendix 10). Sharing the results with the community was particularly important given this project's efforts to increase engagement in and commitment to research.

It has been argued that in research, particularly that involving marginalised groups, it is beneficial to routinely report recruitment outcomes. Research on the effectiveness of recruitment strategies is sparse, and ongoing evaluation of different methods is helpful for others' learning (Brown *et al.*, 2014). This sharing between researchers will serve to inform future recruitment strategies and accelerate advancements in relevant fields (Kling *et al.*, 2021). In the current project, the participants learned about the study via: the Twitter page of a charity (*n* = 1); a Facebook group (*n* = 2; participants did not disclose specific pages); a Reddit post (*n* = 3; participants did not disclose specific forums); information from a friend (*n* = 2; participants did not disclose where the friends learned about the study). Successful strategies involved an element of pre-established relationship and community, which may point to the importance of relationship building for research engagement among The Somali community.

2.7 Procedure

Interested individuals responded to a research advert through email (Appendix 14). Via return email they were invited to read an information sheet (Appendix 3) and privacy notice (Appendix 15) and ask questions before deciding on next steps. Those who wished to proceed had their eligibility confirmed through a conversation (phone, Zoom or Microsoft Teams) before being asked to sign a consent form (Appendix 4).

Due to Covid-19, interviews could only be carried out remotely, but as research finds that flexibility around interview methods facilitates research participation (Heath *et al.*, 2018), participants were offered interviews via multiple formats (e.g., phone, Microsoft Teams, Zoom). Participants were offered an interpreter if they felt they could benefit from this (see section 2.4). The first interview was carried out in June 2021, and the last in September 2021. Interviews lasted on average 32-minutes (range = 29 to 46-minutes; excluding the introductory, demographic and concluding content). After each interview, the researcher journaled her reflections and applied learnings as the project evolved (see Appendix 16 for example).

As the study required considerable commitment from participants (i.e., giving up their time and potentially sharing difficult personal experiences) they were offered a £10 online shopping gift card. Using incentives in research, particularly with underserved communities, is a debated issue (Parkinson *et al.*, 2019; UyBico, Pavel and Gross, 2007). There are concerns about how best to use incentives, their effectiveness, and ethical issues pertaining to coercion. Generally, it is agreed that incentives should not be significant enough to coerce participation, but rather to provide a token of gratitude. There are often further logistical barriers (e.g., project funding) to consider when deciding on incentives. After consulting with PI representatives (see section 2.5) and project funding, a decision was made to offer participants £10 gift card for an online retailer of their choice as a token for their participation.

2.7.1 Ethical Considerations

This research, including data processing arrangements, was approved in September 2020 by the Faculty of Health and Applied Sciences Research Ethics Committee (FREC) at the University of the West of England (UWE; reference number: HAS.20.07.203; Appendix 17). The British Psychological

Society's (BPS) code of research ethics was adhered to throughout the project and ethical issues specifically related to working with this participant group were considered.

Previous research has identified that obtaining consent in research with ethnic minority communities; namely those with LEP; can be challenging and raise ethical issues. For example, consent forms may be lengthy and difficult to understand (Boga *et al.*, 2011). Issues around literacy may also be problematic if written consent is necessary (Israel, 2014). In the current project, whilst written consent was necessary to meet institutional demands, actions were taken to ensure participants provided informed consent. This included a pre-consent meeting to discuss the study, as well as the provision of translated materials. Given that English was participants' second language, and communication challenges could be exacerbated by the remote nature of participant/researcher interactions, these steps ensured a more ethical consent process (Roberts, Pavlakis and Richards, 2021).

Another issue related to consent and possible coercion, concerns participants' distinction between health research and health services. Scholars have argued that individuals may misunderstand the purpose of health research, and be motivated to take part in order to access health services (Townsend and Cox, 2013). As such, in the initial conversation with interested participants the researcher clarified the difference between the research project and any (medical or psychological) services that participants may access. In doing so, she reinforced that the two are not related, and that not engaging with one will not result in repercussions for the other.

2.9 Data Analysis

2.9.1 Reflexive Thematic Analysis

Interview data were analysed using Reflexive Thematic Analysis (RTA; Braun and Clarke, 2022). RTA is a specific approach to TA (Braun and Clarke, 2006), and is regarded as a highly flexible analytical tool which enables the researcher to highlight trends and establish meaningful patterns in the dataset. Braun and Clarke currently distinguish between three main types of TA: coding reliability, codebook, and RTA (Braun and Clarke, 2019). Coding reliability and codebook TA typically centre on the development or application of structured codebooks, which often involve the input of multiple coders (in this case, coding reliability becomes important). Codebooks can also be based on previous theory/knowledge (i.e., a deductive approach). Importantly, these two TA approaches often pay importance to data saturation and frequency of codes/themes (issues further considered in section 2.10.2). In contrast, RTA centres the researcher's subjectivities and encourages ongoing introspection and explication of analytical decisions. As such, the RTA approach is more conducive to the aims of this study, and better aligned with the researcher's theoretical positioning (see section 2.2.2).

2.9.1.1 Choosing Reflexive Thematic Analysis

Phenomenological Analysis (IPA), Grounded Theory (GT), and Discourse Analysis (DA; Braun and Clarke, 2013) were also considered. IPA (Smith, Flowers and Larkin, 2009) facilitates the investigation of individual's lived experiences, as such, it has a phenomenological focus (i.e., how people perceive and discuss specific issues). The interpretative element of IPA recognises the role of interaction in meaning-making, namely, the interaction between the interviewee and interviewer. IPA applied to this project would give insight into how a given person (individual of Somali heritage), in a given context (living in a ‘foreign’ society, having a different appearance), makes sense of a given phenomenon (a combination of those intersections) – as interpreted by the researcher. Given the possible addition of an interpreter in this project, the possible impact on the *interpretive* element of IPA was considered. Arguably, a third party causes triple hermeneutics. As no published guidance on using IPA with an interpreter was found, the creator was contacted for his opinion (see Appendix 18 for email excerpts). Although not able to offer complete clarity, they recognised the dilemma and noted that using IPA in this context would require careful consideration of hermeneutics-related complexities. Further, IPA is not theoretically flexible, and is only able to answer questions about individual experiences and perceptions, rather than explore the role of social contexts (Braun and Clarke, 2021b). As such it did not fit with the ontological and epistemological ambitions of this study. Moreover, IPA has been deemed less useful to applied research, which aims to have ‘actionable outcomes’ (Sandelowski and Leeman, 2012) as is the intention of the current project.

DA focuses on the socially constructed nature of reality (Potter, Wetherell and Wetherell, 1987). In doing so, DA tackles issues of power and language, as these are seen as key to social constructions. As DA adopts an entirely social constructionist position, as with IPA, this approach did not fit with the critical realist ontology and contextualist epistemology of this project (see section 2.2.2). Further, like IPA, DA is not the most helpful approach for a more applied research agenda (Braun and Clarke, 2013)

Finally, GT is a sociological approach which focuses on building theory from the data (Glaser and Strauss, 1967). Issues related to theoretical sampling and saturation are relevant in GT given the focus on the generation of theory. Whilst GT is ontologically/epistemologically flexible and can be for example positivist or constructionist, it is primarily concerned with developing a theoretical model. However, given that the current research topic is under-explored, the development of theory was not a priority. Further, for the purpose of developing theory, GT requires a larger and more heterogeneous sample (Braun and Clarke, 2021b), which again did not fit the current study.

Ultimately, after deliberating on the most widely used approaches to qualitative analysis, RTA was deemed the most appropriate, fitting with the practical and theoretical scope of this project. However as with all analytic approaches, RTA is not without criticism. Some critics posit that (R)TA is basic, unsophisticated and descriptive (Crowe, Inder and Porter, 2015; Vaismoradi, Turunen and Bondas, 2013). In response, Braun and Clarke argue that this greatly depends on the type of TA that is done, and how it is done. They contend that much of TA that has been published is poor - given the flexibility of the approach, it can be misunderstood, particularly when researchers do not sufficiently engage with theory (Braun and Clarke, 2021a). TA can never be atheoretical, and theory will inevitably influence the analytic process. However, researchers do not always explicitly report, or indeed personally acknowledge this, which can lead to weak TA. To account for this, in the current report the researcher has explicitly outlined her philosophical/theoretical assumptions (see section 2.2.2) and has carried out the analysis in line with what has been declared.

Other challenges presented by TA, particularly RTA, is that it can be difficult to apply to larger samples. In these cases, the data may present more complex and at times contradictory accounts, and researchers may find it difficult to capture unique accounts (Braun and Clarke, 2022). As the current study was not seeking a large sample this issue was not applicable. Ultimately, RTA can be weak, or it can be strong if carried out appropriately. The researcher in the current study was committed to quality qualitative analysis and took the necessary steps to ensure the analysis was conducted soundly (see section 2.9.2).

2.9.1.2 Doing Reflexive Thematic Analysis

The six procedural steps to carrying out RTA (Braun and Clarke, 2022) were followed. This involved conducting a close reading (and re-reading) of the entire dataset, noting early analytic observations, and identifying possible items of interest. A subsequent detailed and systematic reading of the dataset was then carried out to identify key features and generate provisional codes. Coding was carried out on NVivo, a qualitative data analysis software (see Appendix 19 for exemplar coding). Then, as patterns formed, candidate themes were developed from the earlier coding. Following this, themes were reviewed and refined, and a thematic map was developed which helped to observe relationships between themes and ensure uniqueness. With input from supervisors, the researcher then finalised and named themes. The last procedural step is the write-up, and Braun and Clarke note that any work on the data, including writing about data, is part of the analysis.

2.9.1.3 Deductive and Latent Reflexive Thematic Analysis

RTA can be inductive or deductive (Braun and Clarke, 2022). An inductive approach is grounded in the content of the data, whereas a deductive approach is guided by existing concepts, ideas, and theory. Similarly, RTA can be carried out in a semantic or latent way. The semantic approach focuses on the explicit content of the data and the latent approach considers assumptions underpinning the data. Whilst there is freedom and flexibility of choice in RTA, it is important that choices are explicitly outlined, remain consistent throughout analysis/reporting (Braun and Clarke, 2022), and are coherent with theory. Whereas (critical) realists interested in reporting reality(ies) may align better with the inductive and semantic approaches, constructionists interested in reporting socially dependent constructions may align better with the deductive and latent approaches. Consistent with ontological and epistemological positions, a (mostly) inductive and latent approach was selected for the current project. The analysis was interested in representing the content of the data (inductive), albeit with the researcher recognising and accepting that her pre-existing knowledge and assumptions about visible difference and broader health research will have influenced coding and theme development (deductive). As such, the current study took a combined approach, encompassing both inductive and deductive ways, which is recognised and validated by Braun and Clarke (2022). An entirely inductive approach would not allow for contextual considerations, whilst an entirely deductive approach could be detrimental in the current context given that the researcher is an ‘outsider’ – which may increase risk of over-analysis, excessive interpretation, and appropriation of knowledge (Reyes Cruz, 2008). Further, given that this study aimed to explore how cultural knowledge and attitudes may influence experiences, the analysis took a latent approach; exploring deeper, more implicit meanings of the data; whilst still maintaining the desire to reflect participants’ accounts accurately (semantic). Abrams *et al*. (2020) suggest that carrying out health data analysis at both semantic and latent levels can facilitate a more comprehensive and intersectional understanding of experiences – whilst a semantic approach gives weight to the narratives of participants, a latent approach enables thought about deeper assumptions and beliefs.

The outlined ontological and epistemological stances, and the chosen method of analysis (which emphasise the researcher's *interpretation)* may seem opposed to the original aim of amplifying participants' experiences. Arguably, any exploration of data by the researcher will affect the way in which results are presented. In acknowledging this interplay, a collaborative relationship with participants was adopted in the current project. At the end of interviews, participants were invited to consent to receiving further information and updates about the study, and all participants agreed. Following analysis, the researcher emailed participants an infographic of the results (Appendix 10) and invited discussion. Whilst no participant had any feedback that altered the results, it was important that the conclusions and findings resonated with participants, and that they felt it was an accurate and sensitive reflection of their experiences.

2.9.2 Quality in Qualitative Research

Although the qualitative method (and RTA more specifically) is flexible, experts provide guidance to maximise the 'quality' of qualitative research. For example, Tracy (2010) recommends eight key markers of quality qualitative research, which include: worthy topic, rich rigor, sincerity, credibility, resonance, significant contribution, ethical, and meaningful coherence. Similarly, Meyrick (2006) lists key criteria for judging the quality of qualitative research which are broadly divided into two fields – transparency and systematicity. While specific checklists have been published for guiding quality qualitative research, for example, the Consolidated Criteria for Reporting Qualitative Research (COREQ; Tong, Sainsbury and Craig, 2007), these may be less appropriate for RTA. For example, the concept of data saturation, found in the COREQ, is one that contradicts the fundamental philosophy of RTA (i.e., subjectivity; Braun and Clarke, 2019; see section 2.10.2 for more information).

With a specific focus on RTA, Braun and Clarke (2022) describe strong and weak analyses. Quality RTA begins with the researcher allowing sufficient time to complete all analytic phases. Before analysis, transcripts should be detailed and accurate. During analysis, each data item should receive sufficient attention, and codes should be inclusive and comprehensive. Themes must move beyond the questions asked during data collection (i.e., topic summaries), and be clear, coherent, rich and distinct – and there should be a central organising concept (i.e., shared meanings between themes). In reporting, data should be *analysed* rather than simply *paraphrased*, and results should be easily understood by readers. There should also be an appropriate balance between data extracts and analytic narrative. Owing to the interpretative element of RTA, in describing the data/analysis, researchers should do so actively rather than passively (i.e., themes do not 'emerge'). Imperatively, theory must be acknowledged and clearly explained and consistently applied. The current project adhered to these recommendations for quality RTA. Braun and Clarke (2021a) also provide a guideline, including 20 questions for research journal editors and reviewers for publishing quality (R)TA. Appendix 20 outlines the current project's adherence to these criteria.

In some qualitative research, practices such as data checks and double-coding are utilised to promote (inter-coder) reliability and consistency – removing supposed personal biases from the analytic process.

However, in RTA, these issues are not influential (Braun and Clarke, 2022). In fact, Braun and Clarke argue that researcher bias and interpretation is relevant, acceptable and intrinsic to RTA. In doing RTA, analysis is inherently subjective and situated. As such, for the current project the researcher analysed the data independently. Whilst RTA intrinsically cannot be ‘accurate’ or subjective, it can be weak (as described above). As such, the researcher made use of the expertise of her supervisory team and asked them to ‘sense check’ her data and analyses. Further, the Director of Studies checked through the NVivo file that was used for analyses, reviewing interview and coding quality.

2.10 Participants

2.10.1 Participant Characteristics

Eight participants took part in interviews, five men and three women, varying in age from 19 to 28 years (mean = 23.5). Visible differences included congenital conditions *(n* = 2; albinism and cleft lip), skin conditions (*n* = 2; eczema and acne), and four acquired facial scarring (through accidents (*n* = 1) and physical conflicts (*n* = 3)). All participants were born in Somalia and had immigrated to the UK when they were between 5 and 14 years of age (*m* = 7.6). Four had university degrees, three had attended college, and one did not complete formal study beyond secondary school. Six participants reported being single, one in a relationship, and one married. Most (*n* = 5) were unemployed, two were employed, and one was a homemaker. Although eight participants took part in an interview, others (*n*=7) expressed interest (Appendix 21).

Participant demographic information is shared in a group format (as opposed to a detailed table breakdown of each participant) to maintain as much anonymity and confidentiality as possible (Morse and Coulehan, 2015). Arguably, concerns about breaks in anonymity and confidentiality in research can be an area of concern for marginalised groups, contributing to reduced participation (Ahlmark *et al.*, 2015). As recommended (Morse and Coulehan, 2015), this report presents only key demographic information and refers to participants as Participant 1, 2, etc., instead of using pseudonyms, which could be misinterpreted. In section 3.3.2, participants’ gender is cited for purposes of contextualising and interpreting gendered narratives, though elsewhere this is omitted.

2.10.2 Data Saturation, Representativeness, Sample Size and Study ‘Power’

Eight participants may initially seem insufficient, and possibly raise issues about data saturation and the ‘representativeness’ of the sample. Data saturation has historically been regarded as a helpful concept for determining sample size in qualitative research, and features in many ‘quality checklists’ (e.g., COREQ). Concerns about data saturation exist, including if novel and key information could be obtained by increasing sample sizes. Fugard and Potts (2015) propose a model for determining sample size in TA, and advocate for a consideration of theme prevalence, theme frequency, and study power. The issue of power has also been (re-)considered by other scholars. Malterud, Siersma and Guassora (2016) propose that power can be calculated by reviewing the study aim(s), specificity of the target group, use of theory to inform analysis, quality of the data generated, and strategy for analysis. A high-powered study is one that has narrow study aims, a small target group of participants, focuses on a topic which is supported by established theory, generates rich interview data, and utilises an analytic approach which allows in-depth analysis of narratives – and ultimately requires less participants. Applying the concept of study power to the current project suggests that it has high power and thus requires a reduced sample size to meet its aims (Appendix 22).

However, Braun and Clarke (2016) caution against such concepts in (R)TA as they do not align with fundamental values and assumptions. Namely, concepts of data saturation, power, and sample representativeness/size draw on essentialist assumptions which are not compatible with the RTA approach (Byrne, 2015; Emmel, 2015; Hammersley, 2015). Instead, in RTA, meaning is generated through interpretation of data, and the analytic process itself is values. Therefore judgements about 'how many' data items/participants, and when to stop data collection, are dependent and on project subjective for researcher(s). Similarly, Low (2019) argues that the notion that saturation can be achieved when no novel information arises is incorrect, as more insights will inevitably happen as new data is collected and analysed. For such reasons, Braun and Clarke (2022) do not generally advocate for specific sample sizes in RTA and further caution that larger samples are not always optimal, as this poses more challenges for meaningfully interpreting and reporting complexities in the data. Further, Braun and Clarke do not discredit pragmatic decisions about sampling, such as those based on funding, time and resource.

The ways in which researchers conceptualise themes is also imperative for considering issues related to data saturation and study power. Braun and Clarke (2016) argue that approaches such as that advocated by Fugard and Potts (2015), view themes as ontologically real and able to be discovered by researchers. Consequently, Fugard and Potts view theme prevalence (i.e., how frequently themes are represented in the data) as key. This view that themes can be found and exist beyond the researcher's unique interpretation of the data aligns with the views of coding reliability/codebook TA - premised on the importance of representativeness. However, in RTA, theme prevalence is often not key (though this is dependent on ontological and epistemological factors), and instead, relevance to the research question is prioritised. Braun and Clarke reject Fugard and Potts' ontological approach and argue that in RTA, it is unnecessary to chase theme prevalence for the purpose of representativeness, because generalisability is not important or possible.

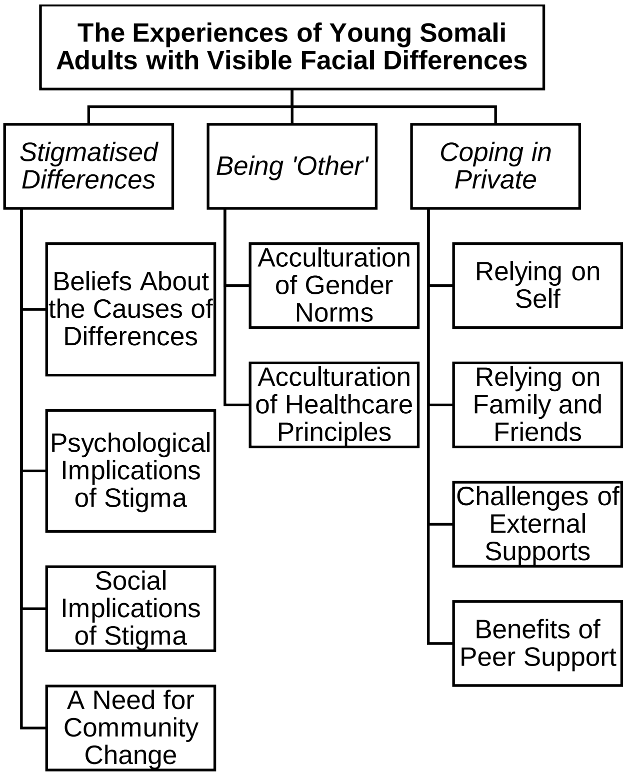
Ultimately, whilst concepts of data saturation, representativeness, study power and sample size are important to some (Malterud, Siersma and Guassora, 2016; Fugard and Potts, 2015), they are largely discredited by reflexive thematic analysts. Considering the intention to carry out RTA in the current study, adopting an essentialist perspective on theme generation (and subsequently sampling), was deemed unsuitable. Instead, the researcher viewed themes as subjective co-productions, and concentrated on relevance over prevalence. Similarly, no predetermined sample size (or quota) was applied. All participants who were interested in taking part (and met the eligibility criteria outlined in section 2.6.1), were offered the opportunity to do so. When new participant interest reduced, the researcher coded the data and explored meaning(s), and with guidance from supervisors decided that a sample of eight was sufficient to answer the research question. Indeed, Braun and Clarke advocate that instead of prioritising data quantity, researchers should devote more time to quality – spending reflective and thoughtful time with their data during the analytic process. This approach was adopted, and the researcher made a situated, interpretative judgement about when to stop analysis and move to the development of themes, and when to stop the development of themes and move to writing the current report.

Results

3.1 Chapter Introduction

RTA identified three themes related to the experiences of young Somali people with visible facial differences: S*tigmatised Differences*; B*eing 'Other'*; and C*oping in Private*. Each theme has several subthemes. A thematic map (Figure 3) provides a visual illustration of the findings. Below, themes and sub-themes are illustrated with exemplar quotes from Participants (P). Quotes have been edited to remove redundant content and improve clarity/readability. Quantifying language; used only for the purpose of explaining findings in this report (see section 2.10.2); follows guidance proposed by Hill *et al*. (2005). "All" participants refers to all or all but one, "most" refers to more than half, and "some" refers to less than half but more than two. Themes are discussed in relation to available literature from the broader health psychology, health and visible difference fields – including that pertaining to Somali people specifically, other 'minority' communities, and 'majority' groups when other literature is not available. This is not intended to dismiss the unique experiences of Somali people specifically or encourage/contribute to a potentially problematic discussion about broad 'BAME' issues (Milner and Jumbe, 2020; Miranda, Nakamura and Bernal, 2003; see section 1.3.1). Rather, it is a way to contextualise the current findings within the (limited) existing knowledge base.

Figure 3. Thematic Map



3.2 1: Stigmatised Differences

3.2.1 Theme Summary

They could hate you for no good reason, they could go ahead and say it's a curse, they could discriminate you (P8)

This theme relates to participants' accounts of the Somali community's negative beliefs about the causes of visible differences, and the subsequent consequences for Somali people affected by visible differences. Participants consider various beliefs, including the idea that visible differences are caused by sin, a curse/punishment from God, or an indication of poor moral character. Then, participants discuss the personal and social implications of these beliefs for Somali people affected by visible differences. Personal challenges include poor self-esteem, symptoms of depression, elevated stress, reduced self-confidence, and overall appearance-related distress. Social challenges include discrimination and difficulties with friends, and romantic partners. These challenges are implied to be the consequence of stigma, and participants advocate for greater community awareness and education on this issue.

3.2.2 A: Beliefs About the Causes of Differences

Most participants reflected on negative beliefs held by some Somali people pertaining to visible differences. For example, P4 shared that visible differences can be perceived as a punishment from God: *"Sometimes you can see that some Somali people, when they realise that you are having such a disease like eczema, they start saying that maybe you have done something wrong to God or maybe something like it's a curse."* Similarly, P7 suggested that visible differences may be viewed as a consequence of familial sin: *"I kind of feel that something bad must have* (happened that led) *to me having the cleft lip. So, I kind of sometimes feel down, I feel bad about it. Basically, in Somali culture, when someone is born with maybe a disorder or something, it is always believed that it has resulted maybe from ancient badness of some kind. When someone, a baby, is born in the community, with any defect, it is believed that maybe the parents or maybe the grandparents did something evil and that is kind of like a punishment to the family. It's always associated with bad things, and I think that has kind of made me feel associated with a bad incident."* In this extract, P7 describes the adverse impact that negative beliefs about differences had on their own development of sense of self.

Beliefs such as those referenced by P4 and P7 above are classed as fatalistic. In health, fatalism relates to the notion that conditions are determined by factors beyond an individual's control (Shen, Condit and Wright, 2009; Straughan and Seow, 1998). Whilst fatalistic beliefs position health outcomes as pre-determined by external forces and inevitable, participants also cited cause-related beliefs linked to individual actions. For example, P5 suggested that some Somali people associate visible differences (specifically scars) with poor moral character: *"Somali people think that a scar is acquired when someone* (is) *a thief or something."* The two belief systems presented by these participants are interesting when contrasted as whilst P4 and P7 place the focus on a higher power, P5 directs attention to the (negative) actions of the individual.

Similar fatalistic beliefs have been found in other areas of health. For example, in a systematic review on cancer beliefs in ethnic minority populations, Licqurish *et al*. (2017) highlighted themes related to limited knowledge and adverse beliefs/stigma. Specifically, in relation to the Somali population, research has found elements of community fatalism and stigma around various health issues, including autism (Fox *et al.*, 2017), tuberculosis (Gerrish, Naisby and Ismail, 2012, 2013), and mental health (Linney *et al.*, 2020; Loewenthal *et al.*, 2012). These types of attitudes have also been identified in other UK-based visible difference research, though not specifically related to the Somali community. (Hughes *et al.*, 2009) explored South Asian people's attitudes towards visible differences and found that looking visibly different could be seen as an indication of reduced intellectual capabilities and poor character – and that people with visible differences could be regarded as 'second class'. In research with psychosocial specialists in UK burn care services, Guest, Griffiths and Harcourt (2018) identified cultural beliefs among minority patient groups, including the belief that burn scarring is a punishment from God, and that scarring will prevent the individual from achieving success. Further, in research about the experiences of South Asian people with vitiligo (Thompson *et al.*, 2010), Chinese women with skin conditions (Lam and Thompson, 2021), minority adults with Cleft Lip and/or Palate (CL/P; Stock, Feragen and Rumsey, 2016); specific group(s) undefined), and South Asian women with breast cancer (Patel-Kerai *et al.*, 2017; Patel-Kerai *et al.*, 2015; Patel, 2014), issues related to stigma and lack of social acceptance, owing to negative assumptions about the causes of conditions, were also identified. Overall, existing evidence suggests that minority groups may have less favourable, and more stigmatised and fatalistic views towards illness and disease, including visible differences. This is supported by the current study's findings in relation specifically to the Somali community's perceptions of visible differences.

Participants also discussed nuances associated with beliefs and considered the various factors that may be influential. For example, P8 cited education and country of residence as important for attitude formation:

"(Attitudes are) *a very individual thing. Like, it depends on the person. If you have the information and you know it's a genetic disorder, you'll understand so you'll not discriminate. You love a person for who he or she is despite the condition. But for people who don't have information they could project a lot of fear onto you."*

"Mostly only when I travel to Somaliland, people will be looking at me and whispering. But (when) *I'm here in the UK I don't get a lot of stigmatisation - people are more informed."*

Theories aiming to explain why those with a visible difference are discriminated against include: evolutionary biases to ally with perceived 'attractive' and 'higher-ranking' individuals (Gilbert, 1997); a 'just world hypothesis' - that is, the idea that a visible difference is deserved (Bernstein, 1976); limited knowledge about visible differences, including incorrect perceptions of contagion; and anxiety about how to interact with people with visible differences (Langer *et al*., 1976). In line with these theories, P8 suggests that being less educated (about health conditions and visible differences) increases opportunities for medically inaccurate beliefs about the aetiology of conditions. Additionally, whether an individual has emigrated from Somalia is also described as key, which could also relate to access to education.

Limited education has been identified as a cause of stigmatised attitudes in the broader health literature. For example, a study with South Asian women with breast cancer (Gurm *et al.*, 2008) found that stigmatising comments and behaviours were more often reported as coming from older, and less educated, community members. Worryingly, ethnic minority groups are reported to be at an increased risk of limited health knowledge. For example, in breast cancer research, ethnic minority women are found to have limited knowledge of breast cancer, particularly if they are less educated and less acculturated to western society (Wood and Scanlon, 2005). In a UK Somali context, Cochrane *et al*. (2016) reported a lack of understanding about hepatitis B. In addition to contributing to stigma, limited health education can also act as a barrier to care. Guest *et al*. (2018) found that negative beliefs of minority patients influenced psychosocial care delivery and patient outcomes in burns care. In mental health, lack of knowledge and understanding limited access to support for Bengali, Urdu, Tamil and Somali communities in the UK (Loewenthal *et al.*, 2012).

3.2.3 B: Psychological Implications of Stigma

Most participants shared experiences which indicated appearance-related distress. For example, P4 reported that their visible difference causes them significant concern: *"When you look in the mirror and you realise that some parts of your body are not that well and are not good-looking, it's really a concern and maybe it even gives someone depression because sometimes it will seem like 'Ok, I shall not even look at the mirror because what I'm going to see will not impress me.'"* P4 also reported engaging in appearance-based comparisons with others and attempting to disguise their skin condition through appearance-enhancing practices such as wearing makeup: "(My appearance) *is a point of concern because when I look at my friends or maybe the people around me, they are trying to apply some make-up and cosmetics on their bodies and so on, so that they can look better. But from my side, I cannot do that because of the reaction the skin is having because of the eczema. So it really becomes a hard moment because you cannot even do the best of your appearance."* P2 reports similar challenges: "Y*ou're trying to fit in, you're trying to apply make-up, you're trying to cover up, then this make-up damages the skin, it makes you look worse*."

Appearance-related pressures from others were also evident in narratives and most participants cited occasions when they were encouraged by others to change their appearance. For example, P2 shared her experiences with romantic partners: "*Some boyfriends want to compare you to someone else and they tell you 'why don't you get a makeover*?'" Similarly, P3 reported being encouraged to have appearance-altering surgery, although they overtly rejected this: "(People) *told me that there are some surgeries that can change it, but I say 'no, I don't need it!' So long as I'm* (happy) *with myself, that is it*." Most participants recognised how their appearance-related distress may be exacerbated by such social pressures. For example, P4 cited a discrepancy between the appearance ideal, and their actual appearance, and posed that this difference causes them significant distress: "*It is really a lot of pressure because nowadays people are just looking good. So, when you're not able to do all that and also look good*, (it's) *depressing and stressful*."

Body image models recognise sociocultural influences on body image dissatisfaction. The Tripartite Influence Model (TIM; Thompson *et al*., 1999) suggests three primary influence variables: peers, parents and the media; affecting body image through the internalisation of societal beauty ideals (i.e., the extent to which an individual subscribes to ideals) and appearance comparisons. The model has also been expanded to include pressure from romantic partners (Tylka, 2011). Participants in the current study discussed experiencing appearance-related pressure from peers, parents and partners, yet pressure from the media was rarely reported. This may be because participants do not feel represented in the dominant Western media, and so are not as negatively impacted (Jankowski, Tshuma and Hylton, 2017). Yet, narratives also indicated high levels of appearance-related internalisation and appearance comparisons among participants. Some reported engaging in appearance-enhancing behaviours (e.g., makeup). As with most psychological research, body image models such as the TIM, have predominantly been validated with White women (Schaefer *et al.*, 2018). Thus, their relevance for other groups remains unclear, though some research suggests ethnic differences related to constructs of the TIM. For example, Javier, Moore and Belgrave (2016) noted differences between European American and African American women in relation to peer attitudes.

The emotional cost of appearance-related distress was evident across all interviews, and participants shared experiences of various psychological challenges associated with having a visible difference. For example, P2 cited low self-esteem: *"The negative is low self-esteem. At times you hate yourself, at times you feel like you're not enough."* P4 also disclosed similar feelings, in addition to depression and social isolation: *"I feel that I've experienced depression because there (*was*) a time that I would just be silent and just stay by myself, and when someone is talking to me, I cannot even notice that they're talking to me. It's not that I don't like interacting with people, it's just that the situation that I had… maybe that's low self-esteem."* Similarly, P7 discussed not feeling socially accepted: *"I've always felt like I don't fit into society. Like I'm different from other people, kind of unique and all that. In most situations, I kind of feel like I'm the odd one out."* The psychosocial consequences of having a visible difference, such as heightened appearance-related distress (increased perceived pressures from others, concerns about noticeability, heightened preoccupation with looks), and a greater overall impact of appearance on Quality of Life (QoL), are commonly cited, including in research with minority ethnic and cultural groups (Lam and Thompson, 2021; Patel-Kerai *et al.*, 2017; Stock, Feragen and Rumsey, 2016; Patel-Kerai *et al.*, 2015; Patel, 2014; Hutchinson *et al.*, 2011; Reekie, 2011; Thompson *et al.*, 2010; Hughes *et al.*, 2009; Rumsey *et al.*, 2004).

P7's account of feeling different to others is perhaps a representation of double jeopardy, as suggested by intersectionality theory which considers multiple dimensions of privilege/discrimination that can influence wellbeing (Viruell-Fuentes, Miranda and Abdulrahim, 2012) - in this case, the combination of living in a foreign culture and looking different. Participants' Somali heritage makes them ethnically, culturally and religiously different to the majority population of their country of residence (UK). In addition, their visible facial differences make them an outsider to both broader society and the Somali community. Whilst feelings of social alienation are not uncommon among those with visible differences, it is reasonable to conclude that for P7 (and the rest of the sample), double jeopardy is at play, making their experiences of visible difference more pronounced and challenging.

Though research from the broader body image and visible difference literature may be helpfully applied to contextualise current findings, existing research related specifically to appearance among Somali people is severely limited. Akou (2004) wrote about the importance of clothing for Somali women in Minnesota (US), including the use of clothing to express a collective identity and hold on to their homeland, culture and history – suggesting that appearance is valued in this community. Gardner *et al*. (2010) conducted, to the author's knowledge, the only published study on body image among Somali people. They explored the perceptions and influences of body image in Somali women in Liverpool (UK) and identified a negotiation of Somali and British culture as a self-protective strategy. That is, the women drew on selected elements from each culture to positively shape their own body image. Gardner *et al*. also discussed the impact of age and gender on ideals of body size and diet. For example, older Somali people favour larger bodies, and Somali men prefer a traditional Somali diet. Given the important influence of body image on wellbeing, more appearance research is needed with Somali groups to understand how they perceive and experience appearance-related issues – both in the general population and among those with visible differences. A specific appearance issue which may be relevant and important for such future research to consider is colourism. Defined as prejudice and discrimination based on skin shade, colourism has been previously highlighted as an important issue for general population ethnic minority individuals in the UK, including Black men (Phoenix and Craddock, 2022). Future visible difference research could explore this issue specifically among different ethnic minority groups (e.g., Somalis) and consider its possible influence on adjustment.

3.2.4 C: Social Implications of Stigma

All participants disclosed negative experiences with others, to varying degrees. These experiences were often rooted in stigmatised beliefs about differences which worked to legitimise discrimination. One example of such discriminatory behaviour was avoidance, as referenced by P4: *"*(Somali people) *are trying to avoid the person. Maybe because they see* (the condition as) *a punishment, and they should not come closer to the person. Or maybe they try to say the person is not worthy and is a sinful person."* Similarly, P8 also cited personal experiences of discrimination, including differential treatment and unwanted questioning/staring: *"People would ask so many questions.* (They) *ask what it was. Others thought I had suffered some bad curse. So many questions from people, many looks. I tend to get mad when people ask."*

Unsurprisingly, for most participants, these negative social experiences adversely impacted their wellbeing. For example, P4 asserted: *"It really affects* (me) *when someone is looking and staring. I also get concerned about what people are going to say - maybe they're going to say as if I don't take good care of myself."* P4 described a strong fear of negative appearance-evaluation, likewise, P7 expressed a history of negative social experiences which had caused them to be cautious of social situations, particularly those involving new people: *"I think I really find it hard to interact with new people and to get to know new people because of my condition. I fear what they may be thinking of me. I always notice how some people whisper when they look at me. It makes me feel bad. I think I'm a bit uncomfortable in public."*

Discriminatory acts by others such as avoidance, differential treatment and exclusion, and unsolicited questioning about their appearance/condition are also reported in existing UK-based visible difference research with other minority groups (Stock, Feragen and Rumsey, 2016; Hutchinson *et al.*, 2011; Reekie, 2011; Thompson *et al.*, 2010; Hughes *et al.*, 2009). Evidence of such stigma is also found in the broader visible difference literature. For example, older adults with burn injuries have described challenging reactions from the public – such as staring and unwanted comments (Jones, Buchanan and Harcourt, 2017).

In the current study, participants also discussed challenges relating to specific social groups, including friends and romantic partners. With regards to friends, some participants reported being excluded due to others feeling ashamed to be associated with them: *“One of my friends denied me to be his friend. He claimed in front of other people that I wasn’t his friend. It was kind of shame to him having a friend with a scar on* (the) *face.”* (P5). P1 also reported feeling rejected by friends and cited the negative impact that this had on their wellbeing, including shame and loneliness: “*At a young age it had a great impact* (on me) *because many of my friends were mainly not well being with me because* (my scar) *was moderately visible. I used to play football but mostly I was segregated by my friends in their teams, so wasn’t selected more often because of my scar. At the time* (it made me) *feel embarrassed, I was ashamed of what was happening. I was just lonely.”*

Similarly, P4 cited friends who believed that their condition was contagious, which led to discrimination: *“Some of my friends, they say that they’re friends, but they don’t even want that contact, because they say as if I’m going to transfer the disease.”* (P4). This concept of contagion indicates limited understanding about visible differences as none of the participants had contagious conditions, though this response is not uncommon. (e.g., Shanmugarajah *et al*., 2012). Perceptions of contagion can be harmful for those with visible differences as they increase negative attitudes from others, such as disgust (Shanmugarajah *et al*.). For one participant, challenges forming friendships in childhood were so pervasive that their school experience was significantly negatively impacted: *“When I was younger, the other children at times did not want to play with me, so most of the time I was always by myself. And it affected me so badly, such that I felt like telling my mum that I* (needed a) *school where there is another person like me, so, I wouldn’t feel like I don’t have friends, I’m not able to play. I would even at times cry.”* (P8). Challenges forming and maintaining friendships have also been reported in other visible difference research, for example, among those with skin conditions (Rumsey, 2018).

Participants also discussed challenges in romantic relationships and disclosed previous negative experiences with romantic partners which were again often rooted in stigma. For example, P4 shared that a previous partner left her for another person because he deemed her unattractive: *“A year ago, I was dating someone, and he just came across another girl and decided that she is more beautiful, and he left, saying that my condition is not good for him, and he is not comfortable with me. That really lowered my self-esteem and, emotionally, I was so stressed and depressed. I could not heal from that statement that he said, because it is not my will to be the way I am. So, it really, really depressed me for a long time.”* Similarly, P8 cited negative experiences with a previous partner: *“I realised that at times we would get* (into) *an argument, just like any normal couple,* (but) *they would use that weak point of* *me to frustrate me. So, I realised that they didn't really accept me for who I was."* Past negative experiences with romantic partners were detrimental to participants' wellbeing, resulting in low self-esteem, increased stress and feelings of depression.

Challenges initiating and maintaining romantic relationships is reported in the broader visible difference literature. In a qualitative study on individuals with visible differences, issues related to individuals feeling unattractive and devalued, in addition to anxieties about disclosing differences to partners, were found to have a negative impact on romantic lives (Sharratt *et al.*, 2018). Though, as with most visible difference research, these were predominantly White individuals. Additional challenges have been identified in romantic relationships specifically in ethnic minority groups with visible differences. For example, the possible influence of community stigma on inclusion, acceptance and relationship/marriage prospects (Stock, Feragen and Rumsey, 2016; Thompson *et al*., 2010; Hughes *et al*., 2009; Rozario, 2007).

The language employed in the narratives above about social challenges provides insight into participants' psychosocial functioning. It illuminates the relationships between experiences with others (and others' views) and participants' adjustment to their difference. For example, in their accounts of social experiences, P4 rejected negative and fatalistic attitudes and denied personal culpability for their condition: *"it is not my will to be the way I am."* Similarly, notions of resistance to stigma and self-advocacy have also been identified in other UK-based health-related research with Somali communities. For example, in a study with Somali parents of children with autism Selman *et al*. (2018) found evidence of parents resisting community stigma about autism, rejecting negative labels, and finding their own (less negative) vocabulary to describe their child's condition. Contrastingly, when discussing challenges in romantic relationships, P8 referred to their condition as *"that weak point of me"*, suggesting that they have, to some degree, internalised negative attitudes about their difference.

Similarly, other participants also appearance to have negatively internalised ideas about their visible difference, and subsequently engaged in self-stigmatising behaviours. Self-stigma may be understood as a process whereby prejudice imposed on the self can lead to self-discrimination (Corrigan, Larson and Kuwabara, 2010). For many participants, it was evident that negative expectations of others was a consequence of internalised stigma.

"I wonder if maybe (the employer) *is not ready to employ someone like me who has some disease* (or) *problem. So it becomes a challenge to even go out and look for* (work)*."* (P4)

"I think I'm single due to the scar. I never approach a girl (because) *she won't be comfortable with me. She'll be running away."* (P5)

In these exemplar quotes, participants expected to encounter discrimination from prospective employers and romantic partners and became avoidant – that is, avoided seeking employment or pursuing romantic relationships altogether. Some of these concerns may be justified. For example, employment-related discrimination and poorer work-related outcomes have been reported in the broader visible difference literature (Madera, 2016). However, current participants' narratives demonstrated the detrimental impact of self-stigma, namely reduced social opportunities.

Thompson and Kent (2001) pose that adjustment to visible differences includes the individual's subjective interpretations of their difference and themselves, as well as interactions with others, and that negative social contexts can lead to internalised/self-stigma. This issue has been observed among various visible difference populations, including patients with skin conditions (Germain *et al.*, 2021) and burns (Maslakpak *et al.*, 2022). In their research, Maslakpak and colleagues noted that among burn patients, societal stigma can lead to self-stigma which can result in negative personal emotional and behavioural responses. The broader health literature also evidences this and demonstrates the impact of self-stigma on health behaviours. In a review of cancer beliefs in ethnic minority population, Licqurish *et al*. (2017) found that internalised attitudes (such as fatalistic attitudes about cancer) could be detrimental and contribute hiding/ignoring symptoms and delayed help-seeking behaviours. Similarly, Owuor and Nake (2015) explored internalised health stigma as a possible barrier to access to health and social care services among ethnic minorities. They found that internalised stigma made individuals more likely to conceal conditions, and less likely to seek support.

3.2.5 D: A Need for Community Change

Evidently, negative social experiences were highly detrimental to participants' wellbeing and had adverse implications for social relationships and opportunities. Overall, this had a significant impact on QoL, as exemplified by P4: *"I don't feel good about myself because of the state of my skin. I feel that my self-esteem is low and I don't get the best of living life."* Given participants' accounts of the pervasiveness of stigmatised attitudes towards and limited knowledge about differences among Somali people, many expressed a desire for community change:

"Somali people need to be educated because, as you have seen, they perceived like, maybe it is a punishment from God. That it is not the way people should be thinking in this generation. So, they really need that education and knowledge as well to know that this disease is just a disease like any other, and it is not caused by something like punishment from God or maybe committing a sin or something like witchcraft and so on. It really requires that the community should be given that knowledge." (P4)

Here, participants argued for increasing community knowledge about differences to reduce stigma. Whilst most participants felt community education efforts were imperative, they did not volunteer specific guidance about how to do this most effectively.

3.3 2: Being 'Other'

3.3.1 Theme Summary

Skins are very different. Your skin is not like my skin (P2)

Acculturation is defined as the act of those from a 'minority' culture adapting to a new society yet retaining their own cultural markers and values. This differs from assimilation, which sees the 'minority' culture forfeit their culture to merge entirely with the 'dominant' culture. This theme relates to certain values, tied closely to culture, which participants drew on when conceptualising their lived experience. The data highlights tensions for participants who live in a foreign society, yet still hold on to more traditional values, including those related to gender and healthcare. This phenomenon is recognised within the Minority Stress Model (Meyer, 2003), which poses that the unique combination of, and possible conflict and tension between, social identities and cultural values contributes to adverse outcomes in minority groups.

3.3.2 A: Acculturation of Gender Norms

When discussing gender, some participants argued that it is not an influential factor in relation to perception towards and experiences of visible differences: *"It is just the same, having a difference, whether you are a male or a female."* (P4; female). However, others explicitly commented on perceived differences between genders. Although the focus of this project was facial differences, one participant believed that Somali men carried a heavier appearance burden, because Somali women can more easily conceal (non-facial) differences with modest clothing: *"*(It is easier for) *a woman Somali, because they mostly wear some loose clothes,* (so it can be covered)*, unlike men."* (P3; male). Yet, most suggested greater challenges for women due to heightened pressures to adhere to beauty ideals and expectations (perhaps specifically here for Somali women, but generally for all women): *"For the girl child* (there's) *challenge. For the boy child, no-one really cares. She's the one who's expected to be… like this perception you're supposed to be beautiful, you're supposed to wear make-up."* (P2; female). Further, participants communicated the belief that existing patriarchal norms and negative bias towards women (i.e., misogyny), irrespective of having a visible difference, also exacerbates challenges: *"I think that the woman would have* (more of) *a difficult time as compared to a man. Women are always diminished and considered inferior. That belief is already there, even without the cleft lip, so with an addition of that condition that will really make it worse, and they'll be much discriminated."* (P7; male).

Whilst explicitly commenting on perceived gender differences, participants also employed certain language that indicated they subscribed to hegemonic gender stereotypes. For example, P3 (male) exclaimed: *"I feel that the community needs me to be tougher. I feel like I need to learn how to live in a hard way. just need to be tough. So, I don't regard (my difference) in a bad way - it keeps me moving and keeps me motivated to always try every day to be successful, because I can* (impact) *my land, my motherland."* P3 denied that his condition has had an emotional impact and instead employed masculine rhetoric associated with toughness, resilience, persistence and motivation. He explained that he does this for the betterment of 'his motherland', which perhaps suggests a felt responsibility to represent his community positively. In addition to these subtler nods to a cultural tendency to endorse traditional masculinity norms, P3 overtly conveyed such attitudes: *"Be a man, be strong.* (There is) *nothing there. Fight for your life, fight for what is yours in future."* These narratives are strongly tied to elements of masculinity and stoicism, which may be interpreted in this example as resilience and suppression of emotion. The issue of stoicism, and its impact on health, has been considered. For example, in cancer and mental health researchers have noted that stoicism is associated with poor help-seeking behaviours (Murray *et al.*, 2008).

3.3.3 B: Acculturation of Healthcare Principles

When discussing healthcare, all participants were positive about their experience of HPs and healthcare. For example, P1 claimed *that "Most* (health) *professionals act professionally in all that they do and how they treat you."* Similarly, in reference to dermatologists specifically, P2 also reported positive experiences and noted: *“I am not a professional here, they are the professionals, so I don’t want to seem like I am, you now, interfering with their workplace - they are doing their work.”* These quotes indicate gratitude and respect towards HPs and professional boundaries.

Yet, participants also spoke about negative experiences of treatment, which presented an interesting picture when contrasted to positive accounts of HPs. For example, despite valuing HPs, P2 did not take prescribed medication owing to previous negative experiences: *“I try as much as possible to avoid medication because the experience I’ve had, it will get even worse or even end up damaging your liver.”* Similarly, P5 reported *“fearing”* medication. These accounts demonstrate treatment-related distress, distrust in treatment efficacy, and hesitancy to engage in future treatment due to possible side effects. One participant also spoke about their dissatisfaction with treatment for their skin condition, centered around creams being ineffective for their (Black) skin*: “At one time I was* (using) *the corticosteroid, something like that. The problem with this now, when I use them on my face, my face gets lighter, so some people think I’m bleaching myself. I receive a lot of allegations, things that are not even making sense because it’s the medication! The skin gets a different pigmentation, a very light one, such that, you now have to go explaining other things! It doesn’t work, only it ends up making me feel like I’m a completely different person because of the skin colour.”* (P2). In this extract, P2 recalled their negative experience with treatment because it made their skin lighter. This suggests that the treatment prescriber/s was/were not aware of, or able to accommodate for, reactions on different skin tones. Subsequently, P2 reported dealing with the social implications of this experience, such as accusations of skin bleaching. For this reason, P2 was unwilling to consider further treatment: *“Skins are very different. Your skin is not like my skin and the condition could be the same, but the treatment will be something different. I could probably be needing something very different. So it’s like an experimentation. I don’t want to do it anymore, I just want to remain the same. If it goes away with old age, fine, but I’m not going to do anything.”*

Importantly, when considering the possible impact of religion of the current sample’s negative attitudes towards treatment, it has been noted that Islam allows for treatment, including that for visible differences, providing that it is not motivated by vanity (Hughes *et al.*, 2009).

Accounts of negative treatment experiences are not uncommon in the existing visible difference literature on minority communities. For example. Patel *et al*. (2014) found dissatisfaction with treatment among South Asian women with breast cancer and identified unsuitable appearance-related options. For example, not all wigs were deemed appropriate for all hair types. Further, previous research highlights cultural variations in perceptions of and engagement with healthcare, with those from minority groups generally reported to have poorer attitudes and experiences. This is theorised to be in part a result of previous negative experiences and/or perceptions of institutional racism and discrimination in healthcare (Shepherd *et al.*, 2018; Johnson *et al.*, 2004; Boulware *et al.*, 2003).

3.4 3: Coping in Private

3.4.1 Theme Summary

I’ve just been surviving on my own (P1)

This theme relates to coping mechanisms, and the strong sense of keeping issues confined; mostly to the self, and if looking to others for support, limiting this to close family and friends. Data also illuminate participants' attitudes towards support beyond their immediate circle; largely characterised by participants' dismissal of the need for external support. Yet, participants recognised and discussed the benefits of peer support and community involvement in support-related efforts.

3.4.2 A: Relying on Self

When considering coping strategies, most participants referenced what may be regarded as maladaptive strategies, including isolation: *"I hide, wanting the least people to know. So, nobody… a lot of people don't know. I don't receive psychological or mental* (support) *due to me hiding the facts from a lot of people."* (P5). Similarly, some participants also reported engaging in social avoidance. For example, P4 chose to manage challenges in school by minimising contact with peers: *"I don't want people staring for me for longer periods, so, I just go for my classes and when the classes are over, I just go back home. I didn't have so many friends."* As an adult, P5 also reported avoiding seeking work due to fears of social exposure: *"The reason I don't want to look for work is only that* (at) *the workplace I'll come across* (and have) *to interact with a lot of people. I don't feel free interacting with a lot of people."* In addition to avoiding social situations, P5 also reported physically concealing themselves from others as a method for managing fear of negative appearance evaluation: *"*(I'm) *coping with things myself. Hide, reduce exposure with people. Maybe in a hood or a hat that will hide my face. I'll avoid going out as much as possible."* Although concealing one's difference (e.g., by wearing a hat) is arguably not an inherently maladaptive strategy, in that it could be effective in managing negative reactions from others and thus facilitate (albeit limited) social exposure, it contributes to the broader issue of avoidance and illustrates how an individual may be struggling to accept their difference.

In addition to isolation and avoidance, some participants dismissed and minimised psychosocial challenges, often choosing to ignore them entirely. For example, to cope with negative social reactions, P1 reported: *"My best thing that I do, I normally just walk away, because I don't like to interact with so many people because of so many questions that can arise. Just to pass by and go like I have just seen nothing. And I don't even think of it again. I can say I can feel bad, yes, but I just control myself and* (continue) *with other things that I was doing."* P1's use of the phrase *"control myself"* is especially interesting and alludes to the concept of self-discipline. Similarly, P2 argued that ignoring negative social reactions was an effective way to protect themselves from harm: *"You hear someone just talk something, some insensitive language, even if you don't know him or her. But now you don't let it get to you because that's when depression will start coming in, just like hating yourself, you wonder why you are different. But not me, I don't let it get to me."* Similarly, P7 also disclosed ignoring social challenges, a way of coping passed on by their parents: *"I kind of try to ignore them because I've always been taught by my parents that I should just ignore them."* This suggests that ignoring problems forms part of a shared mentality about how to deal with life's challenges (i.e., alone).

Coping strategies have been shown to be important and influential to adjustment for those affected by visible differences (e.g., burns; Attoe and Pounds-Cornish, 2015). Participants in the current study showed almost complete reliance on independent strategies, and the notion of coping in private was very clear and consistent. Similar ways of coping have been identified in other health research with minority groups, and the issue of cultural expectations to manage problems independently is believed to be influential. For example, Punjabi breast cancer survivors have reported cultural pressures to keep problems related to their cancer private (Gurm *et al.*, 2008). Whilst avoidance is not uncommon among people with visible differences and has been described as a means for individuals to protect themselves against perceptive social threats, it is a sub-optimal coping strategy which can lead to challenges including increased social anxiety, reduced social opportunities and access to social support, and reduced QoL (Newell, 1999).

From a psychological perspective, participants also reported engaging in what could be regarded as more positive coping strategies. However, these still involved keeping issues to themselves or their close networks. First, participants referenced positive disposition. For example, P1 cited optimism as helpful: *"I think positivity is the main thing. More strength comes when you trust in yourself. I can live a life like any other person. I can achieve so many things like any other person. The sky's the limit. You only have to look out for opportunities."* Further, participants also identified self-acceptance and resilience as coping strategies:

"I saw there's nothing that I can do. So, if there's nothing I can do, I just need to accept myself." (P6)

"Having a scar on your face is not the end of something. You just have to accept yourself and try pushing forward." (P3)

Self-care practices were also discussed. For example, P1 reported that *"reading inspirational books"* had been helpful. Similarly, P8 stated: *"Firstly, learn to love yourself and identify something that you really like doing. If it's a self-care routine, a skincare routine… If it's something to do with hiking, something to do with driving, long walks… If it's dinner you like doing, if it's cooking… Like something interesting that keeps you going and refreshes you at the end of the day - do it."* Self-care, optimism, self-acceptance, and resilience are regarded as effective styles of coping for those with visible differences (Stock and Feragen, 2016; Kornhaber *et al.*, 2014; Egan *et al.*, 2011).

Last, many participants referenced their Muslim faith as an important support system. For example, for P1, their faith was imperative during difficult periods: *"I can mention religion because my strong faith. During tough times, I believe in myself, I believe in Allah. My belief in Allah and religion were some of the main motivations."* Likewise, P6 reported that attending their mosque helped them to *"grow up spiritually and believe in myself."* In discussing the importance of their faith, P8 stated: *"I am a firm Muslim and I believe that God give you something that you can handle, and everything happens for a reason. You don't need to question anything - just live your best life and God will do the rest."*

Research into the experiences of minority women with cancer has also identified religion as a key method for coping, which is argued to be associated with passive acceptance and reduced help-seeking (Patel-Kerai *et al.*, 2017; Patel, 2014). Faith has also been explored specifically in Muslim patient groups, with research identifying it as a primary source of support (Lawrence and Rozmus, 2001). Freeman *et al*. (2013) noted that some Somali refugee patients in the United States (US) viewed the Quran as an instrumental source of health-related support and guidance, and prescribed to the idea of

'God's will'. For some, this reliance on religion resulted in a delay seeking care from HPs. Taken together, this research suggests Muslim patients may be more likely to prescribe to fatalistic ideas about health, and less likely to seek support and treatment (Lawrence and Rozmus, 2001). The current narratives on religion support this notion and draw on the same elements of pre-determinism, passivity, and fatalism (Lawrence, Villar and Armando, 2015) – featuring most heavily in Theme 1 (section 3.2).

Religion and fatalism relate to self-efficacy, the perception of control over circumstances (Bandura, 1977), which has been correlated with health in Somali participant groups (Ebrahim, Davis and Tomaka, 2017; Kehm *et al.*, 2017). Ebrahim *et al*. found self-efficacy to be important for sexual health in Somali immigrants and advised that increasing self-efficacy in this group may promote greater condom use. Similarly, Kehm *et al*. found self-efficacy to be important for healthy eating in Somali women and children and advised that increasing self-efficacy in this group may promote greater fruit and vegetable consumption. Overall, in the current study, participants described fatalistic beliefs and reluctance to engage in/seek further treatment, which may indicate low self-efficacy and an external locus of control.

3.4.3 B: Relying on Family and Friends

Whilst participants mostly relied on themselves (sub-theme A), they also reported seeking support from family and friends. However, the notion of keeping issues confined to close networks was persistent.

Some participants discussed negative experiences with their family and friends. For example, P4 felt their friends were not interested, which made it more difficult to openly communicate: *"*(My friends are) *not interested in knowing anything about me, or they're not even concerned about my condition. I just keep quiet and don't tell them anything."* Similarly, when discussing their family, P7 reported that they doubted the honesty of communication with their parents: *"I kind of feel that my parents are always telling me what I need to hear and they're kind of not telling me the truth. So, that's kind of awful."* Other reported negative experiences with family and friends included unwanted and insensitive questioning: *"My friends at that time they were amused. They* (would) *go 'this is something that you didn't have before'. So, they come out with surprising questions and facial expressions… I wasn't happy at that time."*

Equally, participants talked about positive experiences with family and friends. For example, P2 shared that although they were the only person in the family with a skin condition, they received positive attention from family members: *"I'm the only child with eczema in my family and I don't know - I got a lot of attention when I was a baby and growing up - but I feel like we have had a good relationship. They don't make a fuss of it they don't make fun of me. They just know this is who I am. They don't concentrate on my face."* Positively, P2 expressed not feeling mistreated or excluded by family due to their condition. Similarly, when discussing friendships, P2 also reported feeling well-supported by friends: *"I have good relationships with friends because most of them appreciate me for just the way I am."*

Participants mostly cited family and friends as sources of support: *"I think I have a very strong support system around me - that is my parents, my friends, my brothers and sisters."* (P2). For P1, although they reported still preferring to cope with challenges independently, they also felt they could rely on their parents: *"I can say* (my parents) *are mostly supportive to me because when I'm down maybe they can* *provide me with what I need. Because I always tell them that, for me, I have just to do everything on my own, but whenever I'm down maybe I can seek your support."* In their discussions of family support, P8 highlighted the importance of positive familial relationships for long-term adjustment*: "My mum was the strongest person for me, who would encourage me and tell me I am very unique and encourage me to look at myself in the mirror and say that I am good, I am enough, and I am very beautiful. If that wasn't installed in me at that tender age, I feel like I would be a different person. I would be a depressed person I would be living a sad life really."* Family and friends were instrumental for coping among the current sample, which echoes reports in other visible difference research pertaining to Black and South Asian women with breast cancer (Patel, 2014). In various areas of Somali health, support from the family unit has also been shown to be critical, for example in tuberculosis (Gerrish, Naisby and Ismail, 2013) and maternity care (Konje and Konje, 2021).

3.4.4 C: Challenges of External Supports

In the context of the importance of the 'self' and the immediate circle (family and friends) for coping, participant dismissed the need for external support, for example support from charitable organisations:

"I have never (engaged with charities) *because I haven't known that they exist and also, I haven't seen more much need."* (P3)

"I kind of didn't take (charity support) *into much consideration because I've seen that I have* (adapted) *and I'm doing quite well."* (P7)

Both participants quoted above reported that they would not benefit from external support. Their dismissal is telling when contrasted with their earlier reports of feelings and behaviours that are presently argued could be indicative of poor adjustment.

Some of the participants' reported reasons for not engaging with external support services centred on perceived inaccessibility. P2 discussed the inaccessibly of psychological therapies: *"Having psychologists for people who really need these counselling sessions. Like, free sessions, because psychology sessions are actually very expensive."* In addition to financial barriers reported by P2, P5 considered the inaccessibility of information about services: *"I haven't known about them. (They could) connect with communities in a more effective way."* Similarly, P6 felt that more could be done by service providers to engage and connect with communities: *"They should make themselves popular around the communities and encourage people to join and participate in what is being done."*

In addition, participants considered more personal reasons for not engaging with external support services. For example, P4 expressed that doing this would require self 'composure' and 'confidence', suggesting that the act of seeking support is significant and daunting: *"I feel that I really need it, but I have to take time and get the composure, and also the confidence to be able to share my experiences with anyone else outside my family."* This suggests pervasive negative attitudes towards seeking external support.

In discussions about psychological support, P7 revealed: *"To me, I don't think there's much that can be done. I think the kind of* (medical) *treatment that will be given to people with cleft lip is good and it's enough, and I don't think that there's much that can be done from there."* Here, P7 places more value on medical intervention, and does not recognise the need for or benefit of adjacent psychological intervention. This indicates a fundamental lack of knowledge about support services, particularly psychological. This may imply low health literacy; specifically, a limited understanding about what psychological support is available, how it can potentially help, and how to access it. Previous research suggests ethnic minorities are at greater risk of low health literacy, and this has been noted in research with Somali people (Gele *et al.*, 2016; McEwen, Straus and Croker, 2009). Problematically, low health literacy has been linked to poorer health outcomes (Berkman *et al.*, 2011; Benjamin, 2010).

Despite no previous experience with support services, P7 also theorised that engaging with support (in this case charity support) could hinder coping and make the situation worse*: "I'm not engaged with those kinds of charities. I think that if I continue trying to seek help and all that, that will also kind of make me feel bad. It will kind of make me feel dependent so that's something I usually dislike."* Here, P7 shared a belief that engaging with support would lead to decreased wellbeing and make them feel 'dependent'. Similarly, in reference to discussing psychological challenges, P6 expressed they would "*feel oppressed when someone talks about it."* This again draws on narratives of self-sufficiency, resilience and stoicism, which seemed to be prevalent in discussions about coping. It also points to possible cultural attitudes towards help-seeking behaviour (particularly for psychological need), whereby seeking support for wellbeing could be seen as a personal failure. This has been previously identified with Somali groups in other mental health contexts (Linney *et al.*, 2020).

3.4.5 D: Benefits of Peer Support

Despite dismissing the need for external support, participants spoke positively, and were able to identify benefits of, peer support and advocacy. This was another indicator of the desire to keep issues 'confined' to close networks.

For some participants, connecting with others with the same condition was helpful:

"People who have the same condition, interacting with them, getting to know how they go about their day to day lives, has also meant a lot to me." (P2)

"I've already met one Somali who also has a scar and I have interacted with him, and I've told him to continue moving forward and I think (that was positive for) him as well as me. Because I felt like I'm not the only one." (3)

In these quotes, participants reported the perceived benefits of both giving and receiving peer support. P3's quote also suggests an element of isolation which can be ameliorated through peer support, specifically from another Somali individual. This again draws on the issue of participants' identity intersections (Somali with a visible difference) - possibly making this group particularly 'othered' and in need of peer networks.

For most participants, the most effective support for Somali people with visible differences would be that created by and delivered through the community. For example, P8 suggested that support groups could be effective: *"I feel like information - that is important - could be given through like support groups or something.* (So) *they get to see these people,* (and) *they could form support systems."* Similarly, P6 argued that support interventions should be initiated within the community: *"I think running many of the* *projects from the neighbourhood. So, the organisations who are run by people from the neighbourhoods, appoint people within the neighbourhoods, to try and look for the people with the same problems and try to motivate and talk to them. I just want to make the emphasis on starting from the grass root levels."*

The need for/benefits of peer support has been reported elsewhere in broader visible difference research. For example, among Black and South Asian women with breast cancer, Patel (2014) noted the importance of peer support. Similarly, Dures *et al*. (2011) identified a desire for peer support among those with the skin condition epidermolysis bullosa. Similarly, research on Somali health and wellbeing has found peer support to be an important resource for coping among Somali parents of children with autism (Selman *et al.*, 2018).

3.5 Summary of Findings

The preceding analysis outlines three themes and sub-themes. First, S*tigmatised Differences* related to perceived negative beliefs about the causes of visible differences, and the subsequent personal and social implications for those affected by visible differences. This theme also considered the need for greater community education to reduce stigma. Second, *Being 'Other'* discussed participants' accounts of acculturation, the balance between traditional and modern views on gender and healthcare, and the impact of this process on adjustment. Third, C*oping in Private* discussed the preference to cope independently. Whilst participants reported relying mostly on themselves, they did seek support from family and friends when necessary. External support was generally dismissed, though the perceived efficacy and benefit of community/peer-led support was clear. Though themes are distinct, a relationship between them can be observed. For example, the belief that individuals may be to 'blame' for their difference (Stigmatised Differences) is related to the notion that the individual alone must cope with the consequences (Coping in Private). Similarly, beliefs around blame could be associated with negative experiences of and challenges around healthcare (Being 'Other') – particularly reduced help-seeking behaviours and willingness to seek treatment.

Discussion

4.1 Chapter Introduction

This chapter begins by discussing the implications of the current findings to the field of health psychology. Namely, the development, delivery, and evaluation of psychosocial/educational support. Support for individuals may include promoting positives coping styles for managing the experience of living with a visible difference, while support for communities could serve to increase awareness and reduce stigma about visible differences. However, the existing evidence-base for the efficacy of such interventions among diverse ethnic groups, and especially Somali people, remains limited. This limitation is considered in relation to the applicability of existing frameworks of adjustment and psychosocial interventions. The potential benefit of culturally adapting interventions to be more appropriate for diverse communities is also considered. Socio-political factors are argued to be imperative for intervention work - health psychologists should recognise how broader structural inequalities and discriminations experienced by minority groups serve as barriers to health and wellbeing, and work to improve them. Implications of findings for healthcare are also considered. Current results provide important insights into participants' experiences of healthcare and perceptions of Health Professionals (HPs) and offer suggestions about which factors could be targeted to improve patient outcomes. It is possible that a lack of knowledge of appearance- and culture-related issues negatively influences practice, and thus it is argued that HP training in this area could be beneficial. Whilst recommendations for future research and practice are made throughout the chapter, a section is dedicated to important final reflections from this project for future research with minority communities historically underserved in research. Finally, limitations of the current research are considered, including how the researcher (and her identity) may have influenced the project, as well as issues related to accessibility and inclusivity.

4.2 Implications

Within increasing global migration and diversifying communities, and evidence of subsequent health-related inequalities between groups, Yali and Revenson (2004) conclude that *context competency* in health psychology is essential. They argue that training should cover intersectional concepts, so that the burden of this work does not solely fall on health psychology practitioners from marginalised groups – investment and commitment from the broader health psychology community is key. Yet, in considering the context of health, Yali and Revenson also caution against a comparative approach, where different (e.g., ethnic) groups are evaluated against one another as this can lead to ideas related to 'minority deficit'. Instead, health psychologists should focus their efforts on exploring various factors, including those related to ethnicity and culture, as possible moderators for health outcomes. The findings of the current study highlight the experiences of a group of young Somali adults with visible facial differences; a perspective that has historically been absent from the literature. This offers insights into how visible differences are perceived within the Somali community, psychosocial wellbeing and functioning in affected individuals, as well as preferred coping styles which may be tied to cultural factors. This information can be helpful for informing future work with this group. The following section discusses implications of these findings for health psychology, health service delivery, and research.

4.2.1 For the Provision of Psychosocial Support and Education

To address identified need, psychosocial interventions could be broad (i.e., targeted at the general population), or specific (i.e., targeted at individuals with visible differences). In the current context, broad interventions may reduce social stigma, and by extension improve the experiences of Somali people with visible differences. Specific interventions may provide individuals with more positive coping methods. Arguably, the primary effort should be the development of broader interventions to limit the burden placed on affected individuals. However, it is likely that broad efforts combined with specific individual support would be most effective at ameliorating immediate and long-term psychosocial challenges. The possible different formats of such support are considered below. Finally, the relevance of socio-political factors for health and wellbeing are argued to be key for the practice of health psychologists in this area.

4.2.1.1 For Individuals

Given that body image impacts health (e.g., Rumsey, 2008), and those with visible differences may be at greater risk of body image dissatisfaction (e.g., Teo *et al*., 2016), more research is needed to better understand issues of appearance among Somali people. Although this study contributes to the limited literature base, further research would allow for more accurate and culturally sensitive care/support for Somali people with visible differences. Indeed, whilst most participants in the current study overtly rejected the need for external psychological support, much of their narrative indicated reduced psychosocial wellbeing, which could possibly be ameliorated through appropriate support.

The integrated model proposed by (Kent, 2000) is a widely utilised model of adjustment to visible difference. The model considers a range of experiences and challenges faced by those with visible differences and combines contributions from other theoretical models by including body image disturbance, enacted and felt stigma, and social anxiety/poor social skills (Leary and Kowalski, 1997; Cash and Grant, 1996; Rumsey, Bull and Gahagan, 1986; Goffman, 1968). The current findings reflect Kent's model. Participants discussed experiences of social stigma, subsequent body image disturbance, and consequential social anxiety. Isolation and avoidance were also coping strategies which contributed to poor adjustment. Importantly, participants' narratives indicated a level of internalisation of negative views, and a development of negative self-schemas – resulting in unhelpful behaviours such as negative expectation/interpretation of others, limited social opportunities, and reduced help-seeking.

Kent's (2000) integrated model of adjustment to visible differences has been criticised as limited because it was based on data from White adults with vitiligo, thus it may not be applicable to other appearance-altering conditions or those from different ethnic backgrounds (Clarke *et al.*, 2013; Rumsey and Harcourt, 2004). In response, the Appearance Research Collaboration (ARC) proposed a more comprehensive model of adjustment to visible difference (Clarke *et al.*, 2013). The ARC model considers research on a range of visible differences, and two studies related specifically to minority groups. Indeed, while most of the data that was used to develop the ARC model were still from White samples, one study (Hughes *et al.*, 2009) considered minority ethnic community views of ‘disfigurement’, and another (Thompson *et al.*, 2010) the experiences of UK South Asians with vitiligo. Perhaps for this reason, the model includes ethnicity as a predisposing/sociocultural factor which can impact adjustment. In addition to predisposing factors, the ARC model proposes that cognitive variables influence adjustment, including disposition (pessimism, optimism), appearance evaluation (noticeability, valence, salience), and perceptions of social support/acceptance. Predisposing and cognitive factors are said to influence outcomes for those with visible differences, including wellbeing, mood, shame and appearance-related anxiety. Participants in the current study reported feeling socially unaccepted; and indicated increased preoccupation with appearance including a heightened fear of negative appearance evaluation and low self-esteem; which could arguably influence reported outcomes like anxiety and depression. However, the ARC model also proposes that feeling socially supported and having an optimistic predisposition are related to successful adjustment. This can be applied to the current sample, who generally reported feeling well-supported by close family and friends and approached problems optimistically. However, support from family and friends may be less effective given reports of wider and pervasive community stigma, and perceived optimism may in fact be cultural norms about ‘sharing’ and expectations to remain tough.

Such conceptual frameworks have previously informed the therapeutic content of psychosocial interventions for those struggling to adapt to living with visible differences. For example, in reference to Kent’s model, the promotion of positive social skills (through Social Skills Training; SST) can help individuals respond more positively to social situations, and better handle any related difficulties that arise (e.g., negative reactions or unwanted questioning from others). Further, addressing cognitions related to body image can improve negative assumptions about one’s own appearance (e.g., self-consciousness), promote helpful coping strategies (as opposed to maladaptive ones like social avoidance), and contribute to positive adjustment and outcomes. For example, the online self-help intervention Face-IT (Bessell *et al.*, 2012) was developed and found successful through a Randomised Controlled Trial (RCT). It improved appearance distress using strategies from CBT and SST to increase exposure to social situations, provide skills for individuals to act in a more socially confident way, and target cognitive distortions/unhelpful behaviours. However, the evidence base remains limited. Muftin and Thompson (2013) reviewed self-help psychosocial interventions for individuals with visible differences. Whilst they found some support for the use of self-help to manage anxiety, there was no evidence for other psychosocial difficulties. In the most recent review in this area Norman and Moss (2015) found some evidence for the effectiveness of a combined cognitive-behavioural and SST approach – though they were not able to determine the most effective dose (duration, intensity) and setting (e.g., group, self-help, face-to-face).

Since the publication of Norman and Moss’ (2015) review, further psychosocial interventions have been developed and tested among adults with visible differences. Several contemporary studies have focused on self-help interventions, arguing that they could provide a low intensity and accessible option for administering support to those with visible differences. For example, Hotton *et al*. (2022) found that self-guided information and therapy manuals were acceptable and effective for improving psychosocial wellbeing among adults with facial palsy. Similarly, there is evidence to suggest that self-help intervention based on compassion-focused theory can ameliorate psychological distress among adults with skin conditions (Hudson, Thompson and Emerson, 2020). Compassion has also been combined with mindfulness practice and applied therapeutically to groups with visible differences through Acceptance and Commitment Therapy (ACT). Though this research is relatively novel, findings suggest that ACT may be helpful for improving appearance-related anxiety and distress among those with visible differences (Zucchelli *et al*., 2018). Zucchelli *et al*. (2021, 2022) evaluated acceptability and feasibility of an ACT-based mobile health intervention ('ACT It Out') for improving psychosocial challenges among those with visible differences and appearance-related distress, and found that despite challenges (e.g., safeguarding potentially vulnerable users), relevant stakeholders also identified possible strengths of this approach (e.g., improved access to support). They also found that program engagement/adherence was acceptable, and overall program acceptability/satisfaction was good.

Importantly, some people with visible differences experience positive outcomes, including improved wellbeing and resilience (Garbett, Harcourt and Buchanan, 2017). Egan *et al*. (2011) considered which factors may contribute to positive outcomes, including acceptance, supportive relationships, and positive coping strategies (e.g., active coping). Similarly, in research about psychosocial outcomes in those with facial differences, Eiserman (2001) found that humour, a good sense of self, inner strength, faith, a positive outlook on life, social and familial support and active coping strategies were important. Last, Meyerson (2001) explored outcomes in adults with Moebius syndrome and identified predictors of resiliency and success included: determination, networking, social skills, family support, faith, humour, and a good sense of self. In the current study, participants cited such factors in relation to their coping, namely familial support, inner strength, faith and positivity – though there is the possible influence of cultural expectations on these narratives. Given that adjustment to visible difference is complex and multi-faceted, can be dynamic and changing, and involves positive elements too; intervention efforts could work to support and enhance protective factors. Future work should consider the efficacy of promoting and fostering positive coping strategies among various groups with visible differences, including Somali.

4.2.1.1.1 Cultural Considerations in Interventions

Data used to develop conceptual frameworks were generated predominantly from White Western groups, such that they may neglect other important factors for adjustment which impact diverse groups. While models claim to offer several factors which can be useful for intervention development (e.g., ARC, Clarke *et al*., 2013), concerns persist around how applicable frameworks of adjustment and psychosocial interventions are for more diverse groups with visible differences. In broader health research, the same issue is noted whereby limited inclusion of underserved groups in research has led to a lack of evidence about how different groups respond to intervention (NIHR, 2020).

Figure 4 presents a list of factors from the current research findings that may be important to consider when working with Somali people with visible differences and could be incorporated into models of adjustment/intervention.

Figure 4. Possible Influential Factors for Adjustment Among Somalis with Visible Differences

- Fatalistic and stoic attitudes to health
- Limited health literacy
- Previous negative healthcare experiences
- Balancing tradition and Western values
- Negative perceptions of support-seeking
- Reliance on individual coping
- Important supportive role of family and friends
- Preference for peer/community-led support
- Protective factors
- Stigma from community

First, several personal and cultural factors could be seen to influence overall adjustment, including fatalistic (often associated with religion) and stoic attitudes, limited health literacy, and previous negative healthcare experiences (contributing to distrust for HPs) that negatively impact wellbeing and healthcare engagement. Broad negative cultural attitudes to support-seeking, particularly psychological support - such as the belief that doing so makes someone 'dependent' – could also act as a barrier to help-seeking. The balance between traditional and Western values may also be influential, for example, cultural expectations to remain polite to HPs and not thus manifest dissatisfaction. Second, several factors specifically related to coping were also noted, which are particularly important to consider in intervention development. Whilst the general preference was for coping individually, close networks such as family and friends also played an important role. Further, there was a preference for community/peer-led support efforts. Findings also offer insight into various protective coping skills among Somali people, including the positive use of faith, stoicism, and resilience, which could be fostered in intervention. Finally, overall reduced knowledge and increased stigma towards visible differences among the Somali community was deemed influential to experiences and adjustment.

Following the murder of George Floyd and the Black Lives Matter (BLM) protests that ensued (Barbot, 2020), in a call to action for psychologists, Thornton, Keeling and Ramsey-Wade (2020) argued that efforts to eliminate racism in psychology should involve tackling barriers and ensuring equal opportunity and representation for minority groups, particularly within research and health services. In doing so, Thornton and colleagues note that it may be necessary to "deconstruct and rebuild". Research on access to psychological support among UK minority groups finds several barriers to services including those related to culture, religion, and language (e.g., Loewenthal *et al*., 2012). Greater awareness of these barriers may provide direction on how to adapt interventions; supporting the process of 'deconstructing and rebuilding', proposed by Thornton *et al*.

The concept of cultural adaptation refers to modifying interventions to make them culturally appropriate for a specific group. Research finds that culturally adapting psychological and health interventions can lead to improved outcomes. For example, in a review of meta-analyses on culturally adapted mental health interventions, Rathod *et al*. (2018) found a moderate to large effect of such culturally adapted interventions. The authors note that most adaptations were in relation to language, concepts, family, communication, content, cultural norms and practices, therapeutic alliance, therapeutic goals, and context and delivery. Behavioural health interventions can also be culturally adapted. For example, Barrera Jr *et al*. (2013) reviewed relevant literature and found that, as with psychological interventions, culturally adapted health interventions were more effective at improving health outcomes. The authors suggest that future research should continue to gain a better understanding of the specific cultural variables that may be influential – as these variables can then be incorporated into adapted health interventions. Benish, Quintana and Wampold (2011) argue that an important component of culturally adapted psychological interventions is myth adaptation – that is, recognising and working with individual cultural beliefs and narratives about illness. In doing so, intervention efforts are likely to resonate better with communities. This is an issue that could be particularly relevant when working with the Somali community because, as highlighted in section 3.2, fatalistic beliefs about appearance-altering conditions were reportedly widespread and problematic for adjustment.

There is limited evaluation data on adapted health interventions for Somali diaspora communities. Stadeli *et al*. (2020) designed and implemented a culturally adapted version of a general bleeding control (e.g., post-injury) program, 'Stop the Bleed'. In partnership with community stakeholders, Stadeli and colleagues modified its content and delivery. They found an increase in knowledge and self-efficacy in bleeding control among US Somali individuals following completion of the adapted program. Similarly, Murray *et al*. (2017) trialled the culturally adapted physical activity programme 'STRIDE' among US Somali women. Cultural issues that factored into the adaptation included: incorporating cultural beliefs and behaviours, ensuring diversity and representation (i.e., among programme staff, within programme images), and translating documents to increase accessibility.

Critics of research on the efficacy of culturally adapted interventions raise concerns about rigour, for example, citing studies that fail to include active control comparison groups. Comparisons are often made between culturally adapted interventions and usual care rather than culturally adapted interventions and non-culturally adapted interventions (Rathod *et al.*, 2018; Barrera Jr *et al.*, 2013). This lack of direct comparisons undermines confidence in claims that it is the cultural adaptation element that explains efficacy. Thus critics argue that further rigorous research in this area is needed.

The present study elucidates the experiences of a (young) adult group who have not previously been represented in research about psychosocial adjustment to visible differences, nor appropriately considered in intervention development. The findings suggest key factors which might influence adjustment among Somali people. Future research should continue to better understand such possible influential factors. Given the limited uptake of and negative attitudes towards (external) psychosocial support in the current study, future scholars could also explore and ameliorate perceived barriers. The efficacy of existing interventions should be trialled with diverse groups, or at a minimum, trial research samples should be more diverse and representative. If appropriate, interventions should be culturally adapted according to best practice standards and evaluated using appropriate controls to determine efficacy.

4.2.1.1.2 Peer Support

While participants in the current study were generally dismissive of external support, they indicated the value of peer-led support. A preference for peer support is also noted in the broader visible difference literature, but may be particularly important for the Somali community. Somali migrants may also miss the peer support they had in Somalia (Mölsä, Hjelde and Tiilikainen, 2010; McMichael and Manderson, 2004), and thus have a stronger preference for receiving support from other Somali people in their new country (Makwarimba *et al.*, 2013). Furthermore, there is evidence that peer support in public health interventions aimed at the Somali diaspora is effective. For example, in interventions to increase perceived support and social integration and decrease loneliness among Somali refugees in Canada, peer-support proved effective (Stewart *et al.*, 2011, 2012). Likewise, community-health worker (peer)-led CBT has also demonstrated efficacy as a mental health intervention for Somalis (Pratt *et al.*, 2017). Consequently, it is argued that efforts to support Somali groups should utilise peer support (Selman *et al.*, 2018)

However, implementation of peer support is likely to present some challenges. For instance, Dures *et al*. (2011) note that when the dealing with small populations (e.g., those with a rare skin condition), it can be difficult to identify sufficient people to set up and maintain in-person peer support groups. When working with Somali people in the UK with visible differences, similar issues may also apply. For example, although online peer-support spaces could overcome access barriers and be most effective at reaching individuals, this method poses concerns related to maintaining online security (particularly regarding sensitive health information) and monitoring content and ensuring accountability of the platform (particularly regarding accuracy/trustworthiness of information; Moen, Smørdal and Sem, 2009). More work is thus needed to understand how peer-support can be most effectively utilised and facilitated for Somali people with visible differences.

4.2.1.2 For Communities

Consistent with previous visible difference research with other ethnic minorities (e.g., Lam and Thompson, 2021), the current study identified experiences of stigma and discrimination, often rooted in community misunderstandings related to health conditions and visible differences. Given the reported negative influence of this, participants recommended community education. As such, it is possible that intervention efforts for the broader Somali community, aimed at increasing understanding and reducing stigma, could be beneficial.

In broader health research, academics and practitioners believe that community interventions could: increase knowledge and understanding about positive health behaviours (McEwen, Straus and Croker, 2009); improve health literacy (Gele *et al.*, 2016); promote knowledge about conditions (Cochrane, Collins and Horwood, 2016); and reduce stigma about conditions (Linney *et al.*, 2020). A recent study explored the efficacy of a community education intervention for improving cervical cancer screening among Somali migrant women and found benefits such as raised awareness and screening motivation (Qureshi *et al*., 2021). In broader visible difference research, similar community interventions for minority groups have also been indicated (Thompson *et al.*, 2010; Hughes *et al.*, 2009). Bogart and Tickle-Degnen (2015) reported that educating people via media messages resulted in more positive attitudes toward people with facial ‘disfigurement’. Similarly, Stone and Fisher (2020) found that a brief online intervention was effective at improving perceptions about individuals with visible differences. Authors theorise that improved perceptions may result in increased pro-social behaviour towards those with visible differences. Importantly, Stone and Fisher did not report the specific ethnic or cultural background of their sample (*n*=224). However, most were from Britain (*n*=121), other European countries (*n*=51) and the USA (*n*=23). As such, these findings may not apply to the Somali community, or indeed other minority groups, given that there are various cultural factors which may contribute to stigma and the overall social burden for people with visible difference.

To the author’s knowledge no interventions to reduce appearance-related stigma among the Somali community currently exists. However, research on the efficacy of broader Somali community health interventions, and general population interventions for visible differences shows promise. Similar community interventions may reduce stigma among Somali people in relation to visible differences, however further research is needed to evaluate such efforts.

4.2.1.3 Socio-Political Considerations

The provision of psychosocial support and education to improve outcomes for those affected by visible differences places the focus and responsibility on the individual(s). Within this approach there is little to no consideration of important socio-political influences. Health is widely understood as a product of socio-economic and structural inequalities, including economic barriers, education, and experiences of racism and discrimination (Williams, Neighbors and Jackson, 2003; Karlsen and Nazroo, 2002). Somali people may be at greater risk of racism, xenophobia, and Islamophobia, and those with a visible difference may be at additional risk of appearance-based discrimination. Thus, socio-political factors are crucial to understanding the adjustment of this group and must be fully considered when developing interventions.

Primarily, broad policy designed to tackle inequalities between groups is imperative to improve health outcomes (e.g., employment inequalities between ethnic groups, as proposed by Nazroo (2014). Nazroo argues that although focused/individualised efforts can be helpful short-term solutions (e.g., providing interpreters to increase immediate access to services), broader efforts to tackle marginalisation are essential to ensure ongoing equal health opportunities. Generally, such efforts are deemed beyond the scope of psychology – and considered more appropriate for legislative public health efforts. However, Rosenthal (2016) argues that intersectional psychologists, committed to social justice, should make efforts to consider and address the social and structural inequities that shape individual experiences. Similarly, Ochieng (2013) argued that socio-economic factors are imperative for the efficacy of health interventions designed for marginalised ethnic groups. For the current sample of young Somali adults, it is likely that this issue applies, and support efforts should consider and where possible account for important socio-economic factors which can influence health experiences and outcomes.

4.2.2 For the Provision of Healthcare

Participants did not disclose negative experiences with individual HPs, but they did discuss negative healthcare experiences more broadly. Reasons for negative experiences included differences in skin colour and the (in)appropriateness of treatment (e.g., the bleaching side- effects of corticosteroids on Black skin), and cultural factors (e.g., negative cultural ideas around help-seeking), which influenced both experience and treatment outcomes.

In other areas of health, Somali people have reported dissatisfaction with healthcare more broadly and HPs more specifically (Konje and Konje, 2021; Linney *et al.*, 2020; Loewenthal *et al.*, 2012; Straus, McEwen and Hussein, 2009). From this information, various aspects of care could be adapted by HPs to ensure that support is more appropriate for Somali people with visible differences – many of which are highlighted in current findings. A first step, that acknowledges the possible psychosocial challenges and appearance-related distress that patients with visible differences face, is for HPs to initiate conversations with patients about the subject and invite the disclosure of concerns (Rumsey, 2018). In addition, there may be cultural factors relevant to Somali people' health-related experiences and wellbeing, including those raised by the current sample (see Figure 4), for HPs to carefully consider when working with this patient group. Specifically, the importance of the family unit and religion for support/coping; stoic, fatalistic and stigmatised health attitudes; limited health literacy and language; and previous negative healthcare experiences.

First, participants demonstrated a tendency to keep problems confined to their close networks, like family, rather than disclose concerns to professionals. This preference for sharing among the family unit is likely a consequence of Somali's collectivist culture – characterised by a sense of inter-dependence and cooperativeness (Stewart *et al.*, 2008). Experts have advised that for HPs working with Somali patients, involving and integrating the family into the patient's care may be effective (Konje and Konje, 2021).

Religion is another factor that may be important for HPs to consider when working with Somali patients (Pratt *et al.*, 2017). While the current sample of young Somali adults reported using religion as a method for positive coping, previous research suggests that it could be detrimental - particularly if other methods for coping are disregarded (Freeman *et al.*, 2013). Freeman and colleagues recommend that HPs should become familiar with how lessons from the Quran may be interpreted by Muslim patients, as these could ultimately influence health. For example, patients may delay seeking support/treatment, having relied on guidance from and interpretation of the Quran in the first instance. Further, HPs should be mindful of and accommodate when able, religious practices. For example, it may not be appropriate to recommend certain treatment protocols during Ramadan. HPs can also enhance Muslim patients' experiences of care by taking steps such as providing copies of the Quran, which may be particularly helpful for patients during challenging times such as health-related decision-making. Similarly, the individual's Imam, or other relevant religious/community leader could be engaged in care as appropriate (Pratt *et al.*, 2017).

HPs should also be mindful of Somali people' possible stoic attitude to health, which was evident in most narratives in this study, particularly those of male participants. Somali patients may minimise complaints, dismiss the need for support and engage in reduced help-seeking, which can be detrimental to health experiences and outcomes (Byrskog *et al*., 2014; Wedel, 2012; Finnström and Söderhamn, 2006; Sweden). Though stoicism is relevant for patients of all backgrounds, it may be especially prevalent in minority groups possibly due to cultural perceptions about help-seeking, hegemonic gender roles and responsibilities, and previous lived experiences. For example, Somali refugees may draw upon a stoic mindset to endure hardships (Byrskog *et al.*, 2014). Some research also suggests that stoicism can be conducive to positive health outcomes. For example, Akrim, Rudianto and Adhani (2021) found that among Muslim health workers in Bali, stoicism is understood more positively as a combination of resilience, self-control, fortitude, and optimism. HPs could thus work with patients to draw upon an existing stoic mentality to help foster and build effective health-related strategies/coping mechanisms.

Further, as demonstrated in the current and previous research, cultural health-related taboos, stigma and fatalism are prevalent in Somali communities, and can have detrimental health consequences (e.g., Gerrish, Naisby and Ismail, 2012). As such, this issue should be incorporated into care (Lawrence, Villar and Armando, 2015). HPs working with Somali patients should consider possible stigmatised and fatalistic attitudes towards health conditions and support patients accordingly. To inform practice, more research is needed to explore which elements of fatalism influence health-behaviours (e.g., beliefs about destiny; beliefs about luck; beliefs about divine control; beliefs about helplessness) and the path by which beliefs influence behaviours. This may be facilitated by measures of fatalism that can provide insight about several dimensions of fatalism (Shen, Condit and Wright, 2009).

Health literacy is another important factor to consider. Research reports reduced levels of health literacy among migrant groups more broadly and Somali groups more specifically (e.g., Gele *et al*., 2016). Low health literacy has been linked to poorer health outcomes (e.g., Benjamin, 2010). Importantly, in addressing the issue, health literacy should not be regarded as a personal failure of migrant patients. Instead, it should be the responsibility of HPs to provide care in an inclusive and accessible manner (Stewart *et al.*, 2012). For example, in intervention work with US Somali women, Murray *et al*. (2017) considered health literacy and successfully minimised barriers by simplifying/reducing information (e.g., bullet points). Current participants' narratives implied low health literacy, particularly relating to psychological care. As such, HPs working with Somali patients with visible differences should consider low health literacy and provide support as needed. Related to issues of health literacy, is language proficiency. HPs working with Somali patients should consider language as a possible barrier, and offer support if necessary (e.g., translation/interpretation services; Konje and Konje, 2021).

Last, HPs should be mindful of possible distrust of Western healthcare systems among Somali patients, and work to increase trust (Freeman *et al.*, 2013). Reports by current participants were indicative of previous negative healthcare experiences, and participants explicitly cited these as reasons for declining future treatment. Previous negative experiences may increase suspicion and distrust towards HPs, reduce expectations of healthcare more broadly, and ultimately discourage healthcare engagement/service utilization (Rhee *et al.*, 2019; Memon *et al.*, 2016). In a systematic review about cancer beliefs in ethnic minority populations, Licqurish *et al*. (2017) found that previous negative experiences were a contributing factor to negative beliefs, and decreased help-seeking behaviour. Similar findings have been reported specifically with the Somali community by Konje and Konje (2021), who identified similar issues causing poor patient-provider relationships within UK maternity care. This relationship can be understood as multi-directional: poor health experiences cause and are caused by disengagement with health services. Trust should thus be considered as a determinant to health, particularly with regards to treatment-seeking and -adherence behaviours. For example, in the context of Covid-19 vaccine attitudes and uptake in the US, Rusoja and Thomas (2021) argued that the healthcare system's historical exploitation and persecution of minority groups continues to negatively impact communities and contribute to ongoing distrust. In the case of Covid-19, this led to reduced vaccine uptake among minorities. As such, HPs working with Somali patients should be mindful of possible existing mistrust, how it may influence patient behaviours, and work to improve relationships (Loewenthal *et al*., 2012).

4.2.2.1 Education for Health Professionals

It is possible that HPs working with groups like Somali patients with appearance-altering conditions do not have the knowledge and experience needed to deliver optimal care. Although past research has rarely focused on whether HPs feel culturally competent to deliver optimal care to minority patients with a visible difference, relevant research consistently reports that HPs typically feel ill-equipped to address appearance-related concerns arising from a visible difference, due to limited training and lack of confidence (e.g., Rumsey, 2018). Nonetheless research with European multi-disciplinary HPs caring for patients with a range of visible differences, identified that HPs would welcome further training to address this limitation (Williamson *et al.*, 2018).

Cultural competence - defined as the ability to provide care for a range of individuals with diverse values, beliefs and linguistic abilities - can be enhanced through training that allows HPs to better consider culturally specific factors that influence outcomes (Etherington, 2015). Whereas lack of HP cultural competence has been identified as contributing to health disparities between groups, cultural competence training has been shown to improve patient health outcomes (Betancourt *et al.*, 2005).

In broader health research, education for HPs working with Somali patients has been indicated (e.g., Konje and Konje, 2021). Similarly, visible difference research recommends additional training for HPs working with ethnic minority groups (Patel-Kerai *et al.*, 2017; Patel, 2014). HPs working with Somali patients with appearance-altering conditions are likely to benefit from enhanced training on appearance and culture-related matters. Health psychology may offer insights into how to deliver such training most effectively. Health psychologists have applied behavioural science to the development of HP education. For example, Chisholm *et al*. (2020) evaluated online training intended to support HPs to deliver behaviour-change to patients, and found that the training enhanced HP skills, and increased determinants for change, including motivation, and perceived capability and opportunity. Health psychologists could thus be consulted in the development of any training to enhance the likelihood of change among HPs working with Somali patients who have visible differences.

4.2.3 For Engaging Minority Groups in Research

This section offers reflections from the current study that may benefit future researchers intending to engage groups that have traditionally been underserved in research. In addition to failings from researchers to effectively reach communities (e.g., inappropriate recruitment strategies), other factors are believed to contribute towards reduced engagement, including low education and health literacy, limited English language proficiency, negative attitudes about/previous poor experiences with research (and distrust), and concerns about the nature of the research (i.e., sensitive topic) as well as the characteristics of the researcher(s) (i.e., community outsider(s); Gabriel, Kaczorowski and Berry, 2017; Johnson, Ali and Shipp, 2009; Knobf, 1969). Responses to this research by members of the Somali community offer additional insights.

The discussion generated through a Reddit recruitment post (Appendix 23) highlights concerns within the Somali community related to research. Specifically, the authenticity of research and the risk of deceit, the use of research data (worries about the selling of data), the implications of research findings (i.e., used to further marginalise communities), and the identity if he researcher. For example, some Reddit users expressed dissatisfaction about the advertised study, specifically that the researcher was not Somali: *“This guy isn’t even Somali.”* Some users were also suspicious about how data would be used, as well as the ‘true’ purpose of the project - suggesting that the project was about facial recognition or eugenics, or that findings would be used to marginalise Somali people: *“Don’t do this they will use and abuse us as always”*. Interestingly, other users actively challenged these suspicions - labelling them as ‘paranoia’. Instead, these dissenting voices reinforced the need for and importance of inclusivity and representation in research: *“We’re underrepresented in research because many of us refuse to participate in, much less conduct, scientific research.”*

It is imperative that researchers conduct culturally competent research, regardless of their personal ethnic background. Greater cultural competence in research may reduce participation barriers, ease participant concerns, and build trusting relationships with communities (Wang *et al.*, 2014). For example, Chan and So (2016) suggest that familiarity with traditional calendars (including cultural and traditional festivals) is important to ensure appropriate schedules for research projects. Commitment to cultural competency may be demonstrated by efforts such as cultural competency training for researchers (Jutlla and Raghavan, 2017).

Further, tackling systemic causes of decreased ethnic minority engagement in research is also imperative. Such causes can include discrimination and access barriers (Etti *et al.*, 2021). An effective strategy to minimise such disparities could be community outreach programs to educate members about research opportunities (Ekezie *et al.*, 2021). In addition, research participants could be offered childcare, or have their travel costs reimbursed, to account for logistical access barriers (Wendler *et al.*, 2006; Yancey, Ortega and Kumanyika, 2006).

Future researchers should aim to form and maintain strong relationships with marginalised groups, understand areas of concern (and reasons for such concern), and work to ameliorate any barriers to research participation. Health psychologists, trained on behaviour-change, may be particularly well placed to identify such barriers and devise interventions (Keefe and Blumenthal, 2004). Research highlights that Somali people may be more likely to participate in health research if they understand the relevance/importance of the research to them/their community, are approached with sensitivity and clarity, and feel that participating will lead to improvements for them/their community (Gill *et al.*, 2013). In health research with Somali refugees, Gabriel, Kaczorowski and Berry (2017) noted that clear communication from the research team served to highlight benefits of taking part for interested participants (e.g., altruism, acquisition of new knowledge), and was imperative for engagement. In other research, factors including altruism and a desire to help others, personal interest, enjoyment, curiosity, and the therapeutic benefits of sharing have also been shown to contribute to research involvement among ethnic minorities (Gysels, Shipman and Higginson, 2008). Though participants in the current study were not explicitly asked about their motivations for taking part, in the PI evaluation survey, representatives cited reasons for contributing to the project. These included a desire to help others, learn something new, and an interest in the project overall. While previous work has explored barriers to ethnic minority engagement in research (e.g., Rooney *et al*., 2011) much less has examined motivators. Researchers may wish to explore this, to better understand participants' motivations, and utilise those elements to promote greater involvement.

4.3 Limitations

The following sections present limitations of the current research, particularly with regards to accessibility and inclusivity. Given the historic underrepresentation of the Somali community in psychosocial and health research more broadly, and visible difference research more specifically, accessibility and inclusivity were key considerations for this project. The researcher hoped that within the limits of what is feasible (e.g., financial limits), this study would be as accessible and inclusive as possible - for example, by providing interpreters (section 2.4). However, Covid-19 had a significant impact on the project and is worthy of consideration. In this section, the necessary (remote) method of the study is considered, specifically, how it may have reduced accessibility for those technologically disadvantaged - such as the older individuals. Alternative, perhaps more accessible research methods are considered. The issue of participants with English as a Second Language (ESL) is also discussed in relation to accessibility. Finally, though the issue of sample 'representativeness' does not align with the theory or method underpinning this study, the issue of inclusivity is a core priority. However, the current sample were made up of young, Somali adults, and is thus not inclusive of other sub-groups within the community. Concerningly, some evidence suggests that these excluded sub-groups are the most marginalised and vulnerable to psychosocial and health-related challenges. An intersectional approach to recruitment is discussed as a possible solution to this issue.

4.3.1 Accessibility of the Method

Whilst in-person interviews have historically been considered a 'gold-standard' (Novick, 2008), options to engage remotely can facilitate involvement and reduce barriers to participation. Remote methods can overcome geographical and mobility limitations (Archibald *et al.*, 2019), and reduce recruitment time (Rupert *et al.*, 2017). Chan and So (2016) report that South Asian women may be busy with family duties, and struggle to find time to participate in research. Further, Rooney *et al*. (2011) found that South Asians reported barriers to asthma research, including time and travel – though flexibility in timing and location promoted greater community participation. Similarly, Gabriel, Kaczorowski and Berry (2017) found practical and logistical barriers to research among refugees, including Somalis, such as lack of childcare and time constraints. As such, geographical and logistical barriers can reduce research participation, and the option to engage online from a location of choice may minimise barriers and benefit ethnic minority engagement in research.

However, while Covid-19 necessitated a shift to remote working as safety was prioritised, this transition may have been detrimental for the project. For example, although the researcher consistently maintained her camera on, only a minority of participants chose to keep their cameras on during online interviews, perhaps due to concerns about privacy. While some suggest that videoconferencing methods allow for a natural exchange which could benefit rapport (e.g., Archibald *et al*., 2019), others pose that participants may be concerned about privacy and could regard cameras as an intrusion into their personal space (Sy *et al.*, 2020). Rooney *et al*. (2011) found that for South Asians, trusting relationships with the research team was crucial to successful recruitment, and that personalised approaches were favourable compared to more distant approaches. However, building rapport can be particularly challenging when using remote methods, especially among underserved groups (Dodds and Hess, 2020), and when the researcher is an ‘outsider’ (Roberts, Pavlakis and Richards, 2021). Further challenges for rapport may arise if there are connectivity issues. More, the issue of developing rapport with a Somali sample may be particularly difficult with remote methods given Somali cultural preferences on communication; where oral (and preferably in-person) communication is favoured (Haydarov *et al.*, 2016). The remote method may also have excluded those with limited access to/experience with the technologies needed to participate. Technological barriers to research are noted in other research contexts (e.g., Sy *et al*., 2020). This issue may be particularly relevant for specific sub-groups of the Somali community who may be at greater increased risk of technological disadvantage - such as older generations. Hence, the current findings do not include the experiences of older Somali people (despite active efforts to recruit older members of the community into the study; see Appendix 6).

Advice has been published about how to mitigate for such issues. This includes providing guidance to participants about how to use technological tools (Lobe, Morgan and Hoffman, 2020); building rapport with participants prior to interviews (Parkinson *et al.*, 2019); offering participants the option to have a virtual background to protect privacy (Roberts, Pavlakis and Richards, 2021); and avoiding built-in recording functions of videoconferencing software, instead recording audio-only on a second device (e.g., Dictaphone; Roberts, Pavlakis and Richards, 2021). These strategies may reduce technological biases, increase the likelihood of positive rapport, and serve to further protect participants’ privacy/anonymity, thus offering comfort to participants who may be particularly anxious. The design of the current study aligns with the guidance above, yet further research is needed to investigate how best to carry out remote interviews, particularly with underserved groups. Cultural factors, such as the preference for oral and in-person communication in Somali culture, should also be considered when designing research with communities.

4.3.1.1. Alternative Methods

Initially, interactive methods (i.e., where the researcher has direct contact/interaction with participants) were selected as it was felt that these would allow for the generation of more rich and in-depth data - owing to the ability for the researcher to ask for clarification and/or follow-up questions (see section 2.3.1 for full explanation of decision to use interactive methods). Importantly, this decision was made before the Covid-19 pandemic and subsequent social distancing/remote working requirements. However, considering Covid-19 and the need for participation to be distant and remote regardless of research design, non-interactive methods, such as qualitative surveys, may have been beneficial for the current study.

Affleck, Glass and Macdonald (2013) noted that qualitative interviews may not be well-suited to research involving sensitive topics and participants with limited communication skills. They also posed that for male participants, an interview may not be conducive to open emotional expression, and therefore encourage researchers to consider other methods. Previous health and appearance research with marginalised groups has identified benefits from qualitative online surveys, including the anonymity afforded by the method. As such, qualitative surveys have been argued to be a particularly helpful alternative for research on sensitive topics (Terry and Braun, 2017). However online qualitative surveys also pose challenges with regards to possible brief responses and may lack the richness of interviews (Braun and Clarke, 2013). Qualitative surveys also pose additional problems for accessibility as digital, language, and health literacy barriers could be influential to engagement. Though in the current study, the provision of surveys translated into Somali may have mitigated the issue of LEP.

Previous scholars have advised that multiple data collection methods can facilitate recruitment into research about sensitive topics (Heath *et al.*, 2018). Heath and colleagues found that offering face to-face, Skype, telephone, or email interviews may be beneficial to increasing engagement and accelerating recruitment. While the current study offered most of these options (except face-to-face owing to Covid-19 restrictions), additional method options, such qualitative surveys, may have been beneficial. However, this approach may pose issues such as the possibility that combining data obtained through different methods will lead to variability. Future researchers should continue to better understand how different communities, particularly those most marginalised in society and research, perceive different research methods. In doing so, the most appropriate methods can be identified and utilised to increase accessibility and participation.

4.3.2 Accessibility of Language

Interviews for the current study were relatively short (*m* = 32-minutes; range = 29 to 46-minutes; excluding the introductory, demographic and concluding sections of the interviews), which might indicate reduced participant engagement. Participants largely answered questions succinctly, and did not overly expand on their answers, even when asked follow-up questions. It is possible that this was because participants had nothing more to add to responses, however, it is possible that other factors were influential. These include the researcher’s outsider position and participants possibly feeling less at ease (see section 2.6.2.1); the influence of Covid-19 on the online design (discussed in section 4.3.2);

and the impact of participants having English as a second language (ESL). The issue of ESL is considered further below.

Having an interview in a non-native language can cause challenges for participants, which may act as a barrier to participation in research (Naqvi and Saul, 2012). Conducting research with an individual who has ESL also raises challenges regarding accuracy of communication (Koulouriotis, 2011). Multi-lingual people may also speak and behave differently when speaking different languages (Ramírez-Esparza *et al.*, 2006), which can pose further challenges for the accuracy of communication between participant and researcher. Though previous research suggests that interpreters can promote increased participation among participants with ESL (Irvine, Roberts and Bradbury-Jones, 2008), in the current study, no participants accepted the offer of an interpreter, despite advice from PI representatives, who inspired the recruitment of two interpreters of different genders. It is possible that modifying the research protocol to include interpreters as standard (non-optional) may have been helpful - allowing participants to discuss issues in greater depth. However, a conscious choice was made against enforcing this option as doing so may have deterred prospective participants. Research finds challenges in use of interpreters in research and healthcare. For example, Utne *et al*. (2020) found that Somali people have a limited uptake of interpreters in the context of antenatal healthcare due to fears around misinterpretations and breaches of confidentiality (i.e., interpreters sharing sensitive information with other members of community). Participants in the current study did not justify their decision to refuse an interpreter. Further work is needed to understand how best to meaningfully engage minority groups, and how to optimally utilise strategies for increasing accessibility of research, such as the provision of interpreters.

4.3.3 Inclusivity of the Sample

Though the issue of sample ‘representativeness’ is not one that aligns with the current project’s ontological and epistemological positions, and RTA method (see sections 2.2.2, 2.9.1, and 2.10.2), the issue of inclusivity was a core priority for this project. However, as discussed. some aspects of the project raised concerns around accessibility and engagement. Overall, the current sample of young, Somali adults is not inclusive of other sub-groups within the community. The sub-groups not included are debatably those most marginalised, vulnerable to psychosocial and health-related challenges, and with more pressing need. For example, Somali people with LEP are shown to have poorer health experiences and outcomes (Konje and Konje, 2021; Linney *et al*., 2020). Similarly, older adults with LEP are also reported to have worse health outcomes, owing to reduced knowledge about health and services, more pronounced language barriers, and greater cultural differences associated with health (Ponce, Hays and Cunningham, 2006).

Moreover, the present study’s sample were self-selecting, which poses questions about who self-selects to take part in (qualitative) research, and motivations for doing so. Arguably, those willing to share experiences represent extremes, that is extremely positive or negative experiences, and may thus feel more compelled to share (Peel *et al*., 2006). As such, the current findings are not inclusive of the experiences of broader members of the Somali community.

4.3.3.1 Generation and Migration Status

The present findings represent the experiences a young adult sample of first-generation UK Somalis. All participants were born in Somalia and had moved to the UK between the ages of five and 14 years old (m = 7.6). Whilst challenges around assimilating into a new culture and health system may lead to the assumption that first-generation migrants will experience poorer experiences, some research suggests a Healthy Migration Effect (Kobayashi, Prus and Lin, 2008). Here, first-generation migrants experience better health due to increased access to resources. As posed by the Classical Assimilation Theory (Gordon, 1964), second-generation migrants may have an additional advantage, due to even greater opportunities for upward social mobility. Yet, second-generation migrants could also be more vulnerable to health issues, due to the adoption of certain negative host society habits. Wang and Mak, 2020) found inter-generational differences among British ethnic minorities, in activity-limiting illness, diabetes, asthma, and body-mass index, and noted the nuanced and fluid impact of generation. This is reflected in other research findings. For example, in research with UK Pakistani, Bangladeshi and Indian individuals, Yan *et al*. (2019) found worse health outcomes for first generation migrants, whereas in another study, they found the opposite (Wang and Li, 2019). Such contradictory and inconclusive findings suggest that assimilation is complex and individual. The term "immigrant paradox" has been used to describe this phenomenon (Alegría *et al.*, 2008). The paradox proposes that the more an individual assimilates to their new culture, the more likely they are to experience adverse outcomes. For example, Hispanics who have lived in the US for longer are more likely to experience psychiatric disorders than Hispanics who have more recently immigrated (Alegría *et al.*). This suggests that assimilation can be problematic, however it is unclear whether this is due to acquiring new cultural values and practices and/or abandoning old ones.

Some Somali people in the UK may have arrived as refugees or asylum seekers, which carries a possible burden related to displacement, trauma and anxiety about ongoing conflict in Somalia (Bentley *et al.*, 2012). Research on long-term mental health among war refugees has found that such issues are prevalent – caused by exposure to war and post-migration socioeconomic difficulties (Jorgenson and Nilsson, 2021; Scoglio and Salhi, 2021; Bogic, Njoku and Priebe, 2015).

It is beyond the scope of the current study to comment on the unique experiences of Somali people of different ages, or with different migration histories. However, the impact of generation, and migration status/history (including related adversity) on wellbeing should be considered in future research and practice (Warfa *et al*., 2012).

4.3.3.2 An Intersectional Approach to Recruitment

Intersectionality theory may be drawn on when considering the issue of inclusivity. An intersectional perspective regards multiple social positions, and their contribution to experiences of privilege and oppression (Christensen and Jensen, 2012). Whilst the focus of this study was on the impact of Somali ethnicity, other intersections of Somali identity and experience may also be important to consider. Depending on a study's theoretical positioning, the application of intersectional (intentional/quota) sampling may be appropriate and helpful in ensuring the experiences of those with different intersections (which are deemed important for a given topic) are accounted for (Bowleg, 2017;

Robinson, 2014). In the current study, a recruitment quota of factors which may be influential to Somali health and wellbeing (e.g., age and migration status as discussed above) could have been beneficial. However, arguably the list of possibly influential factors is endless, which poses pragmatic challenges for recruitment. Further, this design did not align with approaches to recruitment and sample selection (see section 2.10.2). At a minimum, researchers should be transparent about their study samples, and acknowledge which experiences are (and are not) represented in the findings (see sections 4.3.1-4.3.3).

Conclusion

This study provided an initial insight into the wellbeing and possible support needs of a young UK Somali sample with visible facial differences. The qualitative method allowed for a detailed exploration of experiences, which was appropriate given the novelty of the research. Whilst some experiences may be comparable to those reported in the broader visible difference literature, there are unique sociocultural factors that should be considered when planning support and care for the Somali community. Findings reflect Somali cultural meanings and understandings of visible differences, and the impact on affected individuals' wellbeing (Research Objective (RO) 1; see section 1.6.1). Results also highlight the unique experiences of this migrant group, and how the process of acculturation – in addition to experiences of discrimination – are important to adjustment (RO 2). Additionally, results provide insight into preferred coping styles, as well as broader cultural perceptions of support, particularly psychological. Findings suggest a need for community intervention work to reduce stigma and raise awareness about visible differences, in addition to the importance of and preference for peer-led or community-involved support (RO 3). These results offer important reflections for various professionals working with this patient group, including researchers, psychologists, medical care providers, and those in the third sector (RO 4). For psychologists, overall existing frameworks of adjustment and psychosocial interventions are not sufficiently comprehensive to meet the needs of diverse groups with visible differences, including Somali people. More research is necessary to better understand the extent to which seemingly influential factors contribute to adjustment, and how best to consider these in intervention.

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Appendices

1: Black Lives Matters - An Illustration of a Reflective Piece

Written by the researcher before data collection.

In May 2020, the murder of George Floyd by Minneapolis police led to a resurgence of the Black Lives Matter (BLM) movement and attracted international attention to issues around race, discrimination, privilege, and police brutality. Protests and demonstrations were observed worldwide, including in the United Kingdom (UK). UK-based protests were not only intended to show solidarity with the United States protestors, they also commemorated the racially-motivated discrimination that continues to take place in the UK against Black people. In June 2020, a BLM protest in Bristol made international headlines when the statue of Edward Colston, a slave trader, was pulled down and pushed into the Bristol Harbour.

I feel it is appropriate for me to reflect here on the events of the past few months in relation to the BLM movement as they have hugely shaped my early thinking and decision-making with regards to this project. The BLM protests have made most people in a range of areas of society look inwards and critically evaluate their own attitudes and practices, both in their professional and personal lives. For most, this has been an uncomfortable though extremely necessary process. For me, it has made me think in-depth about my project, particularly around the fact that I am not Somali. *Is it right for me to do this research? Am I contributing to the problem by taking on this project?*

Before submitting my research ethics, I spent some time reading around relevant topics (e.g., positionality in research, the decolonization of psychology etc.) and having uncomfortable, but necessary and helpful, conversations with friends and colleagues. I also debated this issue with my supervision team. We talked about my concerns, namely that as someone without nuance Somali cultural knowledge, I am not well equipped to carry out project. However, we also discussed how the lack of diversity in appearance (and wider psychology) research is a very real issue that continues to plague the field and needs to be addressed (Hughes *et al*., 2009). *By not carrying out this project, am I contributing to the existing problem and choosing to ignore it?*

I feel more assured by my collaboration with Somali community members – who will offer their lived expertise to guide the project and ensure the work is beneficial to the community.

Community involvement is a core component of this project, and forms part of ongoing considerations about such issues. As the project evolves, I will maintain ongoing communication with supervisors on this to ensure that my intended community allyship is meaningful and effective. Ultimately, I hope this leads to research that is rigorous, and is sensitive to the Somali community.

2: Interview Schedule

Introduction

- Thank participant for their time
- Explain purpose of the study (to understand more about the experiences of Somali people with visible facial differences)
- Outline interview procedure (*you will be asked a series of questions and some may be more or less relevant to you, so the direction of the conversation can be guided by you; the interview can take around two hours*)
- Remind participant that the interview will be recorded but any information they provide will be confidential and that they will never be personally identified
- Confirm participant is happy and begin recording
- Emphasise that the interview may touch upon emotive issues and reassure the participant that they can pause or end the interview at any point (and withdraw their data even after the interview has finished (up until the data has been analysed)). Remind participant that they are also free to skip over any questions that they are not comfortable answering
- Ask participant if they have any questions at this point and remind participant that they can also ask questions at any point during the interview
- [Begin recording]
- Conduct verbal consenting procedure (see consent form)

Demographic information

- Gender
- Age
- Ethnicity/race
- Religion
- Place of birth. *If Somalia, how old were you when you moved to the UK? If UK, when did your family immigrate to UK?*
- Place of residence (if not Bristol)
- Marital status
- Education
- Employment status
- Cause of visible facial difference
- Age of acquisition (if relevant)
- How did you find this study?

Physical wellbeing

- [Provide gentle introduction to questioning – *"I'm now going to explore the effect of your difference on how you feel physically…"*]
- Is your physical functioning impacted by your difference?
- Do you suffer with any ongoing medical/physical concerns because of your condition?

Emotional wellbeing

- [Provide gentle introduction to questioning – *"I'm now going to explore the effect of your difference on how you feel emotionally…"*]
- Please can you tell me a bit about your emotional wellbeing. This includes positive and negative emotions that you may experience (adapting to change, stress, anxiety, depression, self-esteem, optimism, life enjoyment etc.)
- Have you ever experienced or been diagnosed with a mental health condition (eating disorder, depression, anxiety, bipolar etc.)?

Relationships

- [Provide gentle introduction to questioning – *"I'm now going to explore the effect of your difference on your relationships…"*]
- What have been your experiences of romantic relationships?
- What have been your experiences with your family?
- What have been your experiences with friends?
- What have your social encounters been like? What are your experiences with members of the public like?

Appearance

- [Provide gentle introduction to questioning – *"I'm now going to explore the effect of your difference on the way you view your appearance…"*]
- How do you feel about your appearance? If it's a cause for concern, what do you worry about and how often do you worry about it?
- How noticeable do you think your appearance is to others?
- Have you ever felt pressure to change your appearance from others (friends, family, romantic partner, the media etc.)?

Experiences of education and employment

- [Provide gentle introduction to questioning – *"I'm now going to explore the effect of your difference on your educational and employment experiences…"*]
- What were your experiences with schooling? *Only relevant for participants that either have a congenital condition or a condition acquired early in life*
- What were/are your experiences with employment?

Experiences of treatment

- [Provide gentle introduction to questioning – *"I'm now going to ask you about your experiences of treatment…"*]
- What medical treatment have you received for your condition? If relevant, how many surgeries/procedures have you had?
- What health professionals have you seen about your condition? What were those experiences like?
- Are you satisfied with the care/treatment that you have received for your condition to date? Do you feel you were given enough information? Do you feel you were involved in the decision-making process about your care/treatment?

Experiences of support

- [Provide gentle introduction to questioning – *"I'm now going to ask you about your experiences of support…"*]
- Have you ever received emotional support for your condition? If so, who from and what did you think of it?
- Have you ever seen a psychologist? If so, what was that experience like for you?
- Have you ever engaged with any charitable organisations related to your condition (e.g., Changing Faces etc.)? If not, why not. If yes, how was it?
- What other sources of support have helped you (e.g., faith-based support)?
- What could be improved about the support you have or haven't received? Did you feel you had enough? Too much? Too little? The right kind?

Visible difference and the Somali community

- [Provide gentle introduction to questioning – *"I'm now going to ask you about how you think visible differences are perceived among the Somali community…"*]
- How do you think the Somali community perceives people who look different?

• Do you think there is a difference in the experiences of Somali people who look different depending on whether they are male or female, or younger or older? • Do you think information and support for Somali people with conditions that change the way they look could be improved? If so, how? • What advice would you give to another Somali person with visible facial differences?
Positive adjustment and looking ahead
• [Provide gentle introduction to questioning – *"I'm now going to ask you about any potential positive impacts of your difference, as well as your hopes for the future…"*] • What skills, strategies, adjustments, or new ways of thinking have you used or developed that have helped you live with your difference? • How have you worked to overcome any challenges? • Can you describe any areas of personal growth or positive experiences that have resulted from your difference? • What are your hopes for the future?
Debrief
• Any other comments or questions? • Tell the participant the interview has now ended • Tell the participant what the next steps are (i.e., *we are interviewing other people; then we will analyse the data; then we will publish findings in leading academic journals*) • Ask participant whether they would be willing to review and comment on results – if yes, take note of their email • Direct participant to sources of support – these can be found on Participant Information Sheet • Discuss thank you gift card • Thank participant for their time and conclude the interview

3: Participant Information Sheet

3a: English

You are invited to participate in a research project run by the Centre for Appearance Research funded by the Vocational Training Charitable Trust Foundation. Before you decide whether or not to take part, it is important for you to understand why the project is being carried out and what it will involve. Please read the following information carefully and contact Bruna if you have any questions or would like more information: (bruna.oliveiracosta@uwe.ac.uk (0117)3283715)

What is the Centre for Appearance Research?

The Centre for Appearance Research is based at the University of the West of England in Bristol. It is the world's largest research centre focusing on the role of appearance and body image in people's lives. We aim to improve the lives of those affected by appearance concerns.

What are the aims of the research?

Some people with visible facial differences may feel as though they look different, and this can have positive or negative consequences on their lives. Little is known about how Somali people, with visible facial differences, cope with this experience. To inform and improve the care and support that is available to people, this project aims to understand the experiences of Somali men and women with a visible facial difference.

Can I take part?

You are invited to take part in this research if you are over the age of 18 years old, are of Somali heritage, and have a visible facial difference. A visible facial difference could be something like a scar, a cleft lip, hyperpigmentation, vitiligo, skin conditions such as eczema, etc.

What will happen if I take part and what will I be asked to do?

If you choose to take part, you will be invited to an interview. Due to Covid-19 social distancing guidelines, this will be done remotely (e.g., phone, Zoom, Microsoft Teams, Skype etc.). The interviews will last approximately 1 hour and will involve you answering various questions about yourself and your experiences. You do not have to answer any questions you do not wish to. A Somali-speaking interpreter is available if you would prefer to chat in Somali instead of English.

Do I have to take part?

Whether or not you take part is entirely up to you and you can change your mind at any time (even half-way through the interview or after it's been conducted). If you decide you don't want your information to be used after the interview, you can contact Bruna to withdraw your data. Unless your data has already been analysed, it will be removed and destroyed.

What are the potential benefits of taking part?

We hope you'll enjoy the opportunity to share your experiences with us. The information you provide will help us to understand how we can improve the lives of people affected by visible facial differences. As a thank you for taking part, we would like to offer you a gift card.

What are the potential risks of taking part?

We don't expect any significant risks to you if you take part. However, there is a possibility that speaking to us about your experiences will bring up some difficult or sensitive issues for you. We will provide you with details of support organisations that you may find helpful. Remember, during the interview you are free to skip any questions that you are not comfortable answering and can provide as much or as little detail in your answers as you like.

What will happen to my information if I take part?

Anything you tell us will be treated in the strictest confidence and security. All data will be anonymised (i.e., no one will know who it belongs to) and stored securely. Please read through the Privacy Notice for further information on how your data will be processed.

Where will the results of the research be published?

The anonymised findings will be written up in a thesis and may be reported in other reports, presentations, meetings, conferences, and/or leading academic journals. Remember, all of the data will be anonymised.

Who has approved this research?

This project has been reviewed and approved by the Faculty Research Ethics Committee at the University of the West of England. Any comments, questions, or complaints about the project can be raised with the researchers or UWE ethics (researchethics@uwe.ac.uk).

What should I do now?

If you would like to take part in the research project, please contact the lead researcher, Bruna (bruna.oliveiracosta@uwe.ac.uk (0117)3283715).

Who can I contact for support?

If this research project raises any difficult issues for you and you would like some support, you can contact:

- Changing Faces - a charity offering information and support to people affected by altered appearances - https://www.changingfaces.org.uk/
- Mind - a charity offering support for mental health concerns - https://www.mind.org.uk/
- Samaritans - a charity offering a free helpline service 24 hours a day - http://www.samaritans.org/
- Nilaari - a Black, Asian and Minority Ethnic led charity delivering social care support, talking therapies and training for adults and young people in Bristol - https://www.nilaari.co.uk/about-us/
- Next Link - a local charity offering support for women on various issues including domestic abuse with specific services for Black and Ethnic minorities and dedicated Somali workers - https://nextlinkhousing.co.uk/
- Muslim Youth Helpline - a national charity providing faith and culturally sensitive services to Muslim youth in the UK - https://www.myh.org.uk/
- Inspired Minds - a London-based charity aiming to provide faith and culturally sensitive support for Muslims affected my mental health problems - https://www.inspiritedminds.org.uk/
- Muslim Community Helpline - a national organisation offering emotional support to men, women, youth and children of the Islamic faith - https://muslimcommunityhelpline.org.uk/

3b: Somali

Waxaa lagugu marti qaadayaa inaad ka qayb gasho mashruucan cilmi baadhista ah ee ay samayso xarunta cilmi baadhista muulqaaka oo ay maal gelisay Vocational Training Charitable Trust Foundation. Intaanad go'aansan inaad ka qayb gasho iyo in kale, waxaa muhiim ha inaad fahanto sababta mashruuca loo samaynayo iyo waxa soo raaci kara. Fadlan si taxadir leh u akhri macluumaadkan hoose hadii aad wax su'aal ah qabto ama aad doonayso inaad wax dheeraad ah ka ogaato la xidhiidh Bruna: (bruna.oliveiracosta@uwe.ac.uk, (0117)3283715)

Maxay tahay Xarunta Cilmi baadhista duwanaanshuhu?

Xarunta Cilmi baadhista Muuqaalku waxay ku taalaa Jaamacada Galbeedka England ee Bristol. Waana xarunta cilmi baadhiseed ee aduunka ugu wayn oo xooga saarta muuhiimada muuqaalka iyo sawirka jidhka ee dadka noloshooda saameeya. U jeedadayadu waxa weeye inaan hagaajino dadka ay wax yeeladu ka soo gaadhay muuqaalka iyo walbahaarka muuqaalkooda

Maxay tahay u jeedooyinka Cilmi baadhistu?

Dadka qaar aragti ahaan uu muuqaalkoodu duwanyahay waxay dareemi karaan feker ah inay sikale u eegyihiin, waxaay noloshooda u saamayn kartaa si aan wanaagsanayn iyo si caadi ahba. Wax yar Ayaa laga ogyahay sida dadka Somali da ah ee wejigoodu aragti ahaan ka muuqaal duwanyahay siday u maareeyaan raad-reebkaas. Waxaan la socodsiinaynaa in markaa maaro iyo daryeel loo helo loona bandhigo caawimo loogu talo galay dadkaas, mashruucan u jeedadiisu waa inuu fahmo raad-reebka dadka somaliyed rag iyo dumarba ee ay ku keentay aragtida wejiga ee muuqaal ahaan duwan.

Maka qayb qaadan karaa?

Waxaa lagugu marti qaadayaa inaad ka qayb gasho Cilmi Baadhistan hadii aad da ahaan 18 ka wayn tahay, Somali ka soo jeedo, oo uu wejigaagu muuqaal ahaan duwanyahay.

Muuqaalka wejiga oo aragti ahaan duwani wuxuu noqon karaa sida calaamad dhaawac hore, Dibinta oo faruuran, Haaraha wejiga, Baraska iyo xanuunada jidhka sida Xasaasiyada iyo iwm.

Maxaa dhici doona hadaan ka qayb qaato maxaase lay waydiin doonaa inaan sameeyo?

Hadaad go'aansato inaad ka qay qaadato, waxaa lagugu marti qaadi doonaa waraysi. Xaalada Covid-19 iyo kala fogaanshaha bulshada awgeed wuxuu noqon doonaa khadka internetka sida Zoom, Microsoft Teams, Skype iwm.).

Wayrasigu wuxuu socon doonaa qiyaas ahaan saacad, waxaanay noqonaysaa inaad ka jawaabto suaalo kala duwan oo ku saabsan naftaada iyo khibradaada. Hadii aanad doonayn maaha inaad ka jawaabto suaalaha. Aqof Somali ku hadla ayaa kuu turjumi doonaa hadaad ka door bido Englishka.

Miyay tahay inaan ka qayb qaato?

Inaad ka qayb qaadato iyo in kale adigay kugu xidhantahay runtii waanad bedeli kartaa ra'yiyaagaa xiligaad doonto (xataa kala badh baad kaga bixi kartaa waraysiga ama markuu dhamaado). hadaad go'aansato inaan macluumaad kaaga la isticmaalin waxaad la xidhiidhaa Bruna si lagaaga saaro.hadii aan weli la isticmaalin macluumaad kaaga waa laga saari doonaa waa la masaxayaa.

Maxay tahay faa'iidada ku jirta inaan ka qayb galo?

Waxaan rajaynaynaa inaad ka heli doonto fursada aad lana wadaagayso khibradaadaa. Macluumaadkaagu wuxuu naga caawin doonaa in aanu fahanno sida aanu u caawin karno dadka uu raadka ku reebay wejiga muuqaal ahaan duwani. Si aanu kaaga mahad celino ka qayb qaadashadaada waxaanu ku siin doonaa kaadh hadiyad ah.

Maxay tahay dhibaatada ku jirta inaan ka qayb galo?

Isma lihin wax dhibaato ah ayaa kaaga imanaysa hadaad ka qayb gasho. waxaase laga yaabaa inay suurta gal tahay markaad ka hadasho muuqaalkaaga inay kugu keento dareen adag oo oo ku dhiba. waxaan ku siin doonaa macluumaad ururo ku caawin kara oo aad wax tar u arki karto. Xasuusnow, inta waraysigu socdo xorbaad tahay inaad su’aalaha qaar iska dhaafto oo aanad ka jawaabin hadii aanad ku qanacsananyn inaad ka jawaabto ama waxaad ka bixinkartaa inta ugu badan ama ugu yare e aad jeceshahay inaad ku jawaabto.

Maxaa ku dhacaya macluumaadkayga hadii aan ka qaby galo?

Wax kasta oo aad noo sheegtaa waxay noqonaysaa sir si adag loo xafiday. Macluumaadka oo dhan waa la qarinayaa (t.a,lamana ogaan karo qofka leh) waxaana loo kaydin doonaa si ilaalsan. Fadlan akhri macluumaadka sirta si aad wax badan uga ogaato sida macluumaadkaaga loo isticmaalayo.

Xagee ayaa jawaabta cilmi baadhista lagu samaynayaa?

Waxa kasoo baxaa iyadoon la ogayn waxaa laga qori doonaa diyaarin iyadoo laga yaabo in loo isticmaalo riboodada, bandhigyada, kulannada, shirarka iyo joornaalda tacliinta horyaalka u ah. Xasuusnow macluumaadka oo dhami waa qarsoonyahay.

Yaa fasaxay cilmi baadhistan?

Mashruucan waxaa eegay oo fasaxay Gudida Qaybta Cilmibaadhista ee Jaamacada Galbeedka England. wixii hadal, su’aal ama dacwad ah ee mashruucan ku saabsan waxaad u gudbin kartaa Cilmi baadheyaasha ama JGE (researchethics@uwe.ac.uk).

Hada maxaan sameeyaa?

Hadaad doonaysid inaad ka qayb qaadato mashruucan cilmi baadhista ah fadlan la xidhiidh qofka hogaaminaya cilmi baadhista, Bruna (bruna.oliveiracosta@uwe.ac.uk (0117)3283715).

Yaan la xidhiidhi karaa si aan caawimo u helo?

Hadii Cilmi baadhistani wax dhibaato ah kugu keento oo aad jeceshay in lagu caawiyo, waxaad la xidhiidhi kartaa:

- Changing Faces – waa jaarati bixiya macluumaad caawiya dadka ay dhibaatadu ka soo gaadhay muuqaalkooda oo bedelmaya - https://www.changingfaces.org.uk/
- Mind – waa jaarati bixiya caawimo dadka caafimaadka maskaxda ka dhibaataysan - https://www.mind.org.uk/
- Samaritans – waa jaarati bixiya caawimo bilaash 24 saac ee maalintii - http://www.samaritans.org/
- Nilaari – waa jaarati ka caawiya arimaha daryeelka bulshada Black, Asian and Minority Ethnic,waxay la hadlaan ama taba bar siiyaan dadka waawayn iyo dhalinyarada Bristol degan - https://www.nilaari.co.uk/about-us/
- Next Link – waa jaarati ka caawiya dumarkadhibaatooyin kala duwan sida dhibaatada qoyska iyo adeegyo u khaas ah Black and Ethnic minorities and waxaa u shaqeeya qof dadka af-Somaliga ku hadla loogu talo galay - https://nextlinkhousing.co.uk/
- Muslim Youth Helpline – waa jaarati waxay bixiyaan adeeg loogu talo galay dadka Muslimka ah ee da’doodu yartahay ee UK si ay u helaan adeega xaasi ah oo dhaqan ahaana ku haboon - https://www.myh.org.uk/
- Inspired Minds – waa jaarati degan waxaanay caawiyaan dadka Muslimka ah si ay u helaan adeeg ku haboon diintaada oo xaasasi ah waxaana loogu talo galay dadka ay dhibaatadu ka soo gaadhay xaga maskaxda - https://www.inspiritedminds.org.uk/
- Muslim Community Helpline – waa urur caawiya raga, dumarka, dhalin-yarada iyo caruurta haysta diinta Islamka - https://muslimcommunityhelpline.org.uk/

4: Participant Consent Form

4a: English

Researcher: Bruna Costa (bruna.oliveiracosta@uwe.ac.uk (0117)3283715)

If you are happy to take part in this study, please confirm that;

- You have read and understood the information in the Participant Information Sheet which you have been given to read before asked to sign this form;
- You have been given the opportunity to ask questions about the study;
- You have had any questions answered satisfactorily by the research team;
- You understand that your participation is voluntary and that you are free to withdraw at any time until the data has been analysed, without giving a reason;
- You are aware of the potential risks and benefits of taking part;
- You understand how your anonymised data may be used;
- You are aged 18 years or older.
- You agree to take part in the research.

☐Yes

☐No

Date:

Print name:

Signature:

4b: Somali

Hogaamiaya cilmi baarista: Marwo Bruna Costa (bruna.oliveiracosta@uwe.ac.uk (0117) 3283715)

Hadii aad ku qanacsantahay inaad ka qayb qaadato cilmi baaristan, fadlan ii cadee:

- Inaad akhriday oo aad fahamtay warqada macluumaadka ka qayb qaataha taas oo lagu siiyay si aad u akhrido ka hor intaanad foomkan saxeexin,
- In lagu siiyay fursad aad waydiiso su’aalo cilmi baaristan ku saabsan,
- Inaad ku qanacsanatay su’aalahii aad waydiisay jawaabta ay cilmi baadhayaashu kaa siiyeen,
- Inaad fahamsantahay ka qayb galkaagu inuu yahay mutadacwnimo isla markaana aad xor u tahay inaad ka bixi kartid xiligaad doonto, iyadoon macluumaadkaaga weli la dhamayn adigoon wax sabab ah sheegin;
- Inaad dareensantahay khatar iyo faa’iidada ay leedahay inaad ka qay qaadataa;
- Inaad fahansantahay in macluumaadkaaga la isticmaalyo iyaoo la qariyay,
- Inaad tahay 18 jir am aka wayntahay;
- Inaad ogolaatay ka qayb qaadashada cilmi baadhistan.

☐Haa

☐Maya

Taariikhta:

Magacaaga:

Saxeexaaga:

5: Compliance with National Institute for Health Research Public Involvement Standards

Standard	Question	Application to current project
Working together	*Q1: Has the purpose of public involvement been jointly defined and recorded?* *Q2: Have the practical requirements and arrangements for working together been addressed?* *Q3: Is there is a shared understanding of roles, responsibilities and expectations of public involvement?*	The initial one-to-one call with the researcher, and the PI resource pack, offered space to collaboratively plan efforts, and lay these out clearly. The initial meeting between the researcher and the representatives was intended to outline and agree upon details (see Appendix 7 for plan), and the PI resource pack (Appendix 8) also provided representatives with further information for their personal records.
	Q4: Have all the potential different ways of working together been explored, and have these plans and activities been developed together?	Unfortunately, due to Covid-19 restrictions at the time, only remote public involvement was possible, limiting how much flexibility the researcher offered representatives (i.e., involvement had to be carried out remotely). However, as much as possible, representatives were offered choices to facilitate their involvement in this project. This included, for example, the researcher being flexible around timings of meetings and rescheduling as necessary. Representatives were offered the choice about specifics (e.g., video conferencing or phone call, providing feedback via email or via a one-to-one meeting with the researcher, etc.).
	Q5: Have individuals' influence, ideas and contributions' been recognised and addressed?	PI efforts and communications were logged and routinely shared with representatives for transparency and to promote ongoing collaboration (Appendix 9). Most advice from representatives was actioned. This included: recruiting interpreters of different genders; adjusting the wording in the interview schedule to ensure language was sensitive; editing participant-facing materials to ensure they were more appealing to the community; and providing more flexibility and choice in terms of incentives for participants. For example, representatives noted that Amazon vouchers may not be appropriate, as some members of the Somali community may be reluctant to shop online, and so a choice should be given about the type of voucher a participant will receive after participating. Some of the advice from representatives was not

		able to be actioned, such as not being able to increase incentive amount due to budget restraints. However, this reasoning was clearly explained to representatives to ensure that they were aware of how and why their advice was (and was not) being actioned.
Communication	*Q1: Has a communications plan been developed for involvement activities?*	See above (point 1, Qs 1, 2 and 3).
	Q2: Are the needs of different people being met through inclusive and flexible communication methods?	The researcher made efforts to ensure PI involvement was inclusive and flexible (as noted above). However, the remote nature of involvement may have been a barrier for those less confident about technology (e.g., older people, or those with limited access to an internet-enabled device – see section 4.3.1-4.3.3). Unfortunately, due to Covid-19 regulations, this was beyond the researcher's control.
	Q3: Are processes in place to offer, gather, act on and share feedback with the public? *Q4: Are you sharing your public involvement learning and achievements, good and bad?*	See above (point 1, Q5).
Inclusive opportunities	*Q1: Are people affected by and interested in the research involved from the earliest stages?*	Representatives were invited to contribute to this research from the earliest possible stage (i.e., after the researcher conceptualised the research question and put together a proposal on study design). Arguably, representatives should be brought into projects as early as possible (i.e., conceptualising). However, primarily due to logistical time constraints, the researcher was not able to liaise with the community when deciding early research priorities. However, the researcher worked to build and strengthen relations with the community as early in the project as possible and recruited 4 representatives before finalising/beginning the project. Further, despite not having been a part of the project from the very initial stages, the feedback that was received from the representatives lead to a significant shift in the broader research focus – that is away from a focus on *facial scarring* and towards *facial differences*. This resulted from feedback which suggested that *difference* is a more inclusive and relevant term for the Somali community. For example, one

		representative noted that hyperpigmentation (melasma) is a particularly relevant issue for Somali women (though not a scar), that this study should be open to consider.
	Q2: Have barriers to involvement, such as payment for time or accessible locations for meetings been identified and addressed?	Although efforts were limited to remote working, representatives were compensated for their time and contributions (£20 voucher).
	Q3: How is information about opportunities shared, and does it appeal to different communities? *Q4: Are there fair and transparent processes for involving the public in research, and do they reflect equality and diversity duties?*	Various methods were used to promote involvement with this research (see Appendix 6).
	Q5: Is there choice and flexibility in opportunities offered to the public?	See above (point 1, Q4).
Impact	*Q1: Are the public involved in deciding what the assessment of impact should focus on, and the approach to take?* *Q2: Is it clear what information to collect to help assess impact, including who has been involved and how?* *Q3: Are there processes in place to help reflect on public involvement?* *Q4: Are the changes, benefits and learning resulting from public involvement acted on?*	See above (point 1, Q5). In addition to a log about outcomes which was shared with all parties, the researcher also kept a personal reflective log following each interaction with representatives, to reflect on the process and facilitate learning/improvement (Appendix 9).
Governance	*Q1: Are public voices heard, valued and respected in decision making?*	See above (point 1, Qs 1, 2 3 and 5).
	Q2: Are public involvement plans in place that are regularly monitored, reviewed and reported on?	See above (point 1 Q5 and point 4 Q4).
	Q3: Is there visible and accountable responsibility for public involvement throughout the organisation?	Not applicable given that this was a project carried out independently by the researcher as part of her doctoral training.
	Q4: Are realistic resources (including money, staff, time) allocated for public involvement?	The researcher gave up her time, including evenings and weekends, to facilitate PI. Representatives were also compensated for their time and contributions in the form of a shopping voucher.

	Q5: Is the privacy of personal information protected by collecting and using it in a suitable way?	The researcher is familiar with data protection rules and regulations and adhered to these during PI efforts. For example, data were stored in a password-protected cloud space, which only the researcher had access to.
Support and learning	*Q1: Is there a range of support to address identified needs?* *Q2: Have specific resources been designated to support learning and development opportunities for both the public, researchers, and staff?* *Q3: Do the public know where to go for information and support about public involvement?* *Q4: Is there a culture of learning by doing, building on and sharing that learning for researchers, staff and the public?*	The researcher engaged with relevant training opportunities provided by her institution, for example, a workshop by People in Health West of England (PHWE) about co-production when researchers and representatives cannot meet face-to-face (i.e., due to Covid-19). The initial one-to-one call with the researcher, and the resource pack, was intended to provide representatives with relevant information about PI facilitate engagement. Representatives were always invited to communicate with the researcher regarding concerns or questions.

6: Recruitment Tracking

Organisation /individual	Information	Contact details	Contact date and notes	Outcome
[Information redacted for anonymity]				

7: Plan for Meetings with Public Involvement Representatives from the Somali Community

Preparing for meeting	
1.Check representatives have access to technology for Zoom or Microsoft Teams* (preferable due to video feature) – if not, offer phone call.	
2.Send representatives ‘How to use Zoom/Teams’ documents if needed.	
3.Send reminder email at least 3 days ahead of the meeting with all the necessary materials.	Email draft (Note: Adjust tone of email depending on who I am contacting) *Dear X,* *Thank you for agreeing to provide advice on my study which aims to* ***understand the experiences of Somali people with visible facial differences.*** *It is important to me that this research reflects you and your community, which is why I’m so pleased to have you on board as an advisor. This process of consulting you to make sure the research is relevant, useful and sensitive is known as Public Involvement (PI).* *Although I have the research expertise, you have the cultural and social expertise and so I am very motivated to learn from you. It is said that PI can be empowering for communities and can also increase the success of the research. By members of the public taking an active and close role in research, it ensures that research is being carried out “by” or “with” them, rather than “to”, “about”, or “for” them.* *Due to Covid-19 social distancing rules, we unfortunately won’t be able to meet in-person. The next best option though is to talk via video call. Are you able to access online platforms like Zoom or Microsoft Teams? If not, I would be happy to call you on your telephone instead. Just let me know whatever suits you best.* *Ahead of our meeting, I would really appreciate it if you could take a look at the attached resource pack. If you would prefer this sent to you through the post, please let me know and I’d be very happy to do it. The resource pack includes 1) the participant information sheet, 2) the participant consent form, 3) the recruitment plan, 4) the study advert, 5) the interview schedule. Please make any notes about initial thoughts or questions that may come up – we will be discussing this in more detail when we chat.* *As a thank you for your time, I would be very pleased to offer you a £20 online shopping voucher. I will send this to you after out meeting.* *Thanks again. I’m really looking forward to speaking with you on X.* *In the meantime, if you have any questions or concerns, don’t hesitate to contact me.* *Best wishes,* *Bruna*

Running meeting	
1.Allow representative to introduce themselves	Who they are, what they do, what made them want to provide advice on this project. Born in Somalia? If so, how long living in UK? Born in UK? If so, when did parents move to the UK?
2.Introduce myself/CAR	*I'm a researcher based at the Centre for Appearance Research (CAR) at the University of the West of England (UWE). CAR is the world's largest research centre focusing on the role of appearance in people's lives, both body image in the general population (i.e., how people think and feel about their bodies), and visible differences (i.e., an appearance that is different to society's accepted 'norm', e.g., a scar following a burn accident).* *My area of work is more on the visible difference side of things and historically I've done most of my work on craniofacial conditions (e.g., cleft lip and/or palate).* *CAR's work is in recognition of the importance of appearance in people's lives. Appearance affects us all, but for those with visible differences, appearance can be a particularly troublesome issue.* *Alongside my job as a researcher, I'm also a health psychologist in training. I'm currently in the final year of the professional doctorate in health psychology at UWE. This study forms part of my doctoral thesis project.*
3.Introduce the research	*My interest for this topic came about for many reasons. First, as is widely recognised in appearance (and broader psychology) research, historically, groups other than white western middle class (women, typically) have been neglected. As such while the impact of living with a visible difference is well documented for majority populations, less is known about how different (minority) groups view and experience appearance. This is problematic for many reasons but is particularly concerning because the support that is subsequently developed from the research tends to fall short for more diverse groups.* *The very limited amount of research that has been conducted in this area suggests that minority groups may experience overall poorer outcomes. Specifically, research implies that minority groups (particularly those from cultures that are significantly different to British culture), view and experience appearance (and visible difference) differently (and at times less favourably) to the White British majority. Of course, it isn't novel information that there are broader health disparities between different groups, something that the Covid-19 pandemic has sadly highlighted even more over the past year.* *I'm motivated to pursue this line of work to ensure different communities and groups have an opportunity to get involved and share their experiences. With a greater understanding of Somali people experiences, we can help to raise awareness with the aim of improving treatment and psychological support, as well as influence policy makers, and support the work of charitable organisations.*

4.Your contribution	*We want your help to make a difference. In order to make a meaningful impact on the treatment and support that is available to Somali people, our research needs to be addressing the questions that are important to Somali people. We believe all stakeholders (individuals, family members, health professionals, charities) should have a say, and be able to influence the research at every stage of the research process. We want this research to by carried out "by" and "with" Somalis, rather than "to", "about", or "for" them.* *Remember that you are the expert here today.* *Through the literature, we've been able to identify and prioritise the research project. I welcome your help to drive the study including feedback on the design to start off.*
5.Feedback on the study	*I'll talk you through some of the details about the study and ask for your feedback. Feel free to interrupt me at any point and be as honest as possible. Do you have any questions so far…?* *-We have obtained ethics through UWE's committee to ensure the research is safe* *-Our proposed method will be one-to-one interviews, with myself, the participant and an interpreter if needed. What do you think?* *-Advertisement plan* *I intend to recruit participants through (see recruitment plan document)… What do you think?* *-Incentives* *-I have sent you a materials pack, this includes a participant information sheet, consent form, advert and interview schedule. What do you think? (go through each document)* *-Dissemination plans. Who should know about the results of the study? How could we share findings?* *-Any other thoughts? Questions? What do you like about the study? How will the study be improved?* **Note that participant information sheet and consent form, as well as the research advert, will be translated*
6.Close meeting	*We will consider all feedback and make necessary changes – will email you an update on the changes we made (is this the best option – would you prefer me to feedback the info to you in another way?)* *Complete evaluation form (online on complete and return via email – preference?)* *Thank you.*

8: Resource Pack for Public Involvement Representatives

1.An introduction to Public Involvement

Thank you for agreeing to provide advice on this study,

It is important to me that this research reflects you and your community, which is why I'm so pleased to have you on board as an advisor. This process of consulting you to make sure the research is relevant, useful and sensitive is known as Public Involvement (PI).

Although I have the research expertise, you have the cultural and social expertise and so I'm very motivated the learn from you – you are the expert!

It is said that PI can be empowering for communities and can also increase the success of the research. By members of the public taking an active and close role in research, it ensures that the research is being out "by" or "with" them, rather than "to", "about", or "for" them.

2.An introduction to me and the Centre for Appearance Research

My name is Bruna and I'm a researcher based at the Centre for Appearance Research (CAR) at the University of the West of England (UWE). CAR is the world's largest research centre focusing on the role of appearance in people's lives, both body image in the general population (i.e., how people think and feel about their bodies), and visible differences (i.e., an appearance that is different to society's accepted 'norm', e.g., a scar following a burn accident).

My area of work is more on the visible difference side of things and historically I've done most of my work on craniofacial conditions (e.g., cleft lip and/or palate).

CAR's work is in recognition of the importance of appearance in people's lives. Appearance affects us all, but for those with visible differences, appearance can be a particularly troublesome issue.

Alongside my job as a researcher, I'm also a health psychologist in training. I'm currently in the final year of the professional doctorate in health psychology at UWE. This study forms part of my doctoral thesis project.

3.An introduction to this study

My interest for this topic came about for many reasons. First, as is widely recognised in appearance (and broader psychology) research, historically, groups other than white western middle class (women, typically) have been neglected. As such while the impact of living with a visible difference is well documented for majority populations, less is known about how different (minority) groups view and experience appearance. This is problematic for many reasons, but is particularly concerning because the support that is subsequently developed from the research tends to fall short for more diverse groups.

The very limited amount of research that has been conducted in this area suggests that minority groups may experience overall poorer outcomes. Specifically, research implies that minority groups (particularly those from cultures that are significantly different to British culture), view and experience appearance (and visible difference) differently (and at times less favourably) to the White British majority. Of course, it isn't novel information that there are broader health disparities between different groups, something that the Covid-19 pandemic has sadly highlighted even more over the past year.

I'm motivated to pursue this line of work to ensure different communities and groups have an opportunity to get involved and share their experiences. With a greater understanding of Somali people's experiences, we can help to raise awareness with the aim of improving treatment and psychological support, as well as influence policy makers, and support the work of charitable organisations.

4.Study materials

Please take some time to review the relevant documents and make notes of any thoughts, questions, or concerns that come up. Please be as honest as you can!

- **Participant information sheet (attached) -** The information that potential participants will initially receive (will be translated into Somali).
- **Participant consent form (attached)** - The form that participants will be asked to sign if they want to take part in the study (will be translated into Somali).
- **Study advert (attached)** - This is an advert that I will use to reach participants (will be translated into Somali).
- **Interview schedule (attached)** - These are the questions I intend to ask participants during a 1-1 interview (note that participants will be given the option to have an interpreter present if they want).
- **Recruitment plan (attached) -** This is my plan for how to identify possible participants.

9: Example of Public Involvement Impact Log

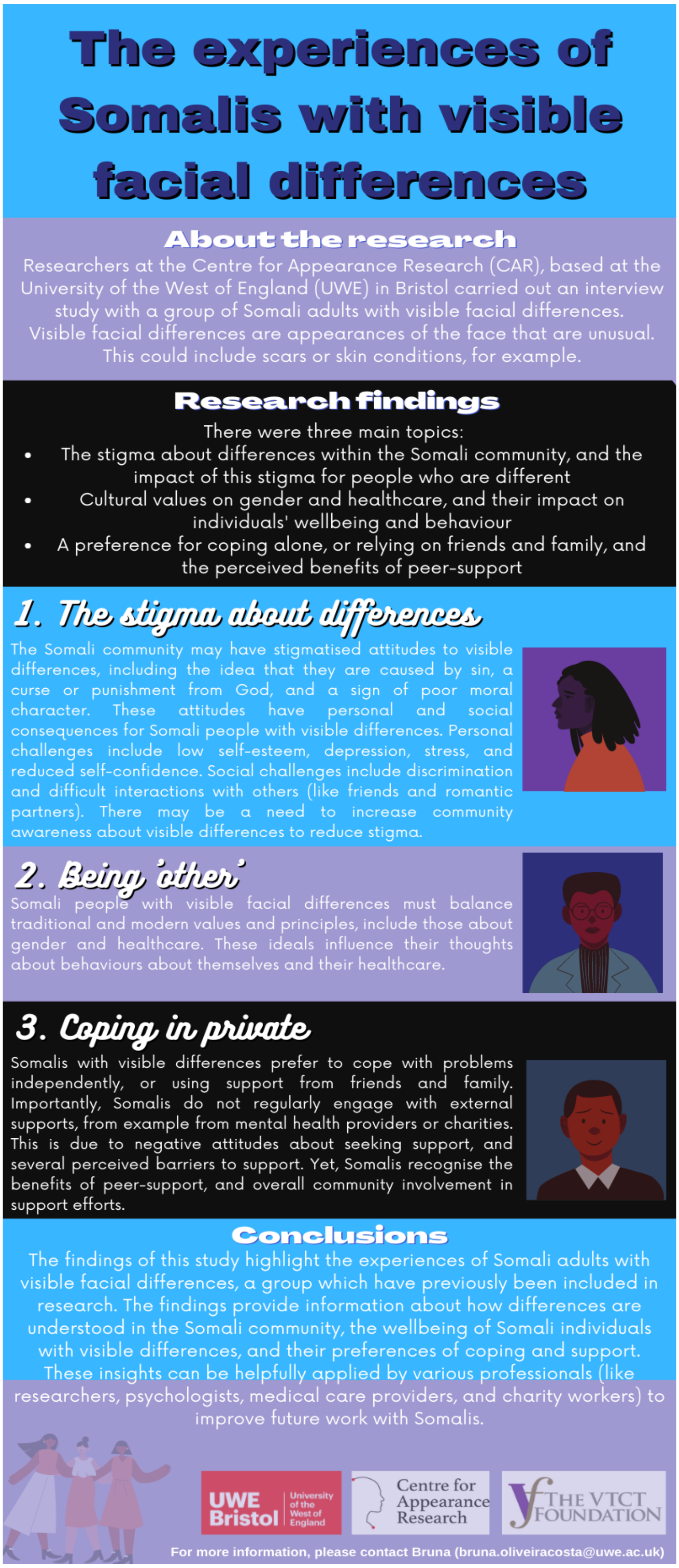
Thank you for giving advice on this study. Below is a summary of our meeting. If you think I've missed anything, please feel free to add to the table and send it back to me.

Date	**Discussion**	**Impact/outcomes**	**Other comments**
02/03/21	We discussed the project in general and considered ways in which [information omitted for anonymity] might like to be involved.	[Omitted] welcomes the research and is supportive. [Omitted] agrees interpreter is a good idea. He mentioned that participants and interpreters might know each other. So let participant know who interpreters are and let them choose. Also pointed out that I should ensure that interpreters can interpret in commonly understood Somali dialect (there are different dialects spoken by different sub-groups).	[Omitted] will: 1.Think if anyone he knows could take part in study 2.Speak to contacts who could support the study in a variety of ways (including interpreter) [Omitted] is interested in coming on board as formal PI advisor. Bruna to email suggested dates for meeting (on Zoom).
12/03/21	We talked about my 'recruitment plan' and the organisations/groups that I have tried to connect with. Overall [Omitted] thinks the plan is exhaustive and good (broad representation of community – men, women, youth, mosques, schools etc.) [Omitted] mentioned that [Omitted] (community elder and manager of Bristol Somali Resource Centre; BSRC) had said that the BSRC has been quite inundated with similar requests from other researchers, so this avenue may not be effective. However, [Omitted] commented that the BSRC is a good organisation to link up with if possible, so I should keep trying. [Omitted] also recommended a few other organisations, including:	In the first instance, based on [Omitted]'s feedback, Bruna will… 1.Continue to try to make contact with the BSRC 2.Make contact with the other groups/organisations that [Omitted] suggested 3.Make changes to the advert as per [Omitted]'s suggestions 4.Have a discussion with supervisors/budget holder about	[Omitted] will review the resource pack in more detail (particularly the 'information sheet' and 'interview questions') and provide further feedback via email. [Omitted] had mentioned that there is no need to give him the £20 shopping voucher as a thank you for his time. Although I acknowledged that this is kind of him, I insisted that he does

	-ACH Refugee Integration & Employment Services -Ashley Community Housing -Easton Community Centre -Other schools (Easton Primary school), although we recognised that working with schools may be particularly challenging at this time. [Omitted] agrees with the suggestion of changing the wording from 'scar' to 'visible facial difference'. We discussed the advert. [Omitted] advised that we should: -Make my email bigger -Add a contact number (phone call preferred to email in Somali community) -Change 'do you have a visible facial difference' to 'do you have a visible facial difference or know someone who does?' -Make logos smaller. [Omitted] commented that logos may put some people off (distrust for organisation) but encourage others (study seen as more legitimate/credible). Middle ground may be to include them but make them smaller. [Omitted] mentioned that the information sheet is too long. Bruna explained that for ethical reasons we need to give people all this detailed information, however, recognise most people likely won't read it so I will ensure to summarise key info before the interview (e.g., 'everything you tell me will be treated confidentially') We talked about incentives. £10 may not be enough. Consider increasing to £15 or £20 if budget allows? We discussed how best to disseminate the results. [Omitted] agrees that it's really important to get the findings out to the community. He suggested that the findings be shared with: -Bristol City Council (to affect local policy making?)	possibly increasing incentive to £15 or £20	accept this token of gratitude for his support of this study.

	-Job centres and other organisations that support affected individuals? -Local community groups and organisations – provide lay summary as well as something else (i.e., something they can do to help) – further resources, a workshop, etc.?		

10: Infographic of Study Findings



The experiences of Somalis with visible facial differences

About the research

Researchers at the Centre for Appearance Research (CAR), based at the University of the West of England (UWE) in Bristol carried out an interview study with a group of Somali adults with visible facial differences. Visible facial differences are appearances of the face that are unusual. This could include scars or skin conditions, for example.

Research findings

There were three main topics:

- The stigma about differences within the Somali community, and the impact of this stigma for people who are different
- Cultural values on gender and healthcare, and their impact on individuals' wellbeing and behaviour
- A preference for coping alone, or relying on friends and family, and the perceived benefits of peer-support

1. The stigma about differences

The Somali community may have stigmatised attitudes to visible differences, including the idea that they are caused by sin, a curse or punishment from God, and a sign of poor moral character. These attitudes have personal and social consequences for Somali people with visible differences. Personal challenges include low self-esteem, depression, stress, and reduced self-confidence. Social challenges include discrimination and difficult interactions with others (like friends and romantic partners). There may be a need to increase community awareness about visible differences to reduce stigma.

2. Being 'other'

Somali people with visible facial differences must balance traditional and modern values and principles, include those about gender and healthcare. These ideals influence their thoughts about behaviours about themselves and their healthcare.

3. Coping in private

Somalis with visible differences prefer to cope with problems independently, or using support from friends and family. Importantly, Somalis do not regularly engage with external supports, from example from mental health providers or charities. This is due to negative attitudes about seeking support, and several perceived barriers to support. Yet, Somalis recognise the benefits of peer-support, and overall community involvement in support efforts.

Conclusions

The findings of this study highlight the experiences of Somali adults with visible facial differences, a group which have previously been included in research. The findings provide information about how differences are understood in the Somali community, the wellbeing of Somali individuals with visible differences, and their preferences of coping and support. These insights can be helpfully applied by various professionals (like researchers, psychologists, medical care providers, and charity workers) to improve future work with Somalis.

UWE Bristol University of the West of England

Centre for Appearance Research

The VTCT Foundation

For more information, please contact Bruna (bruna.oliveiracosta@uwe.ac.uk)

11: Public Involvement Evaluation Survey

Thank you for giving advice on this study. If you can, please complete this quick evaluation about your experience. If you'd prefer to provide feedback on paper rather than online, please let Bruna know.

Name:

1) What was your main reason for agreeing to provide advice on his study?

2) Do you feel you achieved this?

Yes☐ No☐ Partly☐

Please explain:

3) To what extent do you think you were able to influence the planning of this study?

4) What did you like about the experience of providing advice on this study?

5) What could have been better about your experience of providing advice on this study?

6) Is there anything that you didn't mention during your conversation with Bruna that you would like to mention now?

7) Would you be happy to continue as an ongoing collaborator on the project? Collaboration can involve a number of things. Please tick what you would be happy to contribute to in future.

☐Receiving updates about the study

☐Providing further advice on the study in future, including for example about the interpretation and dissemination of results

Thank you very much once again for your time and expertise. If you have any questions or comments, please don't hesitate to contact Bruna.

12: Qualitative Feedback from Somali Public Involvement Representatives

Question	**Response**
What were your initial reasons for contributing?	Representative (Rep) 1: *“I wanted to help the community in this area and learn something new as well.”* Rep 2: *“(I am) passionate about helping community issues.”* Rep 3: *“It’s a good study and perhaps the outcome will help some community (members).”*
Do you feel you were able to influence the study?	Rep 1: *“To some extent.”* Rep 2: *“To some extent. Gave some suggestions, hope they were helpful!”* Rep 3: *“I think I made some influence around finding suitable individuals for this project.”*
What did you like about contributing?	Rep 1: *“It was good to share information.”* Rep 2: *“It was good experience, and my feedback was well-received! Looking forward to the findings!”* Rep 3: *“I think I liked talking to someone who (was) really willing to gain trust with the community that they doing the study for, and also felt that I can contribute in any way I can.”*

13: Example of Researcher's Personal Reflections Following Public Involvement

Name [omitted]	**Information & what went well?**	**What could have been improved?**
-	It was nice to be able to build rapport with [Omitted]. She seemed initially unsure about what the purpose of our scheduled meeting was so I was able to clarify this for her and I thinks she feels more confident now. She's supportive of the research and as a health professional herself, expresses a felt need for it.	Perhaps I should give individuals more information via email ahead of the scheduled meeting so that they feel more prepared. I recognise that public involvement is a concept that may be foreign to many people, so I should do more to make this process as clear and easy to engage with as possible.
-	Our meeting was initially at 8 but [Omitted] pushed it back to 10 as she was having trouble settling her 5-month-old. During the meeting [Omitted] was in her car eating a sandwich and at one point started driving. I offered to reschedule to a more convenience time and she declined. This put me in an uncomfortable position where I did not want to jeopardise her safety (by distracting her while driving). As such, I kept light conversation while she drove, and when eventually parked, I shared my screen and relevant documents for us to review and discuss together. I found out that [Omitted] had been born in Somalia and moved to the UK when she was 7. She's in her late 30's and has a few children (the youngest of which is 5-months old). She grew up in Cardiff and has a Welsh accent. [Omitted] is a nurse.	The only thing that could be improved would be for [Omitted] to be in a better environment for the meeting. However as two of our proposed meetings had already been rescheduled, I was happy to be able to speak with her. Overall, I am pleased with how I managed the meeting and feel it was positive - providing a foundation for what I hope will become a good professional relationship on this project.

14: Research Advert

14a: English

Take part in research

☑ Are you Somali?

☑ Do you have a visible facial difference
(or know someone who does)?

We want to find out about the experiences of Somali people with visible facial differences

Examples of visible facial differences = scar, cleft lip, hyperpigmentation, vitiligo, skin conditions like eczema, etc.

Contact to find out more

☎ ✉

(0117) 3283715

Bruna.OliveiraCosta@uwe.ac.uk

- Interviews in English or Somali
- Interviews on the telephone, or over Zoom/Microsoft Teams
- Gift card as a thank you
- 100% anonymous and confidential

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The VTCT Foundation

14b: Somali

Ka qayb qaado cilmi baadhistan

☑ Ma tahay Somali?

☑ Miyuu wejigaagu aragti ahaan duwanyahay?
(ama miyaad garanaysaa qof kale)?

Waxaan doonay inaanu was ogaano raad-reebka dadka Somalida ah ee wejigoodu duwanyahay

Tusaalaha wejiga duwani waa = nabar, dibin faruuran, haaro, baras, xanuunada jidhka sida xasaasiyada, iwm.

Si aad wax badan uga ogaato la xiriir

☎ ✉

(0117) 3283715

Bruna.OliveiraCosta@uwe.ac.uk

- Waraysigu waa English ama Somali
- Telefoonka, ama
- Zoom/Microsoft Teams
- Kaadh mahad naq ah
- 100% waa sir xafidan

UWE Bristol University of the West of England
Centre for Appearance Research
The VTCT Foundation

15: Privacy Notice

Researcher: Bruna Costa (bruna.oliveiracosta@uwe.ac.uk (0117)3283715)

Supervisor: Heidi Williamson (heidi3.williamson@uwe.ac.uk (0117)3281572)

Purpose of the Privacy Notice

This privacy notice explains how the University of the West of England, Bristol (UWE) collects, manages and uses your personal data before, during and after you participate in the research project entitled: “The experiences of Somali people with visible facial scarring”. ‘Personal data’ means any information relating to an identified or identifiable natural person (the participant). An ‘identifiable natural person’ is one who can be identified, directly or indirectly, including by reference to an identifier such as a name, an identification number, location data, an online identifier, or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person.

This privacy notice adheres to the General Data Protection Regulation (GDPR) principle of transparency. This means it gives information about:

- How and why your data will be used for the research;
- What your rights are under GDPR; and
- How to contact UWE Bristol and the project lead in relation to questions, concerns or exercising your rights regarding the use of your personal data.

This Privacy Notice should be read in conjunction with the Participant Information Sheet and Consent Form provided to you before you agree to take part in the research.

Why are we processing your personal data?

UWE Bristol undertakes research under its public function to provide research for the benefit of society. As a data controller we are committed to protecting the privacy and security of your personal data in accordance with the (EU) 2016/679 the General Data Protection Regulation (GDPR), the Data Protection Act 2018 (or any successor legislation) and any other legislation directly relating to privacy laws that apply (together “the Data Protection Legislation”). General information on Data Protection law is available from the Information Commissioner’s Office (https://ico.org.uk/).

How do we use your personal data?

We use your personal data for research with appropriate safeguards in place on the lawful bases of fulfilling tasks in the public interest, and for archiving purposes in the public interest, for scientific or historical research purposes. We will always tell you about the information we wish to collect from you and how we will use it. We will not use your personal data for automated decision-making about you or for profiling purposes.

Our research is governed by robust policies and procedures and, where human participants are involved, is subject to ethical approval from either UWE Bristol’s Faculty or University Research Ethics Committees. This project has been reviewed and approved by the Faculty Research Ethics Committee at the University of the West of England. Any comments, questions, or complaints about the project can be raised with the lead researcher or addressed to: researchethics@uwe.ac.uk. The research team adhere to the Ethical guidelines of the British Educational Research Association (and/or the principles of the Declaration of Helsinki, 2013) and the principles of the General Data Protection Regulation (GDPR).

For more information about UWE Bristol’s research ethics approval process please see our Research Ethics webpages at: www1.uwe.ac.uk/research/researchethics.

What data do we collect?

The data we collect will vary from project to project. Researchers will only collect data that is essential for their project. The types of personal data that will be processed in relation to this research project are described in the Participant Information Sheet provided to you.

Who do we share your data with?

We will only share your personal data in accordance with the attached Participant Information Sheet and your Consent. In the case of this research project, only the researchers involved in the project will have access to your personal data.

How do we keep your data secure?

We take a robust approach to protecting your information with secure electronic and physical storage areas for research data with controlled access. If you are participating in a particularly sensitive project UWE Bristol puts into place additional layers of security. UWE Bristol has Cyber Essentials information security certification.

Alongside these technical measures there are comprehensive and effective policies and processes in place to ensure that users and administrators of information are aware of their obligations and responsibilities for the data they have access to. By default, people are only granted access to the information they require to perform their duties. Mandatory data protection and information security training is provided to staff and expert advice available if needed.

How long do we keep your data for?

Your personal data will only be retained for as long as is necessary to fulfil the cited purpose of the research. The length of time we keep your personal data will depend on several factors including the significance of the data, funder requirements, and the nature of the study. Specific details are provided in the attached Participant Information Sheet. Anonymised data that falls outside the scope of data protection legislation as it contains no identifying or identifiable information may be stored in UWE Bristol's research data archive or another carefully selected appropriate data archive.

Your Rights and how to exercise them

(1) Under the Data Protection legislation you have the following qualified rights:
(2) The right to access your personal data held by or on behalf of the University;
(3) The right to rectification if the information is inaccurate or incomplete;
(4) The right to restrict processing and/or erasure of your personal data;
(5) The right to data portability;
(6) The right to object to processing;
(7) The right to object to automated decision making and profiling;
(8) The right to complain to the Information Commissioner's Office (ICO).

Please note, however, that some of these rights do not apply when the data is being used for research purposes if appropriate safeguards have been put in place.

We will always respond to concerns or queries you may have. If you wish to exercise your rights or have any other general data protection queries, please contact UWE Bristol's Data Protection Officer (dataprotection@uwe.ac.uk).

If you have any complaints or queries relating to the research in which you are taking part please contact either the research project lead, whose details are in the attached Participant Information Sheet, UWE Bristol's Research Ethics Committees (research.ethics@uwe.ac.uk) or UWE Bristol's research governance manager (ros.rouse@uwe.ac.uk).

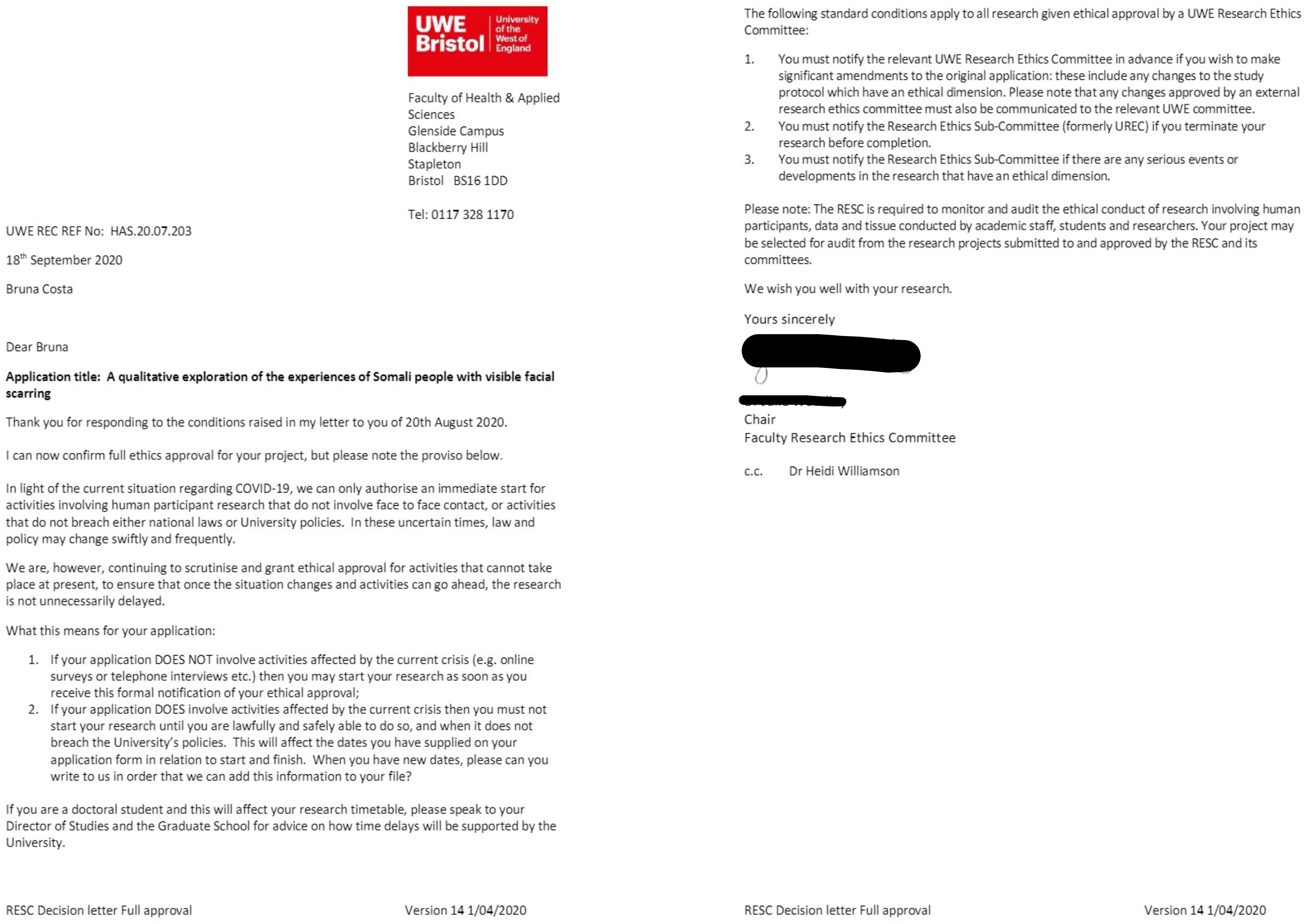
v.1: This Privacy Notice was issued in April 2019 and will be subject to regular review/update.

16: Example of Researcher's Personal Reflections Following Interviews

Name [omitted]	What went well?	What could be improved?
-	Overall, I thought this interview went well. The participant shared with me some of her relevant experiences. My follow-up questions which were well received and seemed appropriate. As this was my first interview for this project, I was particularly keen to test the interview schedule. Some of the questions were not relevant for this participant as is to be expected, but overall at the end, when I asked the participant if they wanted to add anything, they said no as everything had already been covered. This has given me greater confidence in my interview schedule. The interview was held on Microsoft Teams and the participant had her camera off, so initially I was a little apprehensive about whether this would negatively impact rapport and/or ease of conversation. I kept my camera on to try to minimise any negative impacts. The participant may have chosen to keep her camera off for a number of reasons, and I chose not to press her on this issue given the sensitivity of the topic and my desire to increase access to/engagement in research. Despite this, I believe the interview went well. The personal, and at times difficult, insights that the participant shared with me indicates a level of comfortability.	I noticed initially that the participant was quite brief with her answers. She would answer with yes/no, followed by a very brief comment. This worried me with regards to the quality of the data. However, I began asking her to "tell me a little bit more", and found that this encouraged her to expand on the answer. I also made use of pauses, to let the participant have time to add to her thoughts. This also seemed effective at elaborating on responses. I do wonder whether the brief responses were because English was not the participant's first language, and so she needed some more time to think. More, as the topics of discussion were sensitive, it may have been difficult for the participant to go further in-depth during discussions. In light of this, in future interviews, I will: 1) explain to participants at the start of the interview that I'm looking for as much detail as they are happy to provide (to set the tone of the interview), and 2) pause often to give participants more time to think and share their thoughts. I did not ask the participant how she found my study, though I understood through our conversation that it was through an Appearance Collective charity. Recruiting disengaged groups into research is a contested issue yet rarely reported about. Previous research suggests that data on efficacy of recruitment efforts can help. As such, going forward, I will explicitly ask this to participants and report results in the write-up of the research.
-	It had been difficult to speak with this participant and there were lots of times that we had scheduled an interview but she did not show. As such, I was expecting the same outcome today, however was pleasantly surprised. As with my previous participant, this participant also did not have her camera on through the interview. From the background noise, it sounded like the participant was potentially using her phone and doing other things during the interview. At times this was quite disruptive to our conversation. Based on the reflection from my previous interview, I did ask this participant to share as much information as she was comfortable to, and	This participant chose to have her interview on Zoom. It has been a while since I used Zoom, so when it came to the interview, I couldn't find the record button. As such I ended up recording on the Dictaphone. This unexpected yet stressful situation did not cause any negative outcomes for the interview, but was reflective of poor planning and preparation on my part. I will explore the record feature on Zoom in advance of future interviews so I am not caught off guard again. There was quite a bit of background noise during the interview (and even a baby crying regularly), as such it was difficult to hear the

	made use of pauses to give her more time to express her thoughts. I felt this was effective as I was able to obtain more data during this interview.	participant at times. A few times, I had to ask her to repeat herself. In future interviews, I'll ask participants to ensure they are in a quiet, private area, with little distractions (as much as possible).

17: Ethical Approval



UWE Bristol University of the West of England

Faculty of Health & Applied Sciences
Glenside Campus
Blackberry Hill
Stapleton
Bristol BS16 1DD

Tel: 0117 328 1170

UWE REC REF No: HAS.20.07.203

18th September 2020

Bruna Costa

Dear Bruna

Application title: A qualitative exploration of the experiences of Somali people with visible facial scarring

Thank you for responding to the conditions raised in my letter to you of 20th August 2020.

I can now confirm full ethics approval for your project, but please note the proviso below.

In light of the current situation regarding COVID-19, we can only authorise an immediate start for activities involving human participant research that do not involve face to face contact, or activities that do not breach either national laws or University policies. In these uncertain times, law and policy may change swiftly and frequently.

We are, however, continuing to scrutinise and grant ethical approval for activities that cannot take place at present, to ensure that once the situation changes and activities can go ahead, the research is not unnecessarily delayed.

What this means for your application:

1. If your application DOES NOT involve activities affected by the current crisis (e.g. online surveys or telephone interviews etc.) then you may start your research as soon as you receive this formal notification of your ethical approval;
2. If your application DOES involve activities affected by the current crisis then you must not start your research until you are lawfully and safely able to do so, and when it does not breach the University's policies. This will affect the dates you have supplied on your application form in relation to start and finish. When you have new dates, please can you write to us in order that we can add this information to your file?

If you are a doctoral student and this will affect your research timetable, please speak to your Director of Studies and the Graduate School for advice on how time delays will be supported by the University.

RESC Decision letter Full approval Version 14 1/04/2020

The following standard conditions apply to all research given ethical approval by a UWE Research Ethics Committee:

1. You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application: these include any changes to the study protocol which have an ethical dimension. Please note that any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee.
2. You must notify the Research Ethics Sub-Committee (formerly UREC) if you terminate your research before completion.
3. You must notify the Research Ethics Sub-Committee if there are any serious events or developments in the research that have an ethical dimension.

Please note: The RESC is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the RESC and its committees.

We wish you well with your research.

Yours sincerely

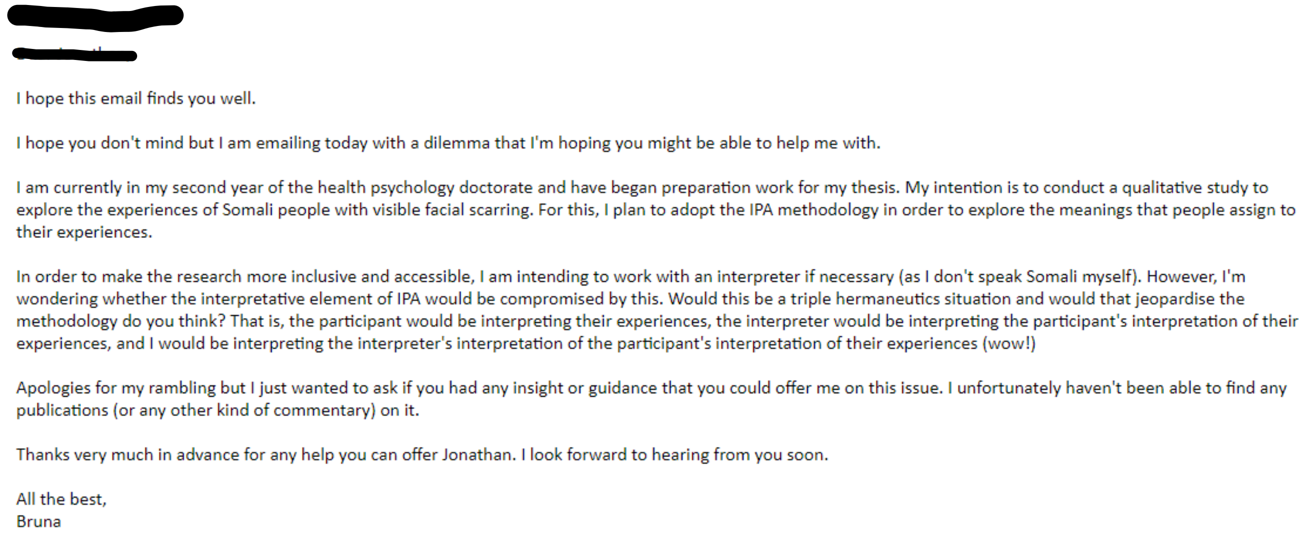
[redacted]

[redacted]
Chair
Faculty Research Ethics Committee

c.c. Dr Heidi Williamson

RESC Decision letter Full approval Version 14 1/04/2020

18: Excerpts of Email Exchange on IPA



[redacted]

[redacted]

I hope this email finds you well.

I hope you don't mind but I am emailing today with a dilemma that I'm hoping you might be able to help me with.

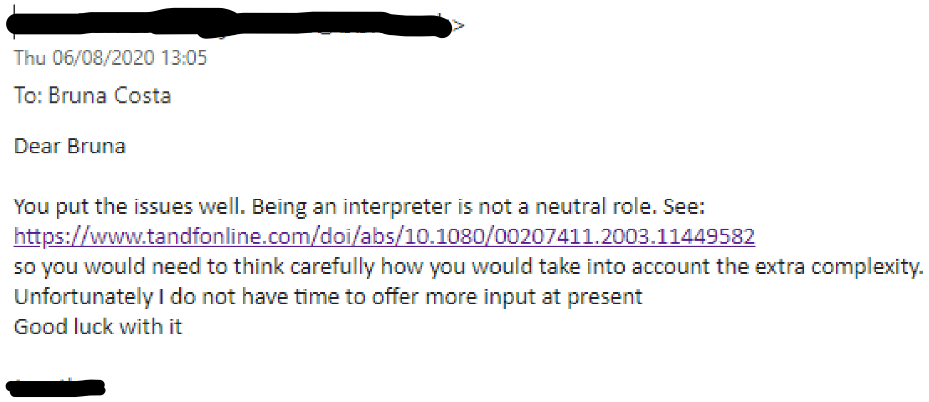
I am currently in my second year of the health psychology doctorate and have began preparation work for my thesis. My intention is to conduct a qualitative study to explore the experiences of Somali people with visible facial scarring. For this, I plan to adopt the IPA methodology in order to explore the meanings that people assign to their experiences.

In order to make the research more inclusive and accessible, I am intending to work with an interpreter if necessary (as I don't speak Somali myself). However, I'm wondering whether the interpretative element of IPA would be compromised by this. Would this be a triple hermaneutics situation and would that jeopardise the methodology do you think? That is, the participant would be interpreting their experiences, the interpreter would be interpreting the participant's interpretation of their experiences, and I would be interpreting the interpreter's interpretation of the participant's interpretation of their experiences (wow!)

Apologies for my rambling but I just wanted to ask if you had any insight or guidance that you could offer me on this issue. I unfortunately haven't been able to find any publications (or any other kind of commentary) on it.

Thanks very much in advance for any help you can offer Jonathan. I look forward to hearing from you soon.

All the best,
Bruna



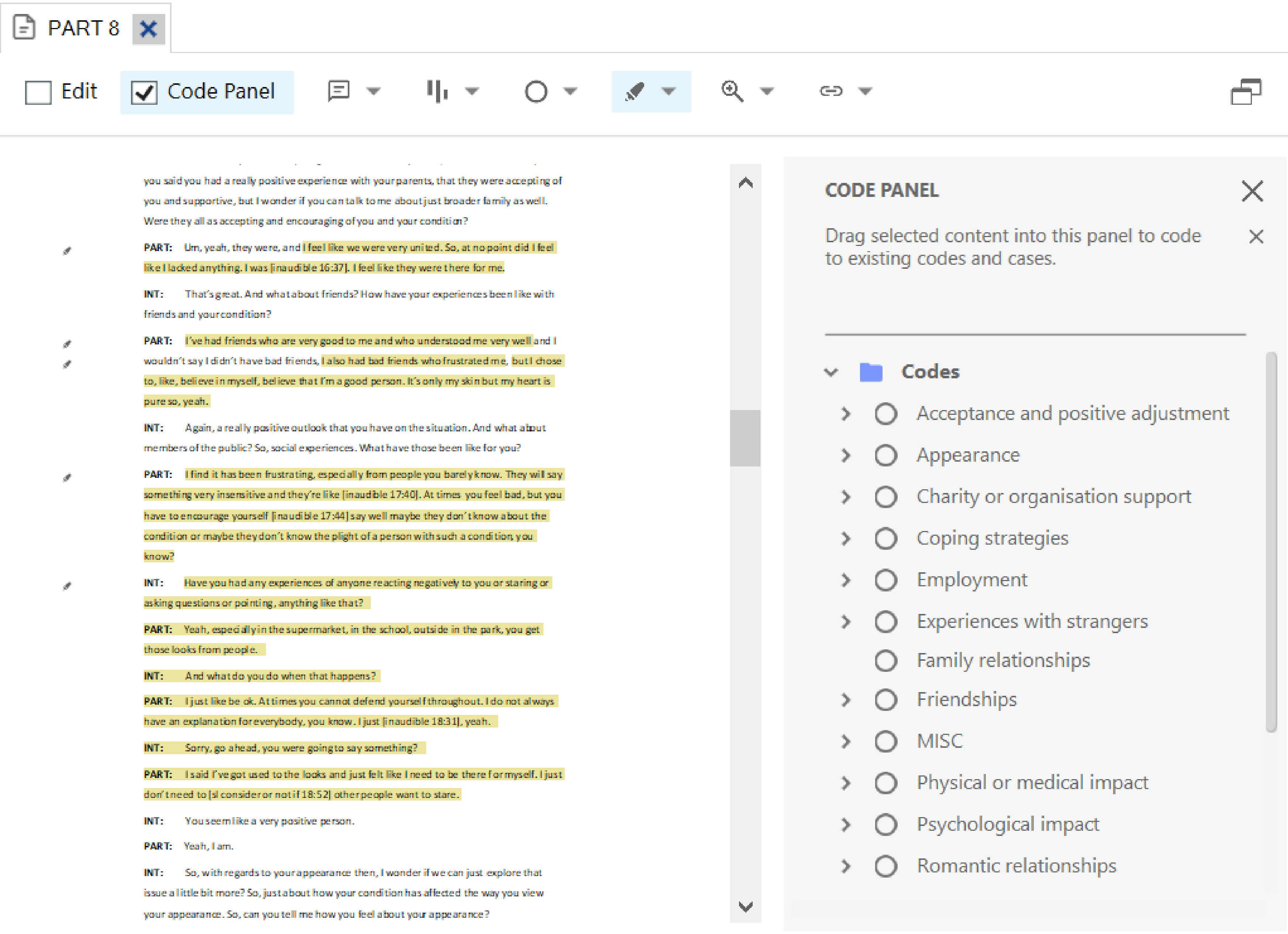
[redacted]>
Thu 06/08/2020 13:05
To: Bruna Costa

Dear Bruna

You put the issues well. Being an interpreter is not a neutral role. See:
https://www.tandfonline.com/doi/abs/10.1080/00207411.2003.11449582
so you would need to think carefully how you would take into account the extra complexity.
Unfortunately I do not have time to offer more input at present
Good luck with it

[redacted]

19: Example Coding on NVivo



you said you had a really positive experience with your parents, that they were accepting of you and supportive, but I wonder if you can talk to me about just broader family as well. Were they all as accepting and encouraging of you and your condition?

PART: Um, yeah, they were, and I feel like we were very united. So, at no point did I feel like I lacked anything. I was [inaudible 16:37]. I feel like they were there for me.

INT: That's great. And what about friends? How have your experiences been like with friends and your condition?

PART: I've had friends who are very good to me and who understood me very well and I wouldn't say I didn't have bad friends, I also had bad friends who frustrated me, but I chose to, like, believe in myself, believe that I'm a good person. It's only my skin but my heart is pure so, yeah.

INT: Again, a really positive outlook that you have on the situation. And what about members of the public? So, social experiences. What have those been like for you?

PART: I find it has been frustrating, especially from people you barely know. They will say something very insensitive and they're like [inaudible 17:40]. At times you feel bad, but you have to encourage yourself [inaudible 17:44] say well maybe they don't know about the condition or maybe they don't know the plight of a person with such a condition, you know?

INT: Have you had any experiences of anyone reacting negatively to you or staring or asking questions or pointing, anything like that?

PART: Yeah, especially in the supermarket, in the school, outside in the park, you get those looks from people.

INT: And what do you do when that happens?

PART: I just like be ok. At times you cannot defend yourself throughout. I do not always have an explanation for everybody, you know. I just [inaudible 18:31], yeah.

INT: Sorry, go ahead, you were going to say something?

PART: I said I've got used to the looks and just felt like I need to be there for myself. I just don't need to [sl consider or not if 18:52] other people want to stare.

INT: You seem like a very positive person.

PART: Yeah, I am.

INT: So, with regards to your appearance then, I wonder if we can just explore that issue a little bit more? So, just about how your condition has affected the way you view your appearance. So, can you tell me how you feel about your appearance?

20: Braun and Clarke: A Tool for Evaluating Quality in Reflexive Thematic Analysis – Application to Current Study

Standard	Question	Application to current study
Adequate choice and explanation of methods and methodology	Do the authors explain why they are using TA, even if only briefly? Do the authors clearly specify and justify which type of TA they are using? Is the use and justification of the specific type of TA consistent with the research questions or aims? Is there a good 'fit' between the theoretical and conceptual underpinnings of the research and the specific type of TA (i.e., is there conceptual coherence)? Is there a good 'fit' between the methods of data collection and the specific type of TA? Is the specified type of TA consistently enacted throughout the paper? Is there evidence of problematic assumptions about, and practices around, TA? These commonly include: Treating TA as one, homogenous, entity, with one set of – widely agreed on – procedures; Combining philosophically and procedurally incompatible approaches to TA without any acknowledgement or explanation; Confusing summaries of data topics with thematic patterns of shared meaning, underpinned by a core concept; Assuming grounded theory concepts and procedures (e.g., saturation, constant comparative analysis, line-by-line coding) apply to TA without any explanation or justification; Assuming TA is essentialist or realist, or a-theoretical; Assuming TA is only a data reduction or descriptive approach and therefore must be supplemented with other methods and procedures to achieve other ends. Are any supplementary procedures or methods justified, and necessary, or could the same results have been achieved simply by using TA more effectively? Are the theoretical underpinnings of the use of TA clearly specified (e.g., ontological, epistemological assumptions, guiding theoretical	Reasons for using RTA (as opposed to other methods such as IPA, DA and GT are outlined. The specific type of RTA that was used is outlined and justified – and the rationale for this is consistent with the aims of the study. The choice of (mostly) deductive and latent RTA is consistent with the critical realist and contextualist ontological and epistemological orientations of this research. The choice of RTA is routinely enacted throughout the write-up and there is no mismatch of approaches (e.g., semantic *and* constructionist). Semi-structured qualitative interviews are compatible with RTA. The researcher has recognised that RTA is flexible; reflected on different types of RTA, justified her choice (considering ontology and epistemology), and was consistent with this throughout her analysis/writing; ensured her themes have a central organising concept and are not simply topic summaries; has demonstrated consistency and avoided mismatched approaches to analysis (e.g., issue of data saturation – as discussed elsewhere in this report). The researcher has provided a full reflexivity section in the report (2.2.1) to 'own her perspective'. Analytic steps have been clearly described.

	framework(s)), even when using TA inductively (inductive TA does not equate to analysis in a theoretical vacuum)? Do the researchers strive to 'own their perspectives' (even if only very briefly), their personal and social standpoint and positioning? (This is especially important when the researchers are engaged in social justice-oriented research and when representing the 'voices' of marginal and vulnerable groups, and groups to which the researcher does not belong.) Are the analytic procedures used clearly outlined, and described in terms of what the authors actually did, rather than generic procedures? Is there evidence of conceptual and procedural confusion? For example, reflexive TA (Braun & Clarke, 2006) is the claimed approach but different procedures are outlined such as the use of a codebook or coding frame, multiple independent coders and consensus coding, inter-rater reliability measures, and/or themes are conceptualised as analytic inputs rather than outputs and therefore the analysis progresses from theme identification to coding (rather than coding to theme development). Do the authors demonstrate full and coherent understanding of their claimed approach to TA?	
A well-developed and justified analysis	Is it clear what and where the themes are in the report? Would the manuscript benefit from some kind of overview of the analysis: listing of themes, narrative overview, table of themes, thematic map? Are reported themes topic summaries, rather than 'fully realised themes' – patterns of shared meaning underpinned by a central organising concept? Have the data collection questions been used as themes? If so, are topic summaries appropriate to the purpose of the research? If the authors are using reflexive TA, is this modification in the conceptualisation of themes explained and justified?	The report outlines analysis and findings clearly and provides a thematic map for a visual of themes and sub-themes. Themes have a central organising concept and are not summative. Themes are not based on interview questions. The author has explained how she conceptualises a theme (in line with RTA). Conducive to the applied aim of this project, the themes discussed offer opportunities for improvements in practice (more information in Discussion). The researcher chose to carry out (mostly) deductive and latent RTA in line with critical realist and contextualist

	Would the manuscript benefit from further analysis being undertaken, with the reporting of fully realised themes? Or, if the authors are claiming to use reflexive TA, would the manuscript benefit from claiming to use a different type of TA (e.g., coding reliability or codebook)? Is a non-thematic contextualising information presented as a theme? (e.g., the first theme is a topic summary providing contextualising information, but the rest of the themes reported are fully realised themes). If so, would the manuscript benefit from this being presented as non-thematic contextualising information? In applied research, do the reported themes have the potential to give rise to actionable outcomes? Are there conceptual clashes and confusion in the paper? (e.g., claiming a social constructionist approach while also expressing concern for positivist notions of coding reliability, or claiming a constructionist approach while treating participants’ language as a transparent reflection of their experiences and behaviours) Is there evidence of weak or unconvincing analysis such as: Too many or two few themes?; Too many theme levels?; Confusion between codes and themes?; Mismatch between data extracts and analytic claims?; Too few or too many data extracts?; Overlap between themes? Do authors make problematic statements about the lack of generalisability of their results, and or implicitly conceptualise generalisability as statistical probabilistic generalisability (see Smith, 2018)?	ontological and epistemological orientations of this research, She was consistent with these concepts in her analysis/reporting. Issues of generalisability and representativeness have been considered (as part of discussions around data saturation), and in accordance with RTA, are not reinforced in this report.

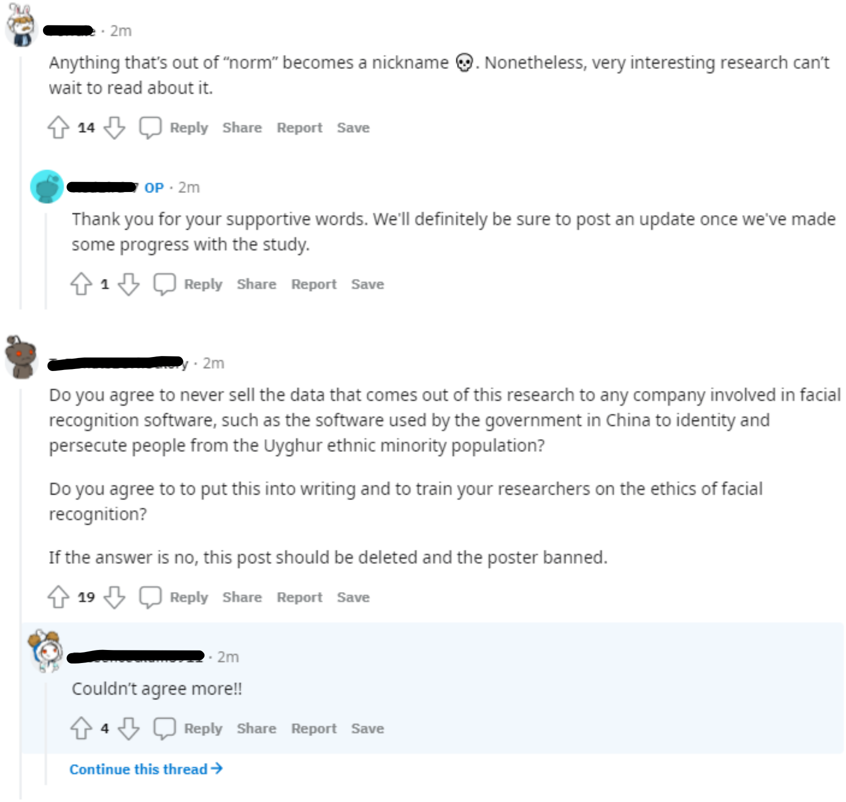
21: Participant Tracking

Name and email [omitted]	**Initial email date**	**Last interaction date**	**Comments**
-	04/08/21	I sent an email on 17/08/21	I have followed up 3 times and have received no response
-	05/07/21	I sent an email on 17/08/21	I have followed up 3 times and have received no response
-	21/07/21	I sent an email on 02/09/21	Lots of back and forth via email. Participant did not show up to our scheduled interview and did not respond to my follow-up email.
-	10/09/21	I emailed on 14/09, participant replied, and I emailed back on 20/09 – then no response.	I have followed up 3 times and have received no response
-	15/07/21	20/08/21	Participant was late to first interview – we rescheduled as we did not have enough time to complete the interview, however participant did not show up and did not respond to my follow-up email.
Not eligible			
-	20/07/21	25/07/21	Living in US
-	06/08/21	17/08/21	Not of Somali heritage.

22: Malterud *et al*. (2016): Determining 'Information Power' – Application to Current Study

Influential factors	**Current study**	**Information power**
Study aims and group specificity	The current study aim(s) are specific and focused on a relatively small homogenous group.	High
Theory	Current visible difference research provides theory to draw from.	High
Data quality	Whilst the researcher hopes that the Results will demonstrate the depth and richness of data obtained through interviews, in the interest of transparency it is important to note that interviews were relatively short (mean = 32-minutes, not including the introductory, demographic and concluding sections of the interviews). This issue is considered in more detail in the Discussion, but to summarise may be due to a) participants having nothing further to share, of b) a combination of factors including: the researcher's 'outsider position'; participants having English as a second language and the interviews being in English (note the lack of uptake of interpreters); and interviews being carried out remotely.	Low
Analysis	In-depth RTA was performed on the narratives of participants	High

23: Excerpts of Reddit Discussion



[redacted] · 2m

Anything that's out of "norm" becomes a nickname 💀. Nonetheless, very interesting research can't wait to read about it.

[redacted] OP · 2m

Thank you for your supportive words. We'll definitely be sure to post an update once we've made some progress with the study.

[redacted] · 2m

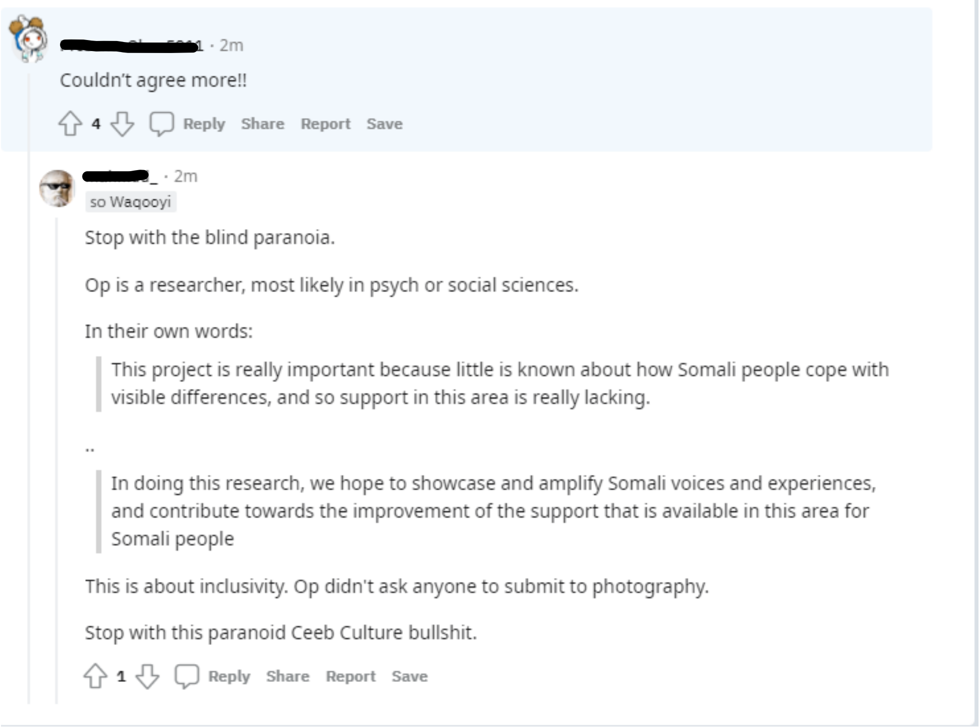
Do you agree to never sell the data that comes out of this research to any company involved in facial recognition software, such as the software used by the government in China to identity and persecute people from the Uyghur ethnic minority population?

Do you agree to to put this into writing and to train your researchers on the ethics of facial recognition?

If the answer is no, this post should be deleted and the poster banned.

[redacted] · 2m

Couldn't agree more!!



[redacted] · 2m

Couldn't agree more!!

[redacted] · 2m

so Waqooyi

Stop with the blind paranoia.

Op is a researcher, most likely in psych or social sciences.

In their own words:

> This project is really important because little is known about how Somali people cope with visible differences, and so support in this area is really lacking.

..

> In doing this research, we hope to showcase and amplify Somali voices and experiences, and contribute towards the improvement of the support that is available in this area for Somali people

This is about inclusivity. Op didn't ask anyone to submit to photography.

Stop with this paranoid Ceeb Culture bullshit.


so Waqooyi

Yet every other week we have a dumbass posting their 23 And Me DNA results..

[redacted] · 2m

So why aren't you deleting and banning the poster? Why do you allow this kind of shit into this sub[redacted] ? WTF.

[redacted] · 2m

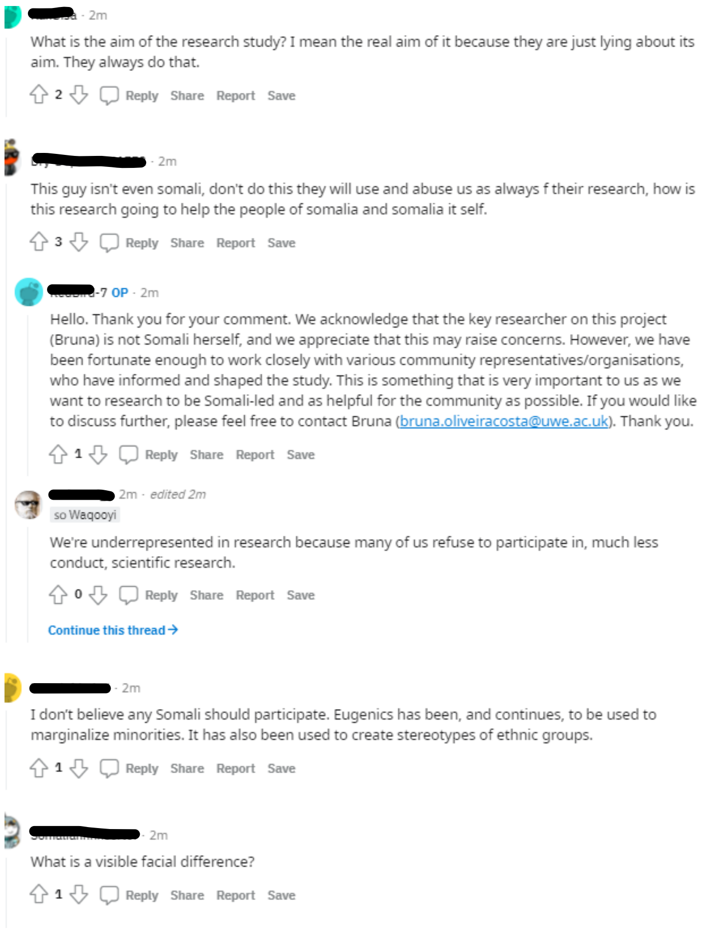
so Waqooyi

1. the subreddit is literally self-moderated, everyone can flag a post to get it removed.
2. I am not in the business of silencing people who are participating in good faith, and aren't breaking reddit-wide rules.
3. if you don't like a post, scroll away. You're an adult, not everything has to be to your liking. Welcome to life.

[redacted] · 2m

yOu r a QaBilIst 👏👏

I don't want to pretend like moderating Somalis is an easy task and can understand for the most part the hands off approach but....I suggest taking a similar approach to r.africa. it's highly educational though a little boring you know ppl are engaging on a very educated level. This space especially at the height of n&n bots was so toxic, ppl weren't even allowed to have differing opinions. This space is important and if moderated effectively can be exemplary for how Somalis should engage one another. But instead ppl are attacked for having different views. That's ghetto.


[redacted] · 2m

What is the aim of the research study? I mean the real aim of it because they are just lying about its aim. They always do that.

[redacted] · 2m

This guy isn't even somali, don't do this they will use and abuse us as always f their research, how is this research going to help the people of somalia and somalia it self.

[redacted]-7 OP · 2m

Hello. Thank you for your comment. We acknowledge that the key researcher on this project (Bruna) is not Somali herself, and we appreciate that this may raise concerns. However, we have been fortunate enough to work closely with various community representatives/organisations, who have informed and shaped the study. This is something that is very important to us as we want to research to be Somali-led and as helpful for the community as possible. If you would like to discuss further, please feel free to contact Bruna (bruna.oliveiracosta@uwe.ac.uk). Thank you.

[redacted] 2m · *edited 2m*

so Waqooyi

We're underrepresented in research because many of us refuse to participate in, much less conduct, scientific research.

[redacted] · 2m

I don't believe any Somali should participate. Eugenics has been, and continues, to be used to marginalize minorities. It has also been used to create stereotypes of ethnic groups.

[redacted] · 2m

What is a visible facial difference?

[redacted] OP · 2m

Thank you for your comment. You highlight an important point. We are governed by, and adhere to, very strict ethical codes of conduct. That includes protecting participants' data and identity. We never sell data or indeed allow any of our participants to be personally identifiable. Before participants take part, they are asked to read and sign various relevant documents including a participant information sheet, a data privacy document, and a consent form - these documents discuss issues related to those you have mentioned. We would be very happy to share these with you. Would you prefer me to attach these here or email you them privately? Let me know. Many thanks.

[redacted] · 2m

Sketchy.

[redacted] · 2m

"RESEARCH STUDY" in other words let me train my surveillance models with more data points.

[redacted] · 2m

so Waqooyi

It's in the UK: the country has the highest levels of surveillance this side of occupied Palestine.

You're training bots just by walking around Britain.

Please read what op is saying. It's about language, treatment, and marginalization of people with "abnormal" facial features.

Holly fuck! Stop with this QAnon-tier bullshit already.

so Waqooyi

We're underrepresented in research because many of us refuse to participate in, much less conduct, scientific research.

[redacted] · 2m

So you want us to be guinea pig for someone's AI? Have you asked yourself why are they interested in physically profiling Somali people?

[redacted] · 2m

That's what I'm saying brother, why do they need us so bad, what's special about our facial structures and $hit.

[redacted] · 2m

so Waqooyi

> So you want us to be guinea pig for someone's AI?

This is not how "AI" works.

The *entirety* of this subreddit's subscribers wouldn't even qualify as enough dataset to train a facial recognition model.

Besides, just ask yourself: why would some entity need to spend the requisite millions of dollars to recognize who is Somali? What is the point?

You can identify Somalis (maximum 25 million people) with a basic network graph.

You should be worried about who you share your contacts with more than who sees your face. And if you have an iOS, Android, or Windows phone .. or if anyone with such a phone has your contacts, you might as well kiss your anonymity good bye.

[redacted] · 2m

U go participate let's see what u get, a coupon 😂😂😂. We need no representation

[redacted] · 2m

[redacted] · 2m
so Waqooyi

We have a saying in Somali: *maxaa lagaa sasabanayaa!?*

I can't translate "*sasabasho*" to English, but the gist of it is basically asking "what makes you think you're so precious?"

Comment removed by moderator · 2m

[redacted] MOD · 2m
so Waqooyi

Why did you need to call me the N-word?

[redacted] · 2m

You lot are dumb as fuck. I've participated in numerous studies. Partly because I know people who look like me don't usually and so our experiences and voices are never included. There's nothing wrong with it. I highly recommend it. It's also a normal part of higher education. Don't expect services, products etc. that are tailored to our needs if this is your attitude!

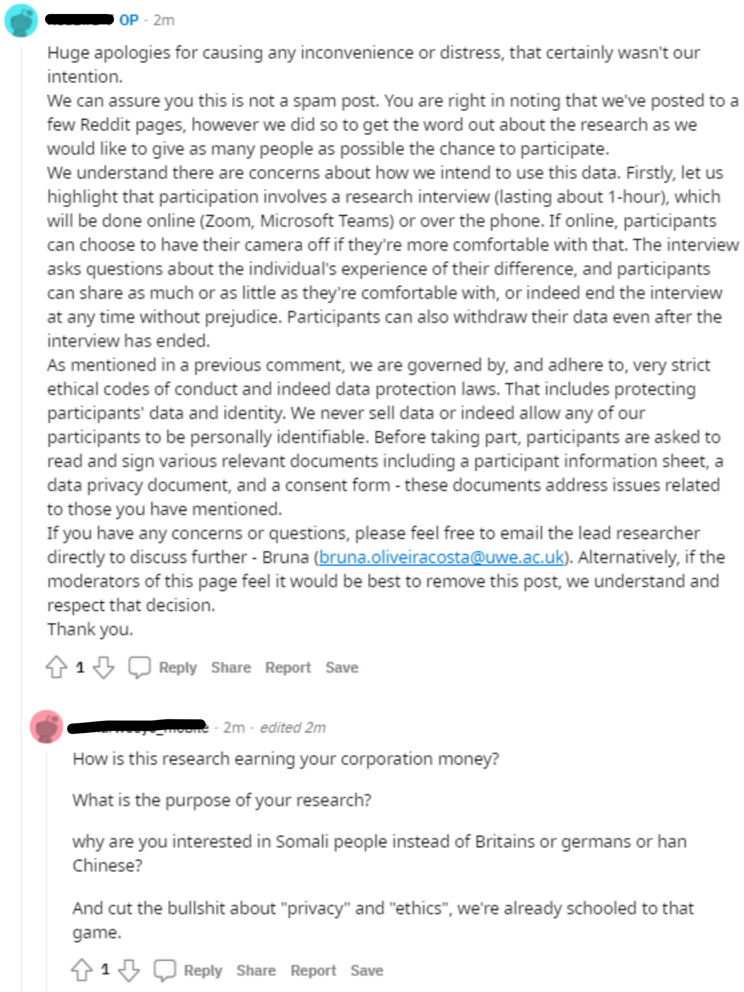
[redacted] · 2m

Go ahead and share all your personal data with faceless name less organizations who only care about controlling you or turning into a product.

Go get a 21nMe test

[redacted] · 2m

We choose to not participate because these studies are typically used to marginalize Somalis and minorities in general...



[redacted] OP · 2m

Huge apologies for causing any inconvenience or distress, that certainly wasn't our intention.
We can assure you this is not a spam post. You are right in noting that we've posted to a few Reddit pages, however we did so to get the word out about the research as we would like to give as many people as possible the chance to participate.
We understand there are concerns about how we intend to use this data. Firstly, let us highlight that participation involves a research interview (lasting about 1-hour), which will be done online (Zoom, Microsoft Teams) or over the phone. If online, participants can choose to have their camera off if they're more comfortable with that. The interview asks questions about the individual's experience of their difference, and participants can share as much or as little as they're comfortable with, or indeed end the interview at any time without prejudice. Participants can also withdraw their data even after the interview has ended.
As mentioned in a previous comment, we are governed by, and adhere to, very strict ethical codes of conduct and indeed data protection laws. That includes protecting participants' data and identity. We never sell data or indeed allow any of our participants to be personally identifiable. Before taking part, participants are asked to read and sign various relevant documents including a participant information sheet, a data privacy document, and a consent form - these documents address issues related to those you have mentioned.
If you have any concerns or questions, please feel free to email the lead researcher directly to discuss further - Bruna (bruna.oliveiracosta@uwe.ac.uk). Alternatively, if the moderators of this page feel it would be best to remove this post, we understand and respect that decision.
Thank you.

[redacted] · 2m · *edited 2m*

How is this research earning your corporation money?

What is the purpose of your research?

why are you interested in Somali people instead of Britains or germans or han Chinese?

And cut the bullshit about "privacy" and "ethics", we're already schooled to that game.