

University of Bedfordshire



**EXAMINING THE SOCIOCULTURAL
IMPACTS OF CONSANGUINITY AND
IMPLICATIONS FOR HEALTHCARE**

A Case Study of Pakistanis in Luton

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A Thesis submitted to the University of Bedfordshire, in partial fulfilment of the requirements
for the degree of Doctor of Philosophy

Submitted in July 2013

EXAMINING THE SOCIOCULTURAL IMPACTS OF CONSANGUINITY AND IMPLICATIONS FOR HEALTHCARE – A Case Study of Pakistanis in Luton

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ABSTRACT

This thesis aims to understand the sociocultural aspects of the practice of consanguinity and the implications for healthcare. Consanguinity refers to intra-familial marriage and is commonly used to refer to cousin marriage. While consanguinity remains a global phenomenon, in the recent past, it has mostly been associated with non-Western populations, and has become a taboo in Western culture. Consanguinity is linked with negative health outcomes, mostly due to genetic disorders, although the extent of this link remains debatable. In the UK, consanguinity is linked mostly with the Pakistani community, which also have an overrepresentation of children with genetic disorders. In Luton, local health reports have suggested that consanguinity in the large Pakistani community plays a role in increased infant deaths. This makes Luton and the local Pakistani community, ideally placed for understanding the practice of consanguinity and the implications for healthcare.

This thesis is conceptually grounded within a constructionist approach to understanding consanguinity with a critical analysis based on theories of discourse and power and knowledge. A qualitative research design was employed using an instrumental case study approach which focused on understanding consanguinity through Luton's Pakistani community. Three main sample groups were selected, members of the Pakistani community who are not married to their cousins and are defined as lay members in this research, members of the Pakistani community in consanguineous marriages, and local service providers (primary and secondary care).

A total of seventy-five participants (service providers N=17, Pakistani, lay community N=31 and consanguineous community N=27) participated in a total of thirteen in-depth interviews and eleven focus group discussions. The framework method was used to analyse the data collected from the discussions with NVivo 10 software used for data management.

The main themes emerging from the data were the roles of culture, marriage customs, genetics and healthcare in relation to consanguinity, and the strategic actions needed to improve local healthcare and knowledge about genetics. The key findings from the discussions showed differing areas of focus on consanguinity between the health professionals and the local community. The service providers focused on the clear link they saw between consanguinity and negative health outcomes, while the community members grappled with the sociocultural fallout of arranged marriages, immigration, discrimination and social deprivation. The findings also showed a lack of understanding of genetic risk both in the community members and the primary care service providers based possibly on an over-emphasis on defining genetic risk through consanguinity. There is a need for increasing the genetic awareness amongst both groups, as well as a need to improve genetic services and implement clearer referral pathways to these services. Better cultural competency amongst the service providers is also needed along with a shift towards preventative medicine which addresses underlying social determinants of health and addresses the full causal pathway rather than focusing only on consanguinity. Consanguinity needs to be understood as a cultural aspect of an integrated multi-ethnic society that contributes to, but is not solely responsible for, a changing local health spectrum.

“O My Lord! Expand my breast for me. And ease my task for me; and loose a knot from my tongue, (That) they may understand my saying” – Moses, Qur’an (20:25-2)

For Abbu, Ammi and Sara

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ACKNOWLEDGEMENTS

I would like to begin by thanking all of the participants in the study, without whom this study would not have been possible. I would like to thank them for taking the time out of their busy lives and realise that this study represented a real chance for them to make an impact on an issue of vital importance to the local community. This of course includes the service providers who chose to take part in the study, first by taking time out of their extremely busy schedules and then by openly discussing an issue that had been politicised locally and deemed a very sensitive topic.

Many important people aided in the recruitment of these participants and I would like to acknowledge them next, starting with the service providers study. The support given by Diana Hardy at the R&D Department of the Luton & Dunstable Hospital in getting local approval for the study and then in reaching possible participants was very helpful. I would also like to thank Elaine Hide for signing off on the study as the local contact at the L&D. My sincere thanks to the local genetics services team at the hospital for their advice and participation. I am also thankful to all the local GP surgeries that participated in the primary care discussions of this thesis. Thank you also to the NHS for approving this study and allowing access to your employees. The recruitment on the community discussions was greatly aided by the very hospitable folks at the Khidmat Organisation and the Discover Islam Centre, and thank you for allowing me to use your facilities to hold some of the discussions. I am very thankful to the Friends of Bright Eyes charity who made possible a very special focus group discussion. I would also like to thank Mark Diggle, the Head of Career Services at the University of Bedfordshire for all his assistance in recruitment for this study.

Also at the University, I would like to start by thanking the IHR representatives at the Research Graduate School for always dealing with my special requests. On the subject of special requests, my heartfelt gratitude goes to Melanie Coulson, our research administrator in IHR, for accommodating many such requests. I am also thankful to all my fellow PhD students, especially my co-travellers for most of this journey, Erica, Chloe and Yvonne. Our intellectual debates on research methodology and current literature were both entertaining and helpful. I would also like to thank Pat, Fariha, Kulwinder and Muhammad at IHR for all their support. Outside the University of Bedfordshire, I would like to especially thank Professor Alan Bittles for providing mentorship both through personal communications and through his immense contribution to consanguinity research.

I was lucky to have a very talented supervisory team who kept me in check throughout my July 2013

PhD and never let me slip. Professor Gurch Randhawa is the reason why I chose to come to the University of Bedfordshire. Thank you for accepting me as your student, guiding me with your keen eye for the bigger picture and for the countless career advice besides my PhD. Thank you for also approving all those holidays back to Canada and allowing me to attend the most interesting international conferences. I owe a great deal to Dr. Nasreen Ali for her immense support in not only advising me on aspects of theory and critical analysis, but also for her detailed feedback on earlier drafts of this thesis. I would like to thank my supervisory team for always giving honest feedback and for always believing in me.

Although a PhD is considered an individual accomplishment, I would not have been able to start, let alone complete this PhD without the support of my family. First, to my parents for inspiring me to attempt this endeavour and then supporting me by giving their most precious possession, their time. Thank you Abbu and Ammi, for your love, encouragement and prayers. I would also like to thank my siblings for letting me monopolise our parents' time during these three years. My children, Zujaja, Ahneb and Mishkaat, have also made the sacrifice by allowing their father to be absent from their young lives for long stretches of time, I can only hope to make up for the lost times.

Finally, I would like to thank my unbelievably supportive wife Sara. This is your PhD as much as it is mine. You have been my most unwavering supporter and motivator. You first helped me get through my Masters and you have now endured through this PhD, allowing me to be a continent away. Thank you for holding the fort while I have been away. I can never hope to repay you for your time, support and love, nor could I ever express the gratitude I feel in words, but I hope I can make you proud with my work.

Declaration

I declare that this thesis is my own unaided work. It is being submitted for the degree of Doctor of Philosophy at the University of Bedfordshire.

It has not been submitted before for any degree of examination in any other university.

A handwritten signature in black ink, appearing to read 'Mubasshir Ajaz', written in a cursive style.

Mubasshir Ajaz Dated:

June 7, 2013

INTRODUCTION

Consanguinity refers to intra-familial marriage and is commonly used to refer to cousin marriage. Consanguinity is defined by the World Health Organisation as a union between people who are second cousins or closer (Bittles, 2001, Hoodfar and Teebi, 1996). Marriage within cousins is a common marriage practice amongst a billion of the world's mostly non-Western population, while it is mostly considered a taboo in Western societies today, where it is often controversially associated with the incest and inbreeding (Bittles, 2009, Modell and Darr, 2002b, Bittles and Black, 2010a). These populations are spread mostly across from Indian Subcontinent to the Western Sahara, and the numbers could be even higher as currently there is no reliable data from the Central and Southern parts of the African continent (see Figure A). Since the majority of these populations practice Islam, consanguinity is also incorrectly associated with Islam (Bittles, 2001, Clarke and Parsons, 1997). Consanguinity however, is not exclusive to Muslims as it is practiced by people of many faiths, including Christians, Jews, Hindus, Buddhists, Taoists and indeed Muslims, hence it not specific to any faith group (Bittles, 2001). The particular characteristics of consanguinity and arrangements of cousin marriage can be culturally specific making it relevant locally to countries with highly consanguineous populations (Bittles, 2009, Durey, 2008, Ottenheimer, 1996). However, economically driven migrations and current patterns of globalisation have ensured that cultural traditions are no longer exclusively localised and neither are their impacts, as such, the sociocultural context of consanguinity has to be understood within the globalisation background.

Consanguinity is common in Pakistan, with some of the areas reporting up to approximately 77% of marriages taking place between cousins (Hussain, 1999). There has been significant mass migration from Pakistan to the UK during the 1960s and 1970s and subsequent settlement (Ali *et al.*, 2006). As well as disease aetiology, migrants “transport” cultural practices and beliefs through the migration process (Brieger *et al.*, 1997, Gupta and Ferguson, 1992). The cousin marriage tradition has continued amongst the British Pakistanis, both as a means of cultural continuity and

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immigration of other family members from Pakistan (Shaw, 2006). The British Pakistanis are one of the largest ethnic minorities in the UK, and in Luton, they are the largest ethnic minority (Office of National Statistics, 2004, Khanum, 2008, Office of National Statistics, 2011), making the sociocultural certainties and health profiles of this population important from a local perspective. Within the UK, the discussions around consanguinity have taken political shape owing to its classification along ethnic lines (Ahmad, 2006, Ahmad, 1994), especially as it pertains to the British Pakistanis (Shaw, 2000). This national politicisation is seen locally in Luton as well, where local health reports have linked poor health outcomes to consanguinity and mostly within the local Pakistani community (Taylor, 2011, Taylor and Whiterod, 2011).

In terms of health, certainly consanguinity has been the subject of much genetic and medical research with frequent linkages to diseases, disorders and physical and mental traits, some of which are hotly debated (Bittles, 2012, Bennett *et al.*, 2002, Bittles and Black, 2010a). A commonly stated fact about the risks associated with consanguinity is that the children of consanguineous couple have double the risk of developing a genetic disorder (Darr and Modell, 1988); however, the possible increase in risk is reported to be highly variable (Bittles, 2012, Bennett *et al.*, 2002, Bittles and Black, 2010a). Nevertheless, there is the potential of genetic mutations being expressed when the influx of external genes is reduced, a problem limited not only to consanguinity but to endogamy (Bennett *et al.*, 2002, Bittles, 2001, Clarke, 1997, Hoodfar and Teebi, 1996, Miguel and José, 2005, Modell and Darr, 2002b, Teebi and El-Shanti, 2006, Woods *et al.*, 2006). Consequently, genetic disorders ranging from metabolic (Özalp *et al.*, 1990) to congenital disorders (Teebi, 2010), physical (Modell and Darr, 2002b) and mental disabilities (Farag *et al.*, 1993), as well as fertility (Edmond and De Braekeleer, 1993) and infant mortality (Stoltenberg *et al.*, 1999) have been linked to consanguinity. Association of these health concerns with consanguinity makes it an important issue in terms of healthcare service provision and efficiency.

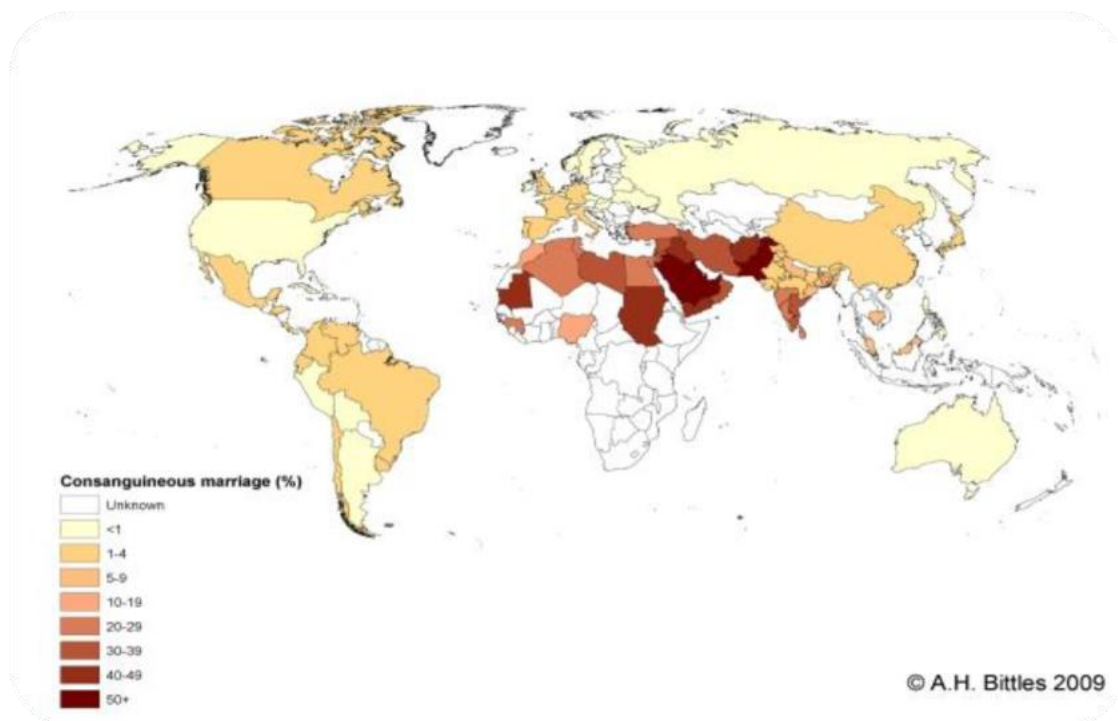


Figure A – Global Prevalence of Consanguinity (www.consang.net) (Bittles, 2009)

Consanguinity is a global phenomenon with sociocultural and healthcare implications which is relevant in the local and the national context of Luton and the UK because of linkage of negative health outcomes to the local Pakistani community who traditionally prefer cousin marriages. The approach of this research is to understand consanguinity as an evolving praxis rather than a presumed fact. For this reason, this research will take a constructionist approach which will consider different views on consanguinity, from past and current research, as well as the underlying influences that have generated ideas and research about consanguinity, and expand on them further through the opinions and beliefs of the research participants.

I. Research Question

“What are the sociocultural impacts of consanguinity and what are the implications for healthcare?”

II. Aims and Objectives

The aim of this research is to examine the sociocultural impacts of consanguinity and the

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implications for healthcare, which will be achieved by meeting the following objectives:

- Explore the discourse around consanguinity globally, nationally and locally;
- Examine the views and experiences of consanguinity in Luton's British Pakistani community;
- Ascertain health service providers' knowledge and views towards consanguinity in Luton.

III. Structure of the Thesis

This thesis is composed of eight chapters, as well as an introduction and a conclusion. The first three chapters of the thesis serve to provide context to the issues around consanguinity as well as describe the theoretical approach taken in this thesis. These are followed by the methodology chapter, which is then followed by the last four chapters presenting and discussing the findings of this thesis. This introduction provides a brief overview of consanguinity as a practice relevant both globally and locally in terms of its sociocultural and healthcare impacts, providing a brief rationale for this research and the aims and objectives of this research. Since this is a constructionist research, the background and context of this research is crucial to understanding the debates around consanguinity.

Chapter 1 provides this background information and expands on the rationale of this study by presenting consanguinity as a sociocultural phenomenon with implications for healthcare. In chapter 1, the sociocultural significance is explored in terms of ethnicity and social categorisation as they relate to consanguinity through an in depth look at the migration and settlement of the Pakistani community in the UK. The sometimes ethnocentric and ahistorical approach of health statistics is addressed setting the stage for this research and its constructionist approach to understanding consanguinity. Chapter 2 describes this approach with a detailed look at the

theoretical underpinnings of this research. In this chapter, the constructionist approach is justified by exploring alternative approaches and finally refined through the constructivist-interpretive paradigm. Later in the chapter, a critical lens through Foucault's concepts on discourse and the influence of power on generation of knowledge, is applied to the overall approach. The purpose of this critical constructionist approach is to recognise the alternative viewpoints on consanguinity and contextualising those viewpoints by exploring the invisible influences that may have shaped them. This contextualising is done through a genealogical literature review of current understandings of consanguinity in Chapter 3, which along with Chapter 1 relates directly to the first objective, which is to examine the discourse around consanguinity globally, nationally and locally. These current understandings of consanguinity revolve around three main areas of knowledge, which include: the anthro- psychological theories which have attempted to define or predict consanguinity as a phenomenon; sociocultural elements which include issues related to social norms, cultural and religious customs around marriage and sexual relationships, as well as sociocultural responses to differences in ethnicity; the knowledge of genetics as an evolving discipline and as a healthcare service. This chapter also provides an in depth look into the genetics behind consanguinity with an analysis of genetic services pertinent to consanguinity.

The methodology is detailed in Chapter 4, which includes both the breakdown of the proposed initial methodology and the details of fieldwork with any alterations made to the proposed methodology. This chapter starts with explaining the choice of methodology, and much like the conceptual framework, it gives a breakdown of alternative methods that were broached but not chosen, giving context to the methodology deemed best suited. The methodology chosen is a hybrid qualitative instrumental case study, which includes elements of both phenomenology and ethnography, to examine the issues raised in the first three chapters about consanguinity through the lives and experiences of Luton's Pakistani community and service providers. This is followed by a look into the research strategy, with details of the proposed samples, methodological tools

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used, recruitment, analysis technique and expected constraints. The fieldwork included both focus group discussions and in-depth interviews, for which a topic guide was designed based on the issues raised in the first three chapters. The data analysis would be done using the framework method utilising the NVIVO software. This chapter also includes details of the ethical considerations for this research, for which approval was sought and obtained from the NHS Research Ethics Committee as well as the University of Bedfordshire's Institute for Health Research Ethics Committee. The final section of this chapter addresses the fieldwork and issues encountered during data collection, including any refinement needed to the initial research strategy.

Chapters 5, 6, and 7 present the findings of the fieldwork, with each chapter covering the different sub-groups that participated in the discussions, which included the service providers (both primary and secondary care), lay community members and the consanguineous community members of the local British Pakistani community, respectively. The findings in these three chapters are presented along the major themes that were prevalent in the discussions, which aligned well within the three sub-groups as well as with the current understandings of consanguinity that dominate this discourse. The detailed discussion on the key findings from all three chapters is presented in Chapter 8, where the findings are analysed in light of the literature and issues raised in Chapters 1, 2 and 3. The thesis is concluded with a conclusion section that includes a reflection on the journey taken in this research, the contribution this thesis makes to the field, some limitations of the research, followed by the understanding of consanguinity that has emerged from this thesis and the recommendations and future research that should hopefully follow this work. All supplemental information is presented in the appendices that follow the conclusion section.

CHAPTER 1 – BACKGROUND: CONTEXTUALISING CONSANGUINITY

1.1 Introduction

In this chapter, consanguinity is presented as a sociocultural practice which has implications for healthcare. Consanguinity, as stated earlier, refers to a relationship by blood or between close relatives, where an ancestor is shared. It is commonly referred to as cousin marriage, and the World Health Organisation defines it as a union between people who are related as second cousins or closer (Bittles, 2001, Hoodfar and Teebi, 1996). Sociocultural refers to a hybrid of both society and culture, used as a framework for analysing research of sociocultural systems involving multiple elements of society and culture (Scupin, 2011). Although sometimes used interchangeably, society can be referred to as a totality of social organisations, with groups of people sharing a common territory, consisting of patterns of relationships amongst those people and their collective lives, and culture can be seen as a by-product of these relationships and interactions, a shared experience of language, knowledge, art, beliefs, morals and customs acquired as a member of society (Panopio and Rolda, 2007, Scupin, 2011). However, the limits of both cultures and societies can surpass the boundaries of regions and nations, for example members of a Western society can be British, American or German, but may belong to different cultures, and similarly, British Pakistanis may share a culture with Pakistanis in Pakistan, but they will belong to different societies. So, societies may contain multiple cultures and cultures may transcend across societies. This may be one reason why sometimes there is a lack of distinction made between the two, as it can be deemed artificial (Scupin, 2011), but in this chapter and throughout this thesis, sociocultural will be used to address common elements of the sociocultural system relevant to consanguinity, and distinctions will be made only as and where applicable. While this thesis uses the experiences of the British Pakistanis in understanding consanguinity, it is important to remember that consanguinity is a global phenomenon and the preferential pattern of marriage for a large proportion of the world's

population, as stated in the Thesis Introduction. Throughout this thesis, studies from varying parts of the world will be used in understanding all of the healthcare, genetic and sociocultural impacts of consanguinity. However, the specific contextual backdrop for other communities across the world practicing consanguinity will naturally be different, for example: in the United States and Canada, consanguinity is mainly seen in isolated communities (Hammond and Jackson, 1958, Jackson *et al.*, 1968) or founder groups (Gilbert *et al.*, 1956, Lebel and Opitz, 1983, De Braekeleer, 1996), and communities face specific legal challenges in terms of the banning of consanguinity in many different states (Otteneimer, 1996) as well as issues of incest and inbreeding (Bennett *et al.*, 2002); consanguinity in Asia is seen mostly through the genetic outcome perspective in China (Du *et al.*, 1981, Wu *et al.*, 1987), India (Basu, 1978, Rao and Inbaraj, 1979) and Pakistan (Shami *et al.*, 1991, Hussain, 1998), as well as in Japan (Neel *et al.*, 1949, Schull *et al.*, 1970, Imaizumi *et al.*, 1975), where lowering rates of consanguinity have been attributed to industrialisation (Bittles, 1998); consanguinity in North Africa and the Middle East is practiced by a majority population (Panter-Brick, 1991, Teebi, 2010, Gowri *et al.*, 2011), except in Israel where it is seen mainly in minority Arab groups and certain Jewish sects (Sharkia *et al.*, Zlotogora, *et al.*, 2007, Zlotogora and Shalev, 2010) and the focus in these regions is on the genetic implications of consanguineous marriages (Tamtamy *et al.*, 1994, Abdulrazzaq *et al.*, 1997, Al-Gazali *et al.*, 1997) and formulations of legal and health policies stipulating genetic screenings but not banning consanguinity (Teebi and El-Shanti, 2006, Hamamy and Bittles, 2008); there is little to no data available from Central African populations in terms of consanguinity (Bittles, 2012), however, there is evidence that both endogamy and exogamy were practiced amongst some Central African populations (Westermarck, 1891, Goody, 1983), while in South Africa (Stevenson *et al.*, 1966), West Africa (Scott-Emuakpor, 1974) and East Africa (Tanner, 1958), as well as in Oceania (Stevenson *et al.*, 1966, de Costa, 1988), Europe (Stoltenberg *et al.*, 1997, Cavalli-Sforza *et al.*, 2004, Teeuw *et al.*, 2012) and South America (Liascovich *et al.*, 2000), consanguinity is seen in minority groups, mainly migrants, who

have been studied mainly in terms of the genetic impacts. Consequently, this thesis will attempt to ascertain the essence of the consanguinity discourse, learning through one of the many communities around the world which practice consanguinity, the British Pakistanis, and at the end of this thesis, consanguinity will be deemed in light of a globalised society.

In this chapter then, consanguinity is presented as a phenomenon that has an impact on society and culture, but also is impacted by sociocultural elements, the combination of which along with possible impacts on healthcare contribute to the overall understandings of consanguinity. These impacts will be examined through a look at the migration and settlement of British Pakistanis in Luton, the use of social categorisation and the possible impacts on healthcare, setting the stage for the rest of the thesis where these issues will be further examined.

1.2 Migration and the British Pakistanis

An important aspect of culture is ethnicity, where a group of people are distinguished from others based on different ancestral origins and their shared historical and cultural heritage (Scupin, 2011). Such an ethnic group, the British Pakistanis, are used in this research to collectively describe any British National with a Pakistani descent. However, the Pakistanis in Britain, like other ethnicities, are not necessarily a homogenous group and are further divided by sub-cultures based on languages, geographical locations, religion and customs. They have distinct identities and have, to a large extent, followed different patterns of migration to Britain. In fact, by some estimates, 60% of Pakistanis in Britain are from the Azad Kashmir region (The Change Institute, 2009, Ballard, 2003), in the disputed Kashmir territory between Pakistan and India, who often associate themselves with a distinct Kashmiri identity (Ali, 1999). Although Pakistani settlers can be found across the UK, the largest Pakistani populations are found in the old industrial towns and cities of Greater London, Birmingham, Bradford, Kirklees and Blackburn. The majority of British Pakistanis are Sunni Muslims and most speak either or both Urdu and Punjabi, or a dialect of the two. Pakistani

migrants from Azad Kashmir speak Pahari, a dialect of Punjabi, although there are UK based Kashmiri nationalist movements that argue Pahari is a separate and distinct language (Ali, 1999).

Roger Ballard (p. 9, 1994) calls migration “above all an entrepreneurial activity,” where if not for a large investment, the return may not be that great. Theories about migration have evolved as the patterns of migration have shifted over the years responding to the overall globalisation movement (Massey *et al.*, 1993). In the beginning of the twentieth century, most migrations were from Europe to other areas (mostly of) the New World, whereas the latter part of the century has seen migrations to Europe from Asia, Africa and the Pacific. Migration is more than just a financial risk, it is an emotional and physical risk, and thus there is usually a significant reason for moving. Most theories about migration try to define this reason behind migration. A detailed discussion of all migration theories is beyond the scope of this thesis, or even identifying the single theory that applies to the migration of the British Pakistanis. However, there are clues within migration theories that do apply to the migration patterns of British Pakistanis.

Ravenstein’s Laws of Migration (1885) form the basis of most migration theories today. Ravenstein’s model was based on the disparity of socio-economics between two places, forcing the people of one place to another. However, this nineteenth century “push-pull” model maybe too simplistic for today’s globalisation movement and also for the British Pakistanis, as it presumes no obstacles in migration, like education and skill level of the migrating population, the distances between places of migration is usually short and above all it assumes the freedom to migrate at will. Migration never was and still is not an easy decision, as Guinness (p. 46, 2010) suggests, “The specific circumstances of individual families and communities in terms of urban contact are of crucial importance in the decision to move, particularly when long distances are involved. The alienation experienced by the unknown new migrant to an urban area should not be underestimated and is something that will be avoided if at all possible.” Keeping this in mind, Lee’s (1966) modification on the classic push-pull model, in which intervening obstacles are accounted for as

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well as the individuality in determining and negotiating these obstacles to migration is probably more suitable for the Pakistanis that moved to Britain. The British Pakistanis first came to Britain in large numbers during the 1950s, when the post-World War II shortage of labour was filled with workers from ex-colonies. Later in the 1960s, during the building of the Mangla Dam in Pakistan's Azad Kashmir and mainly Mirpur region, those displaced by the massive construction were offered work permits for the UK (The Change Institute, 2009). The voucher system introduced by the British Government, where relatives of migrants could arrange for jobs and "vouchers" in the UK for their friends and family back in Pakistan, further increased the migration of Pakistanis, although following more of a chain migration model. This model moves away from the push-pull model and explains the movement of groups of people as a result of encouragement from seeing others like themselves who have moved and have built successful lives and then seeking their assistance in moving as well and having their initial hurdles taken care of by these pioneer migrants. Chain migration is cited for development of ethnic neighbourhoods within the new adopted country, because the new migrants would want to live near or with their friends and families who have already established themselves (MacDonald and MacDonald, 1964, Ali, 1999). This type of migration certainly strengthened family and friendship bonds and links to Pakistan in the case of the British Pakistanis. This was enhanced further when new curbs on immigration in Britain meant that only immediate family members could emigrate from Pakistan; this increased the number of marriages and further developed transnational networks of families. Migration due to family links continue to this day from Pakistan, albeit at a slower pace than the 1960's, mostly due to increasingly stricter immigration rules; however, economic based migration has shifted from fulfilling labour class worker shortage to highly skilled professionals from Pakistan and is thus less restricted in terms of geographical exclusivity in migration. Where a single geographical location in Pakistan, northern Punjab and Azad Kashmir, and its surrounding areas contributed to a majority of the migrants into Britain, modern migration is now more evenly distributed across Pakistan. So

the British Pakistani experiences of migration to Britain have moved through different stages and different models of migration have been applicable at these various stages. The decision-making model in Figure 1.1 is a good representation of the various factors that must be tackled by each individual migrant before a decision to move can be made and clearly shows influences of both push-pull and chain migration theories, a more inclusive model which could be applied to partly understand the British Pakistani migration experience.

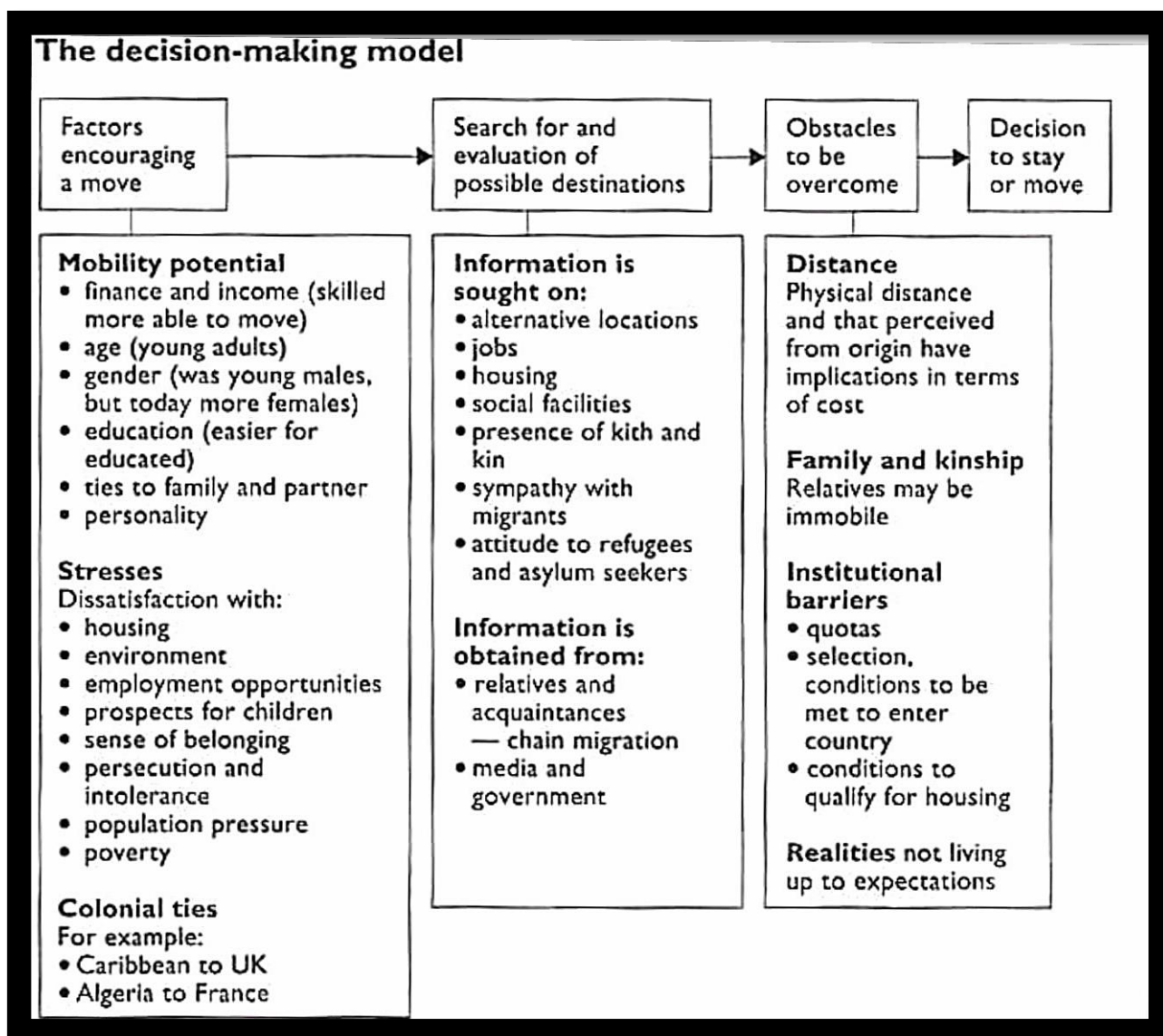


Figure 1.1 - The Decision-Making Model (Guinness, 2002) – Model represents the various factors that must be tackled by each individual migrant before a decision to move can be made.

Although the above model is meant for the general population when it comes to migration

in a globalised age, it presents factors that are very relevant to the British Pakistani experience, such as Colonial links, the employment opportunities, dissatisfaction with native lands, ties to family, quota systems and then the realities faced once in Britain. The situation in Britain once the migrants arrived is also relevant to the overall British Pakistani identity and experience and ultimately in understanding consanguinity through the British Pakistanis. Unlike the European migrants who moved to the United States, the migrants moving from Pakistan and other ex-colonial states to Britain were mostly visible minorities, making them quite clearly the *other* group of people (Ballard, 1994). As more and more of these “ethnic” neighbourhoods emerged amongst the local populations, it was not only the skin colour that made them separate, it was the religion, language and culture. This was difficult to come to terms with for the existing local populations, predominantly White (Anglo-Saxon/European) populations, but also overwhelming for the migrants, and they became more and more reclusive (Ballard, 1994). Along with struggling to fit in to this alien land, the new migrants fought hard to maintain links to “home,” as if to suggest that at some imaginary point in the future, they might return once they had made enough money.

No matter how bad the social and material conditions they may have left behind, and no matter how great their achievements abroad, migrants invariably feel a grievous sense of loss. They miss -- and therefore long once again to experience -- the familiar sights, sounds and smells of their birthplace, and the warmth and conviviality of everyday domestic life. All of them yearn for closer contact with their now-distant kin, and for closer involvement with the linguistic, cultural and religious world which once gave comprehensive meaning and purpose to their everyday lives; no wonder, therefore, that most make every effort to construct a more meaningful world in their otherwise alien destination. (Ballard, 1994, p. 9)

This myth of return (Anwar, 1979) created further dilemmas for the early migrants, as they

struggled to balance the burden of wanting to connect and take care of family left back in Pakistan, with the need to provide and develop the lives of their British born offspring, changing migrants to settlers. The responsibility of kith and kin back home was transferred over to the offspring of migrants as they sought to fulfil some of their parents' roles and duties whilst developing their own British identity (Ballard, 1994). The myth of return dissipated over time as British Pakistanis settled, carved out a niche in British society by recreating a home environment through mosques, shops and community centres, achieving what Breton (1964) termed as institutional completeness. It has also been helped by ease of travel, where going back to Pakistan and reconnecting with families is no longer difficult. Although, some argue that the current waves of Islamophobia, ethnic strife and increased feeling of alienation amongst the British Pakistani youth has resulted in a resurgence in the myth of return (Bolognani, 2007). The journey from migrant to settler to British Pakistani has certainly been rife with racial, political and legal struggles and has rarely followed the template which would have been predicted by an immigrant imaginary (Sayyid, 2004). Sayyid (2004) argues that there exists a racial paradigm, a vision of an immigrant imaginary, that reduces the new settler into a people without history, not effected by the changing political scene, deploying a colonial gaze to outline the settlement of a population such as the South Asian settlers, assuming for example that the second and third generations of these settlers will be secularised and integrated into the Western lifestyle as a matter of inevitability (Ali *et al.*, 2006, Sayyid, 2004). Under this paradigm, an ethnocentric view of cultural differences exists, only to separate the other from the norm, positing a superiority in the existing norms over the culturally different others and as such establishing a power dynamic where the balance of power remains firmly against the other (Atkin, 2006). The norm in this case being the White/Anglo-Saxon/Eurocentric, majority way of life, which the assimilation policies and tightening immigration laws hoped would limit the influence of the "coloured" new citizens (Doyal, 1995), thus making the majority lifestyle everyone's way of life, ignoring the other, the minority, or in this case, the British Pakistani lifestyle.

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However, the prediction of an American style “melting pot” (Bisin and Verdier, 2000) settlement of the British Pakistanis did not take place. The effects of chain migration may well have helped in the establishment of ethnic neighbourhoods, but it was also the type of jobs available, and the financial constraints of the new migrants that dictated where they settled. In most instances, the areas of cheap housing that were closer to the workplace, mostly factories or mills, were run-down, with multiple inequalities in terms of housing, social and educational services and were rife with unemployment. Even though this was the case even before the arrival of the new migrants, in the eyes of the locals, this new visible minority’s added numbers made them view these neighbourhoods as being run-down because of these *others* and they came to define these areas through this filter (Ali *et al.*, 2006). However, it was not just the economic conditions that drove the formation of such neighbourhoods, institutionally racist allocation of housing also aided the grouping of ethnic minorities like the new migrants from Pakistan into areas which were less desired by the majority. Rex and Moore’s (1967) study in Sparkbrook, Birmingham takes a Weberian look into the social and political order and its influence on the treatment of migrants, where these minority groups were essentially placed in areas that were deemed unfit or undesired for the white majority, which resulted in creating what they termed as ‘housing classes’. These classes were determined so as to highlight the minorities’ inferior economic and social positions (Abbas & Reeves, 2007). Such concepts of ethnic neighbourhoods and housing classes develop from what Foucault refers to as discursive formations (1972) about social orders, where the ideas of the majority are propagated through every level of society marking their superiority over alternative views, an idea explored further in the next chapter.

Looking through a linear history, the racial tensions only increased further as the new settlers sought more rights to include their individuality into the British lifestyle and also as they responded to the changing political developments in the country and around the world. These political developments were constituted by issues like the policy of dispersal, which sought to spread out the

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Black and Asian kids into schools out of their district so as not to crowd particular schools with Black and Asian kids, the struggle to make available halal food in restaurants, the Honeyford affair, where a White principal of a mainly Asian school spoke out against the multicultural adjustments being made by the schools for a rising Asian population, the Salman Rushdie affair, the author of the controversial and in the eyes of the Muslims, blasphemous *Satanic Verses*, invoked the wrath of the Muslims worldwide and thus uniting the British Pakistanis with the larger Muslim identity taking shape in Britain. Issues such as these resulted in further isolation and introversion of the British Pakistanis, closeness to the larger Muslim population beyond nationalist boundaries and the realisation that even when the “Western” institutions recognised multiculturalism, it was mainly to their disadvantage as policies were implemented to fade it out (Ali *et al.*, 2006). The struggle and debate about multiculturalism continues even today, polarising communities, and thus it is no surprise to find areas of the country which are much more “multicultural” than others.

The healthcare response to multiculturalism in the UK has to an extent been shaped by trying to address the differences of ethnic minorities in terms of language, religion and cultural from the norm (Srivastava, 2007). This approach however, as mentioned above, posits a power dynamic thereby giving an inferior status to the culturally different, failing to recognise that indeed everyone, including the majority population is different (Atkin, 2006). Several reports, as well as laws like the Race Relations Act, have highlighted the existence of institutional racism in the UK’s public services such as the health service, whereby policies and procedures are implemented and applied, knowingly or unknowingly, in a one-size fit all approach, negating or failing to recognise the needs of an ethnically diverse population (Atkin, 2004). Such practices can act as discursive formations within the consanguinity debate, which may drive opinions, approaches and treatment of health issues as negative outcomes and perhaps the only outcomes of culturally different health behaviours and practices like consanguineous marriages of an ethnic minority such as the British Pakistanis.

This fails to address perhaps the real causes behind an illness, rather places the blame on cultural practices and behaviours of the patients (Walker and Ahmad, 1994, Owens and Randhawa, 2004), which if were in line with 'Western' beliefs, would undoubtedly result in better outcomes (Atkin, 2006).

The reason why the British Pakistani community is being used to further examine consanguinity, is because consanguinity is common in the community and this has sometimes been related to health statistics that highlight elevated numbers of infant mortalities, with an over representation in children with disabilities (Taylor, 2011, Taylor and Whiterod, 2011, Hussain, 1999). Furthermore, the British Pakistanis are the largest minority ethnic group in Luton and as such, anything that may have a bearing on this group's health, will be important from a local public health perspective. In order to better understand the community dynamics and to contextualise the relevance of consanguinity in their sociocultural elements, it is important to explore how and why they have migrated to Britain and how the community has settled and evolved over the years, as it has an impact on their belief system, social interactions, health behaviour and ultimately, possibly, health outcomes.

The importance, in terms of public health, of the development of the British Pakistani identity and the debates on multiculturalism is two-fold. One, the establishment of ethnic neighbourhoods in already deprived areas of town and cities furthers the disparities faced by the British Pakistanis. Second, the development of doubt towards health and social services because of a "history of defining health problems faced by South Asian populations in terms of cultural deficits, for which the main solution offered would be a shift towards a 'Western' lifestyle" (Atkin, 2006, p. 249). Relating ethnicity to causation can be discriminatory and unhelpful. However, using categories of culture and ethnicity to explore further the association and underlying determinants of health problems by addressing inequalities can be useful when done responsibly.

1.3 Social Categorisation

The census categorises people based on their ethnic background for purposes of identification and understanding local populations. In the UK, the census has used White, White (other) or various Black and Minority Ethnic (BME) categories that people can use to describe themselves for others to identify them. These categories have evolved from simpler divisions as simply White or Other and have now evolved to include deeper classifications in terms of religion and multiple classifications like Black British and Asian British and so on. However, it is unclear if they go far enough to identify each group or each individual appropriately and more importantly, responsibly. When social categories such as ethnicity are used to define, identify or explore causation of health problems, such as within the consanguinity discourse, the consequences can be significant and far reaching.

Bateson (1958) suggested that defining cultures through categories, assigning structure, is an arbitrary exercise useful for communication. Defining a society itself is a categorisation, a classification that is not real but an abstraction, useful only when given context. Categorisation, when done responsibly and for the right reasons, in research can be useful in further exploring health issues of concern, something which is hoped this work will achieve. However, such research can also create rifts and barriers when simply relating ethnicity to causation, inadvertently or otherwise. An example of such was presented by Nazroo (2012), in explaining the presence of institutional racism towards people from the Caribbean in Mental Health Services, as people from the Caribbean are three to five times more likely to be diagnosed with first stage psychosis at hospitals in the United Kingdom, but the numbers do not correlate with the Caribbean itself, where the numbers are much lower, pointing to over diagnosis and possible prejudice. Prejudice because categories have been used to imply causation, seeking explanations in social categories rather than empirical data, like linking heart diseases to South Asians, sexual diseases to the younger Black population, or

hinting that high suicide numbers in young South Asian women must be as a result of a patriarchal society, whereas the reasons turn out to be the same issues that affect young White women (Nazroo, 2012). Similarly, in the case of haemoglobinopathies like thalassaemia and sickle cell disorder, which are prevalent in people of Asian, Caribbean and Middle Eastern ethnicity, there was an attempt by some in the medical field to target these high risk groups (those that trace their origin to country where 1 in 1000 people may be a carrier) for screening and counselling, however, it was later discovered that those classified as White British may also fall in this high risk category and strategy that looked beyond ethnicity as a sole determinant of causation was needed (Dyson *et al.*, 2012). This instance also highlighted the racist undertones involved in categorising ethnicities with health conditions, as the White majority did not appreciate being labelled alongside these minority groups who tend to carry haemoglobinopathies (Dyson and Atkin, 2011).

Consanguinity has often been pathologised based on ethnic categories (Jorde and Pitkänen, 1991, Ahmad, 1994, Leck and Lancashire, 1995). It is ostracised based on the risks involved for infant mortality, genetic disorders and other developmental issues (Bittles, 2012). Similar dangers exist in lifestyles not classified along ethnic lines, like smoking or *in vitro* fertilisation (IVF) treatments. While the public health policy response to smoking has come a long way in the last few decades, with an eventual ban on smoking in public places, smoking has not been banned completely, even though there are considerable risks associated with smoking which start from impacting double-strand breaks in DNA (Leng *et al.*, 2008) to resulting in numerous cancers in adults (Carbone, 1992) and cardiovascular diseases (McBride, 1992) let alone developmental effects during pregnancy (Abel, 1980). IVF and other assisted reproductive treatments (ART) have grown from being a last hope for couples with fertility issues to becoming a lifestyle choice for older aged parents and same-sex couples, despite religious, legal and ethical concerns (Schenker, 2011). Yet smokers are given alternatives for their nicotine addiction and IVF parents are not only briefed about the risks involved in the treatment but the positive outcomes are also highlighted

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allowing patients to make informed choices void of any guilt, something which has lacked at times for consanguineous couples, based on cultural taboos and ethnic categorisation of disease.

La Barre (1975), whilst talking about the Native Americans, suggests that shunning categories altogether would limit rational activity and communication, which would have a negative impact on intellectual freedom, rather a recognition of such categories as artificial means of classification for ease of communication is required. As globalisation progresses and as racial divisions blur, ethnic groups are becoming more and more heterogeneous, making it difficult to even define ethnicity (Atkin, 2006). Consequently, using factors like culture and ethnicity in isolation to at best identify a problem or at worst to explain causation, as has been done at times with consanguinity (Morton *et al.*, 2002), is becoming more and more problematic and there is a need to address other determinants of health along with and beyond culture and ethnicity. Sociocultural factors must be accounted for, however, it should be for purposes of cultural relativism rather than ethnocentrism, to add a critical perspective that addresses the feasibility of giving preference to dominant Western medical systems rather than the ethno-medicines and indigenous health systems of non-Western societies (Hahn, 1995). Health research prioritises the physical and clinical aspects with regards to disease and treatment, whereas globalisation and population health call for an expansion to cover sociocultural factors which help determine health factors (Le, 2011). In the current climate, focusing on the biomedical model of health alone is inadequate without addressing sociocultural factors, and there is a need to shift towards a bio-psycho-social approach to improve clinical methods (Katon and Kleinman, 1981).

1.4 Consanguinity and Healthcare

Consanguinity is generally perceived to be viewed by healthcare professionals and genetic specialists as being negative (Farmer, 2005, Farmer *et al.*, 2004), especially in terms of genetic risks to the children of such marriages; yet, more than a billion of the world's population, or about twenty percent, traditionally marry within cousins and a third of those are between first cousins (Hamamy
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et al., 2011). However, because most of these populations are part of traditionally non-Western cultures (although they may be part of Western society, as discussed earlier in section 1.1), there is an ethnocentric tendency to focus on the genetic risks of the cultural practice of consanguinity. Ethnocentrism, or the tendency to interpret situations based on one's own cultural background is a hindrance in public health (Breton, 1964), whereas cultural relativism allows to understand sociocultural elements within the context of the very same cultural system, which includes health beliefs, illness causation, and treatment options leading to better cultural competency and indeed better care (Cargo and Mercer, 2008). It also aims to contextualise these in terms of other cultural elements, like the politics, economy and religion. It posits that societies and cultures are best understood holistically and that the local populations, not the outsiders are the experts on their own sociocultural environment (Hahn and Inhorn, 2009). When it comes to consanguinity, it seems the intention by health professionals to factor in health beliefs in understanding consanguinity fails to fully account for all other cultural elements involved in sociocultural relationships, and culture thus becomes as a means of exerting power and a form of stigmatisation for the other, the studied, the ones that practice consanguinity (Ahmad and Atkin, 1996). Hahn & Inhorn (2009) call for a need to attend to the historical context of health programmes and the political environment in which they evolve, to counteract the imbalance created by power and dominance of health professionals and classical assumptions of the biomedical model of health.

Given this dominance of biomedical models in terms of research and treatment, public health focus with regards to mortality and morbidity has also gradually shifted towards it, now focusing on genetic diseases. The emergence of genetics and global decline in infectious diseases (Hamamy *et al.*, 2011) in the latter half of twentieth century has catapulted genetic research and studies to a privileged position in medicine today (discussed in more detail in section 3.4.1)(Waters, 2008). Consanguinity in turn has been reported to be associated with lower fertility (Assaf *et al.*, 2009, Hussain, 1998, Rao and Inbaraj, 1979), higher pre-reproductive infant mortality (Bittles and
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Black, 2010b, Cavalli-Sforza *et al.*, 2004) and early childhood morbidity such as congenital disorders (Güz *et al.*, 1989, Harlap *et al.*, 2008, Stoltenberg *et al.*, 1997, Zlotogora and Shalev, 2010), metabolic disorders (Özalp *et al.*, 1990, Sanderson *et al.*, 2006), intellectual disabilities (Janson *et al.*, 1990, Sharkia *et al.*, 2010, Temtamy *et al.*, 1994), higher infant mortality (Bittles, 2012, p. 123-134), and higher adult mortality and morbidity (*Ibid*, p. 162-176), usually through autosomal recessive disorders. There is a high level of variability in the reported association of risks to consanguinity, with other studies showing opposite results, as in the case of fertility rates (Abdulrazzaq *et al.*, 1997, Gowri *et al.*, 2011); moreover, some of these studies have inadequate controls in place for socio-economic heterogeneity and sample size, while some have contradictory studies making results highly variable (Bittles, 2010b, Bittles, 2012). However variable the results and however poor the quality control of some of the studies may be, the fact remains that consanguinity has been linked to genetic diseases, it has become a discursive truth and common knowledge, known generally but understood scantily, making it at least a point of discussion for public health if not a priority.

1.4.1 Healthcare Impacts

The 2010-2011 Annual Public Health Report for Luton (Taylor, 2011), a key document for the area's Joint Strategic Needs Assessment, focused on the health of Luton's Black and Minority Ethnic (BME) groups. The report highlights that Luton is one of the more deprived areas nationally, as it ranks high on the Index of Multiple Deprivation scale. Moreover, certain wards of Luton are among the very worst nationally when it comes to deprivation. Luton also has a large population of BME groups, almost a third of its entire population, and a higher percentage of these minority groups live in the most deprived wards (see Dallow and Biscot Wards in Figures 1.2 and 1.3). Life expectancy is also lowest in Luton in these wards, and again Luton is ranked poorly on a national scale. The BME population of Luton consists mainly of Pakistani, Bangladeshi, Indian and African Caribbean communities, with the 2001 Census statistics showing the Pakistani population as the

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largest minority (ONS, 2004). Even after the wave of post-EU migrant workers in the recent past, the largest ethnic minority group in Luton is in fact the Pakistani community (ONS, 2011). Ethnic population projections for Luton indicate that the Pakistani population will increase by 43% in the next twenty years, a larger increase than any other ethnic minority group (Luton Borough Council, 2012).

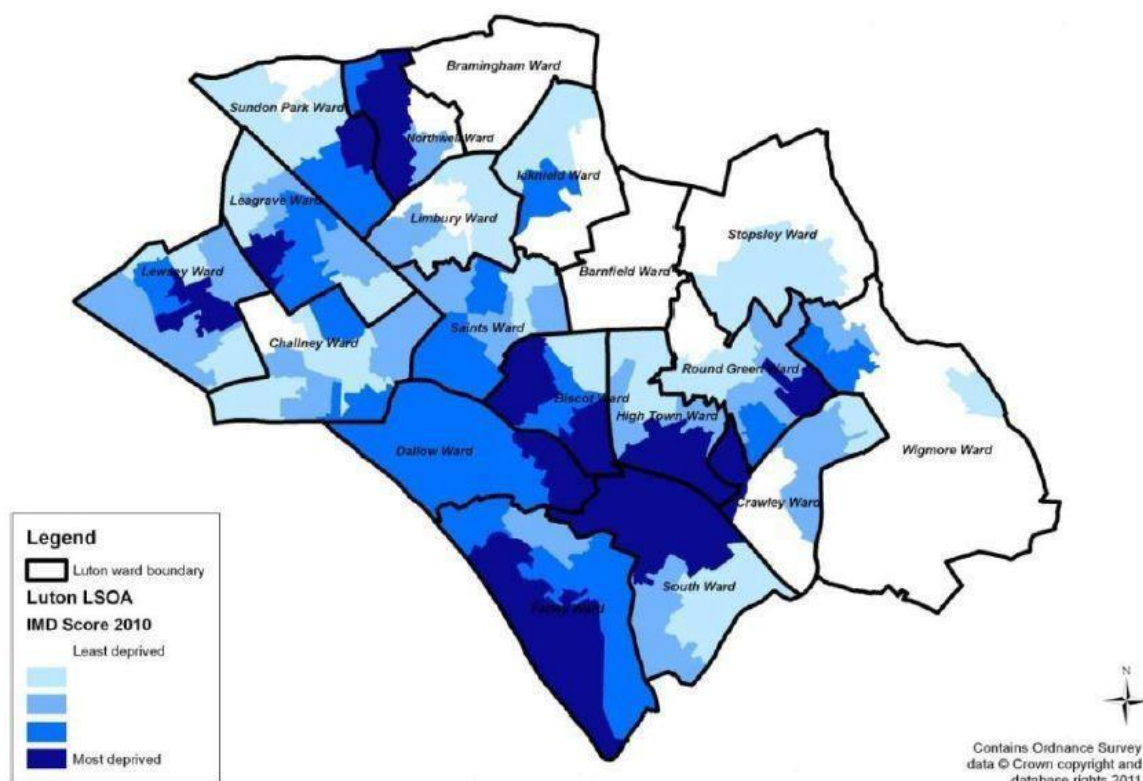


Figure 1.2 - Index of Multiple Deprivation (IMD) Map in Luton – Areas with high BME populations, like Bury Park, reside in the areas with some of the highest levels of deprivation, like lower Dallow and Biscot Wards. *LSOA stands for Lower Super Output Area

According to the 2011 Annual Public Health Report for Luton (Taylor, 2011), Luton has the 8th highest birth rate in all of England, and that a quarter of these births are to mothers of Pakistani descent. Infant mortality in Luton has also been significantly higher from 2000-2010 than the rest of England, and out of the 98 infant deaths reported between April 2008-March 2011, Pakistani mothers accounted for 31% of those deaths, a large number of those (39%) dying within early hours of life. Half of the infant deaths in the Pakistani community in Luton have been due to congenital anomalies, which are conditions present at the time of birth. In fact, while Pakistani mothers account

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for only 4% of total births in England, they account for 30% of those with autosomal recessive disorders (Modell and Darr, 2002b). It has also been reported that out of the 98 infant deaths reported in Luton (2008-2011 as above), consanguinity has been identified as a modifiable factor in 20% of these deaths. By modifiable, the assumption being made is that if this factor was changed, that is the parents of the infant were not consanguineous, then the number of infant deaths would be lower, but there has been no expansion on this point in the report and no details have been given as to the validity of this assumption, which is a cause for concern in terms of the quality of this report; consanguinity has nonetheless been highlighted as a significant factor in infant deaths in Luton, as per the annual report presented to the local council (Taylor, 2011, Taylor and Whiterod, 2011). South Asian families, however, also account for a higher proportion of children with disabilities in Luton. The number of South Asian children registering at the Lady Zia Werhner School, a specialised local school for children with serious learning disabilities was 69% in 2008 (Kaur-Bola, 2009, Taylor, 2011). Given the numbers above of composition of Luton's ethnic population, it would be safe to assume that some of these children are from Pakistani families; however, the association to consanguinity has neither been reported nor explored in depth. Taken together, the population distribution and the numbers on infant mortality alone are alarming enough in terms of Public Health that even the suggestion of an association to consanguinity or to ethnicity should be a concern.

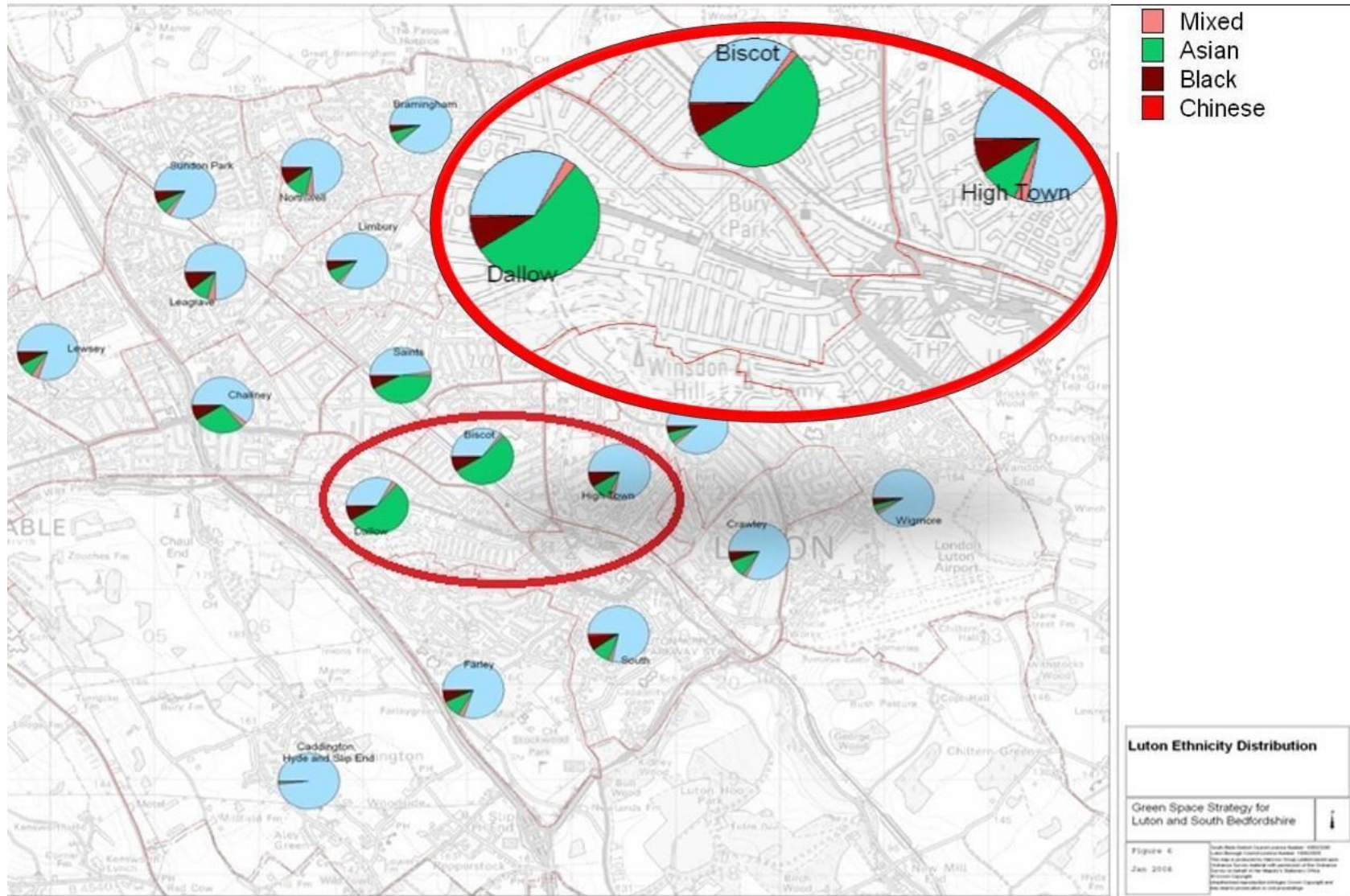


Figure 1.3 – Luton Ethnicity Distribution - Areas with high BME populations, like the magnified Bury Park region, reside in the areas with some of the highest levels of deprivation, like lower Dallow and Biscot Wards. *light blue represents White ethnicity and green for Asians includes Pakistanis and other South Asians **used with permission from Luton Borough Council)

1.4.2 Health Inequalities

As suggested above by the local public health report for Luton, the ethnic minorities like the British Pakistanis, who have high incidences of infant mortalities, also happen to live in some of the most deprived areas of not only Luton, but also the entire country. Health inequalities based on socio-economic status have reportedly played a role in some of the negative health outcomes that have been attributed to consanguinity (Bittles, 2012). The disparity in health outcome between individuals or groups, either avoidable (inequity) or unavoidable (inequality), are seen as unjust differences that need to be addressed through public health (WHO, 2012). Inequality does not mean that an equal amount of care should be provided across the spectrum, equality in opportunity, because those that are already at an advantage will benefit more from such improvements, rather services should be provided where and for whom they are most needed (Johnson and McGee, 2010). It is the social and economic conditions of the people that determine their lifestyles and behaviours which then give rise to inequalities. Essentially, the poorer members of the population usually suffer from poorer health and this runs down the social gradient, meaning the effects of inequality can be seen in all levels of socio-economic status, not just the most disadvantaged. The Department of Health, through the London Health Observatory, has provided a simple example of the health inequalities that exist between different areas of London, by showing that every two tube stops East of Westminster on the Jubilee Line, represents a loss of a year of life expectancy (London Health Observatory, 2010). In Luton, the Slope Index of Inequality, which measures this difference in life expectancy between the most and least deprived groups, stands at 8.5 years for males and 7.4 years for females, meaning that the most deprived in Luton live an average of 7.4 to 8.5 years less than the affluent (Luton Borough Council, 2011a). Globally, there is in fact a 20 year life expectancy difference between the 60% of the low-income countries' population and the 1/6th living in high income countries (Graham, 2009, p. 10). In the Strategic Review of Health Inequalities in England Post-2010, the Marmot Review recommended that in order to reduce inequalities, focus must be on

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the underlying social determinants of health and the wider elements that were the cause behind the cause of poor health outcomes (Marmot, 2010). The World Health Organisation (WHO) defines social determinants of health as “the circumstances in which people are born, grow up, live, work and age, and the systems put in place to deal with illness. These circumstances are in turn shaped by a wider set of forces: economics, social policies, and politics” (WHO, 2012). Health inequalities could then be due to geography, level of deprivation, socio-economic status, ethnicity, disabilities, employment, health behaviour and other determinants that dictate the divide on the social gradient (London Health Observatory, 2012, Skolnik, 2012). Health inequalities could also be a result of institutionally racist policies and practices, as discussed above (Atkin, 2006), as diversity of populations must be addressed in health impact assessment (Johnson and McGee, 2010), and a failure to do so is unfair and disadvantageous to those facing these inequalities.

Earlier in this chapter, statistics were shown for Luton that showed higher infant mortality rates, particularly in the British Pakistanis of Luton. Health outcome indicators often use race and ethnicity as both a measurement and a variable of inequality. It is one thing that those indicators and expected normal outcomes are based on Eurocentric populations without accounting for population diversity (Collins and Johnson, 2009), moreover, there is rarely a description as to the usefulness of using race and ethnicity as variables (Dressler *et al.*, 2005). In a critical review of literature looking into health disparities (inequalities), Dressler *et al.* (2005), have classified the approaches taken into assessing health disparities as belonging to five models, a racial-genetic model, health-behaviour model, socioeconomic status model, psychosocial stress model and a structural-constructivist model. In their view the psychosocial stress model and the structural-constructivist model offer a better explanation of health inequalities because:

- the racial-genetic model fails to adequately prove health disparities exist due to genetic variations in race (a construct which seems based less on genetics and more on social elements)

- the health-behaviour model can be relevant to disease risk assessment but a review of studies suggests there is little evidence of this model explaining health inequalities, as ethnic minorities alone do not practice unhealthy behaviours
- in the socioeconomic status model, where studies account for the over-representation of ethnic minorities in lower socioeconomic groups, controlling for this over-representation still does not negate the health inequalities that exist between groups, and thus offers only a partial explanation of the existence of these inequalities

The psychosocial stress model and the structural-constructivist model represent a holistic approach where social experiences of ethnic minorities are taken into account when assessing health outcomes and where the very construction of race and cultural categorisation is addressed in understanding health inequalities, respectively (Dressler *et al.*, 2005). These approaches encompass not only individual variables used to indicate inequalities but also address the possible underlying determinants of health. When discussing consanguinity and relatively higher infant mortality rates in British Pakistanis, health reports are not addressing these other factors. Using ethnicity as an inequality for the British Pakistanis in Luton in terms of health would be meaningless without also seeing ethnicity as a social identity, one which is shaped by cultural location and resources that map health behaviours and support circles (Nazroo and Karlsen, 2009). However, while ethnicity helps describe and identify a group of people, it should encompass a wider range of dimensions than just skin colour, like health beliefs, health behaviour, cultural behaviour, social taboos, diet, language and even religion or interpretation and implementation of religion. It should also address economic inequalities, Luton after all has the lowest Gross Disposable Household Income rate in the East Region of England and is well below national levels (Luton Borough Council, 2011a, Taylor, 2011). The unemployment rates within the Pakistani community are higher than other groups in Luton, and despite recent reduction, Luton itself traditionally rates poorly to national unemployment rates. Luton ranks low in other statistics like unemployment benefits claims, unskilled workers, and lower

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test scores and GCSEs achieved (Luton Borough Council, 2011a, Taylor, 2011). Luton also has a higher average of people with no qualifications as opposed to the rest of the country (Luton Borough Council, 2011b). Geographical inequality highlights issues related to both the deprived areas from which the majority of the Pakistani population immigrated from in Pakistan, mainly Azad Kashmir, Kotli and Mirpur in particular (Shanahan, 1997), but also the wards of Biscot and Dallow in Luton where a large majority of the community resides, and has contributed to inter-generational inequalities, where the adult's inequalities continue to effect the children. Furthermore, the social identity that has been shaped by the British Pakistani experiences of social and racial strains, as discussed earlier, has an impact on health outcomes (Nazroo and Karlsen, 2009). Placing people in categories, accordingly associating risk and labelling ethnicity as an inequality alone is not enough, as the statistics above have shown, the wider social determinants of health collectively play a role in health outcomes.

One of the variables used as a determinant of health and in turn inequalities is health behaviour, which can have good health practices and bad health practices, and is difficult to quantify as opposed to some of the other determinants discussed above. Moreover, health behaviours are closely linked with cultural beliefs and perceptions of the body and what constitutes illness and how to go about addressing it (Skolnik, 2012). One of the most widely used conceptual theories for understanding and changing health behaviour is the Health Belief Model, shown in Figure 1.4 (Skolnik, 2012, Champion and Skinner, 2008). This is similar to the decision-making model for migration, and it presents an overview of the construction of understanding health risks

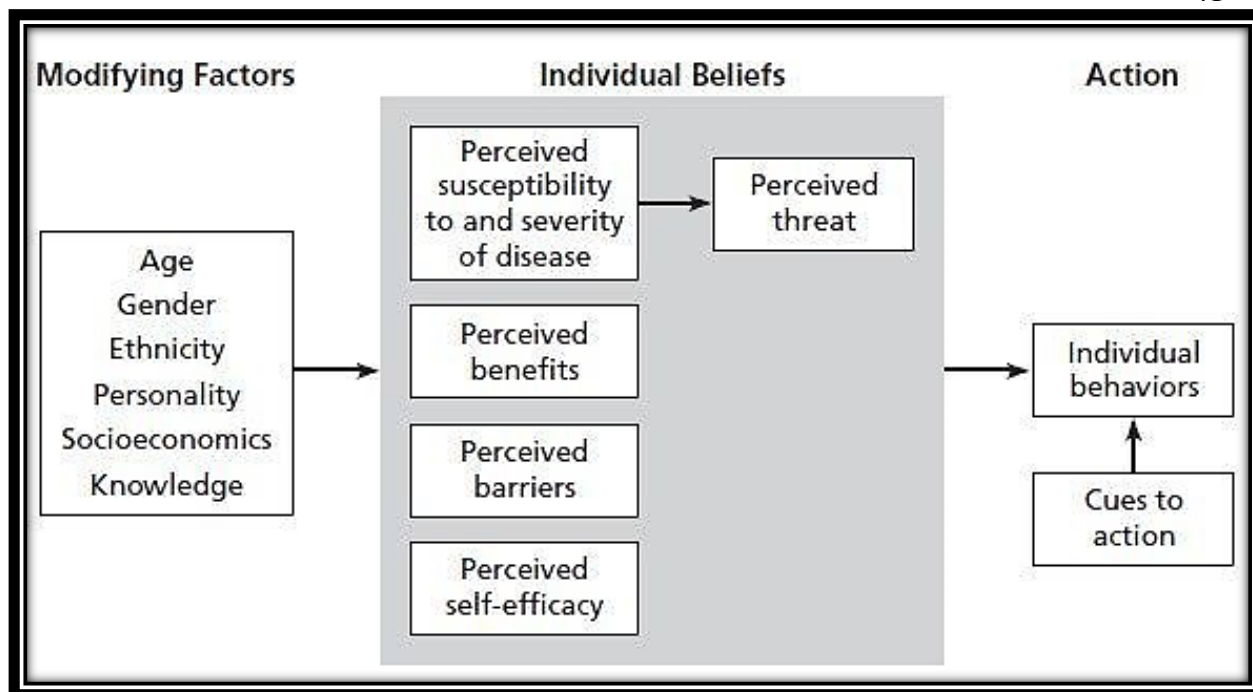


Figure 1.4 - Components of the Health Belief Model (Champion and Skinner, 2008) – A model which addresses individual's assessment of health risk and actions needed to be taken, if any, to address those risks

and the decision on actions to be taken, if any, to overcome them. The model states that people's health behaviours depend on their perceptions of the severity of the disease and the risk of them contracting it, the benefits of partaking in prevention behaviour, and the barriers they will face in accessing or implementing that prevention behaviour, the self-belief that one can actually execute the behaviour required for prevention and the cues that can trigger action (Champion and Skinner, 2008, Skolnik, 2012). Other models like Ajzen's Theory of Planned Behaviour (1991) as well as Fishbein and Ajzen's Theory of Reasoned Action (1980) have been used as cognitive models attempting to predict health behaviour, they however lack the flexibility to account for individual emotional influences on behaviour (Dutta-Bergman, 2005).

One commonly used example in explaining this model is that of a person's decision making process in deciding to use a condom for prevention of a sexually transmitted disease. This decision, based on the model, will be dependent on how fearful a person is of a sexually transmitted disease, how serious he or she believes this disease to be, how much a difference using a condom will make in prevention of contracting this disease and how easy it is to buy and use a condom and getting the

partner to agree to use it as well (Skolnik, 2012, p. 125- 126). Much like the Ravenstein's laws of migration, which have been criticised to an extent for being a-historic (Ali, 1999), and other models which try to predict human behaviour like the TPB and TRA, the health belief model to a certain extent also fails to account for other elements that may impact health behaviour, such as levels of education, health and social policies, and geo-politics, all of which are very relevant to the British Pakistanis of Luton. In terms of consanguinity, there may well be a balancing act that individuals may or may not undergo in assessing the perceived risks against the possible social benefits that are often cited for the preference of consanguineous marriages (Bittles, 2012). Nonetheless, this model has been successful in assessing behaviour and has been useful in implementing health promotion and awareness (Champion and Skinner, 2008), and is deemed to be more flexible in its consideration for individual influences on behaviour (Dutta-Bergman, 2005). The health behaviour of the British Pakistanis may or may not be so trivial and it may or may not be all encompassing, but a model such as this can be useful to at least address base level information regarding health behaviour, any resultant inequalities and the possible impacts on health outcomes. However, as discussed earlier, it should only serve as one element of a wider approach to understanding health inequalities and health outcomes and how they relate to the perceived impacts of consanguinity on healthcare.

1.5 Summary

This chapter has highlighted the importance of sociocultural factors in addressing consanguinity, along with a discussion on the impacts of these elements on the possible healthcare bearings of consanguinity. Both culture and ethnicity are heavily embedded in the consanguinity discourse, this was exemplified through the settlement story of the Pakistani community in Britain. The British Pakistanis, like other ethnic minorities are sometimes subjected to superficial and ethnocentric treatment based on health models that ignore cultural context, categorising them along ethnic lines for poor health without addressing underlying causes of health outcomes. Consanguinity also falls along these lines as it is perhaps one factor along a causal pathway of health

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outcomes, but without addressing all other factors in this pathway, it would be difficult to assess impacts. These other factors may be related to medicine, health behaviour and genetics, but they also include sociocultural factors, such as poverty, ethnicity, religion, gender and identity, as well as the discrimination faced in light of these factors, be it for access to care or for allocation of resources, and the inadequacy of healthcare and research which either fails to recognise these elements, or fails to implement actions to overcome or compensate for them. Thus, the practice of consanguinity and the associated discourse is complex. A constructionist approach provides the means for studying this complexity. In the next chapter, the centrality of the contribution of constructionism will be discussed in understanding the sociocultural aspects of consanguinity and the implications for healthcare.

Chapter 2 - CONCEPTUAL FRAMEWORK

2.1 Introduction

Carrying on from the assertion made in the previous chapter that an approach to understanding consanguinity should include the historical, sociocultural context along with the healthcare implications, in this chapter, a conceptual framework heavily indebted to a constructionist paradigm will be laid out which will guide the approach, methodology and analysis throughout the thesis. In constructionism, reality is based on context, be that through social interactions and processes or through individual cognitive meanings. There exists an ambiguity in the use of constructionism or constructivism, which are separate but similar concepts. This ambiguity is discussed in detail in this chapter, as are the differences with other approaches, like positivism, as the journey to arrive at a constructionist approach is outlined by evaluating the foundations and development of each approach, which again adds context to those approaches. The constructionist approach allows to understand consanguinity in the context of the sociocultural experiences of the most relevant stakeholders, and the meaning they derive and apply to consanguinity within their daily lives. This constructionist approach is further embossed with theoretical underpinnings relevant to understanding consanguinity like theory of discourse, orientalism and representation of the other. The resultant approach will be constructionist in nature with refinement to remain relative to understanding consanguinity and will be applied throughout the methodology and analysis of this thesis.

2.2 Research Paradigms

Research by nature poses questions and then tries to answer or make sense of those questions. Social research in particular can lead one to question the very framework that holds together the basic understandings of the world and being. As Hughes and Sharrock (1997, p.7)

suggest, “We might be dreaming, deluded, blinded by personal prejudice or have learned cultural practices and beliefs that are false.” It is possible then to question and be sceptical about every truth that has come to be known, and to indeed question if there is any truth at all (Hughes and Sharrock, 1997). Truth must then be classified in terms of context, such as scientific facts and theories, religious beliefs, cultural practices and then have it encapsulated with time, as “truths” tend to change with time. In this research, an attempt will be made to re-evaluate the understandings of consanguinity without the influences of dominant views. It is important then, to set the foundation, the theoretical foundation that will guide this entire research process. While all research may seek to answer questions, the approaches differ, there may be a different ontology, way of understanding what is, and there are different epistemologies, ways of understanding what it is to know (Crotty, 1998), as well as different methodologies in how to go about looking at what one believes can be known? (Guba and Lincoln, 1998) These different approaches or paradigms or worldviews help shape the entire research design, in terms of the theoretical framework, methodology and research tools. So, before any “research” could begin, it first had to be situated in its worldview, given direction before broaching the subject of consanguinity.

Based on the ontological, epistemological and methodological differences, it can be said that there are four major worldviews which have then given rise to further paradigms moulded together by similar basic beliefs. Positivism has been described as the “received view” which had been at the forefront of scientific research for over 400 years (Guba and Lincoln, 1998). In the past century, criticisms about the rigidness of positivist views gave rise to postpositivism, which holds modified basic beliefs from positivism without perhaps going completely out of the realm of positivism. Also in the past century, alternative paradigms to positivism have evolved under

the blanket term of critical theory approach that has a more subjectivist epistemology. A further break from positivist approach in terms of ontological shift from realism to relativism is seen in the constructivism and interpretivism worldviews (Guba and Lincoln, 1998). As mentioned above, an in depth look will now be taken into these paradigms and their development into worldviews to see why the constructionist approach is the most appropriate for this research.

2.2.1 Positivism

Often synonymous with the *scientific approach*, the positivist worldview evolved from the European Age of Reason, the Enlightenment era in the seventeenth century (Hughes and Sharrock, 1997, Crotty, 1998). It is described as “the study of social reality utilizing (sic) the conceptual framework, the techniques of observation and measurement, the instruments of mathematical analysis, and the procedures of inference of the natural sciences” (Corbetta, 2003, p.13). The basic principle outlining positivism is that it strives to provide an unequivocal and precise knowledge of the world (Crotty, 1998). It presumes that research can conclude the true state of affairs (Guba and Lincoln, 1998). This worldview grew in stark contrast to the prevailing religious and theological views that dominated the supposed intellectual darkness of the Middle Ages toward a more scientific and secular vision (Hughes and Sharrock, 1997). However, it is from religion that one finds the derived meaning of positivism adopted by scientists. Posited in religion refers to that which is the divinely revealed truth and is a given, not to be questioned. Similarly, positive science is something that does not evolve out of speculation, but is rather based firmly, something that is posited, through direct experience (Crotty, 1998). While the roots of positivist thoughts can be traced to the debate between Bacon and Descartes about empiricism and rationalism to define the foundations of human knowledge be it in scientific ideas or mathematical principles (Hughes and Sharrock, 1997), it was Comte in the nineteenth century

who followed Bacon's empiricist ideals and is credited by some with coining the phrase positivist philosophy (Crotty, 1998, Corbetta, 2003). Comte is important also because he, seeing himself as a scientist, brought positivist ideology of observation, experimentation and comparison as a way to study social phenomena, seeing them as natural things subject to natural laws. The application of Comte's principles was done by Durkheim in the twentieth century, who accepted that social facts were not subject to human will and deterred human intervention, but they functioned like things in nature, according to their own rules and thus would have "deterministic structure that can be discovered through scientific research" (Corbetta, 2003, p.15). Although criticism of Durkheim's ideas point to the fact that he may have overdone the thing-like nature of social facts, some say it was his application of positivist thought that gave rise to social science (Hughes and Sharrock, 1997).

Still, positivist approaches are more suited to quantitative research rather than qualitative, and this study is more suited to qualitative research. From an ontological perspective alone, the positivist paradigm is not suitable due to its naïve realism, where the knowledge of the way things are is generalised, void of context and time and the research results are proclaimed as the true state of affairs (Guba and Lincoln, 1998). There are studies in the recent past that have looked at consanguinity in this manner, mostly clinical studies, but as stated before, it is the intent of this research to shed light on scientific facts and perceived realities, in contrast to positivism. There are further concerns about epistemological stance of dualism of the researcher and research subject and objectivism, as well as methodological insistence on experimentation that make the positivist paradigm unsuitable for this research, as there will be subjectivity in the derivation of meanings as experienced by stakeholders, including the researcher and there is also an absence of a hypothesis to defend.

2.2.2 Postpositivism

Positivist thought had dominated the world of science since the latter part of the millennium. However, criticism of its rigidity and absoluteness led to other schools of thought being developed mostly in the twentieth century. The first revisions of the positivist thought were from the minds at the Vienna Circle, in the form of logical positivism (or neopositivism). Central to logical positivism was the idea of verifiability, based on the precision of mathematics, now being applied to social sciences. This is important because while verification of analytical statements was simple through analysis of the subject, synthetic statements had to be verified through experience of sensed data, thus excluding philosophical thoughts, deemed cognitively meaningless (Crotty, 1998). This then led to the dismissal of broad theorisation in philosophy to focus on critical analysis of theory and paid attention instead to methodological problems in all science (Corbetta, 2003). One such problem arose when Bohr and Heisenberg questioned the uncertainty principle and absoluteness of positivism while studying subatomic particles, which could not be directly observed, leaving room for ambiguity and questioning objectivity in observation (Crotty, 1998). Popper, originally a member of the Vienna Circle, also started to question the inductive nature of positivism in making generalisations, where only a single occurrence of an observation of a phenomenon being slightly different than that proposed, can refute the assumption. Kuhn's further criticism of positivism is important for this research because it introduced the idea of scientific revolutions and paradigms, suggesting that scientists carry out experimentation based on a belief system, a paradigm, that has been established in their time, which becomes the normal science for that period, until a newer scientist comes not indoctrinated in this paradigm to revolutionise the views and cause a paradigm shift (Hughes and Sharrock, 1997, Crotty, 1998). Feyerabend too questioned the positivist thought based on his

belief of counterinduction that science itself was anarchist in nature and could not be held to current beliefs or limited based on social norms and practices (Hughes and Sharrock, 1997). Today, most clinical research on consanguinity posits a negative relationship with genetic disorders and disabilities, making it difficult to explore alternative points of view. However, this gradual reworking of the positivist approach, termed postpositivism, is inappropriate for this research as it ontologically adheres to critical realism. So, while admitting the imperfect nature of reality, in postpositivism a singular reality still does exist and is waiting to be discovered through theories and observations of the researcher as objectively as possible even if not perfectly apprehendable (Guba and Lincoln, 1998). This would be problematic for a research into consanguinity and its sociocultural impacts, as that would involve social relationships which have both subjectivity and relativity in the derivation of meaning.

2.2.3 Critical Theory

In the view of some thinkers of the twentieth century, postpositivism did not distance itself enough from the positivist approach to truly revolutionise or at least galvanise research strategy, and it certainly did not challenge the status quo to an extent that would produce actionable research. Critical theory is a worldview used to describe a number of alternative paradigms that have emerged as a result of a world deemed in need of reinterpretation post World War I, and the reinterpretation was provided by the Institute of Social Research and what became known as the Frankfurt School (Kincheloe and McLaren, 1998). However, it is key to note that the school of thought is a reinterpretation rather than a reinvention of existing thoughts, which means it is not critical for the sake of dismissiveness, rather it is critical to gain a deeper and perhaps better understanding. Still, being critical is to be political, and no criticism should be deemed value-free (Sim and Loon, 2004). Critical theorists found inspiration in the traditions of

Marx, Weber, Kant and Hegel, and the historical struggles for equality in social classes, as they confronted the injustices and suppressions they felt shaped the world around them. After relocation to America after the rise of Nazi Germany, the mostly Jewish Frankfurt School members like Horkheimer tackled American pragmatism and all philosophical views that did not question the status quo (Crotty, 1998). This would however be mentioning just one branch that evolved from the critical theory worldview, other important views besides the neo or post-Marxist nature of Adorno, Marcuse and Horkheimer would be the genealogical works of Nietzsche and Foucault, poststructuralist deconstruction of Derrida and critical reflections of Paulo Freire amongst others, as well as current critical theoretical movements such as postmodernism, postcolonialism, feminism and queer theory. It is not in the domain of this thesis to elaborate on each developing theory to come out of the critical theory worldview; instead, through this brief introduction, it is important to realise the impact and paradigm shift critical theorists have caused since postpositivism.

Critical theory as such would represent a unique paradigm, as it encompasses many different worldviews, although all critical of prevailing thoughts, it would seem a daunting task to summarise the concepts of a uniform critical theory. However, Guba and Lincoln (1998) have managed to break down the ontological, epistemological and methodological stances of critical theory worldview and its related ideologies, helping decide the appropriateness of this approach for this research. In critical theory, an apprehendable reality exists, albeit influenced by a historical interaction with social, political, economic and ethnic factors. While a subjectivist approach to knowledge through interaction between the researcher and subjects exists, it is the acknowledgement of an existent reality, even virtual, may put it at odds with the goal of this study to learn and perhaps build a relative understanding about consanguinity. However, the historical

realism notwithstanding, the dialectical nature of methodological inquiry that exists in critical theory promotes a transactional dialogue between researcher and participants, a feature conducive to this research. It is possible to take elements of individual concepts that have emerged from critical theory and utilise them in giving a critical lens to the overall design of this research.

2.3 Constructionism

In the introduction it was mentioned that a constructionist approach to understanding consanguinity will be taken in this thesis. Consanguinity will be seen not only as a medical and social phenomenon, rather it will be approached as a research into human beings, which involves sociocultural relationships and the development of those relationships and their elements through the historical context of power and domination within society and cultures along lines of class, race, gender etc. and includes the development of healthcare programmes and their response to consanguinity within that context. In order to achieve this in depth understanding, an in depth approach is required, which starts with constructionism and then is narrowed further into a constructivist-interpretive worldview with an underpinning of critical theory of discourse. After a brief description of other worldviews in the sections above and how they are not most suited to this research, a more detailed look will now be taken into the evolution of constructionism, its linkage to interpretivism and hermeneutics, ambiguity with constructivism and the resultant constructivist-interpretive paradigm.

Like most alternative paradigms, constructionism has a relatively recent history, dating back to only the middle to later parts of the past century and is perhaps still undergoing constant critical reinterpretations as positivism and postpositivism once endured. Crotty (1998, p.42) defines constructionism as a “view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between

human beings and their world, and developed and transmitted within an essentially social context.” Others have linked constructionism, constructivism and interpretivism together based on the common goal of understanding the complexities of lived experience from the perspective of those who live it (Schwandt, 1998). As the development of constructionism and interpretivism will show, different approaches within the same frame of worldview have developed as the paradigms have matured, much like the critical theory worldview has yielded a number of different approaches under the same umbrella principle.

Keeping in mind that constructionism and interpretivism evolved as alternative paradigms to the positivist approach, they share the critical approach to scientific objectivity and phenomenological subjectivity. If one were to look at the linear history of the development of these approaches, it would seem that interpretivism evolved first through the writings of Weber and constructionism can be seen as a refinement of this approach starting later perhaps with the works of Merleau-Ponty (Schwandt, 1998). On the other hand, one could see the co-development and intertwining of these approaches and the evolution of the constructivist-interpretive paradigm due to the similar critiques and ultimate goals and worldviews that they try to achieve. Both constructivists and interpretivists deliberate “on the processes by which (social) meanings are created, negotiated, sustained, and modified within a specific context of human action” (Schwandt, 1998, p.225).

This process of understanding human action to appreciate social reality in terms of intersubjective meanings is referred to as *Verstehen*, a concept highlighted by the work of Weber and Dilthey. However, the subjective phenomenological nature of *Verstehen* came under attack from neopositivists, who diminished its importance by claiming it to be but a mere process in the overall implementation of the empirical scientific process. It was to be used to generate a better

understood hypothesis alone, which would then require empirical testing to garner any valuable results. The proponents of this concept argued that it was more than a mere means of understanding a subject's state of mind, rather it was to gain a broader understanding of interactions and activities that constitute social life (Schwandt, 1998). Added input from Taylor's hermeneutical representation of the interpretive thought further developed this approach as a method of inquiry. Hermeneutics involves the theory and practice of critical exegesis, applied mainly in interpreting religious texts, legal proceedings and literary work (Smith, 2004). The obvious goal of hermeneutics was to attain a better understanding of texts, as such it developed interpretivism into an approach that engrossed itself in the subject to realise its context and conversely better understand the subject and the text. This has come to be defined as an interpretive or hermeneutic circle by Taylor and Heidegger (Schwandt, 1998, Crotty, 1998).

In the same disposition, another concept behind the development of the interpretive thought is the philosophy of pragmatism and the interpretive science of symbolic interactionism, both of which are common in the development of the constructionist thought. So then, before discussing pragmatism and symbolic interactionism, it is useful to look at the parallel development of the constructionist thought. Constructionism involves, as the word suggests, construction of meaning, as opposed to searching for a meaning that already exists. Merleau-Ponty is cited as saying that "the world and objects in the world are indeterminate. They may be pregnant with potential meaning, but actual meaning emerges only when consciousness engages with them" (Crotty, 1998, p.43). In constructionism, meanings are constructed by human beings as they connect with the world they are interpreting. As Crotty (1998) points out, constructionism mirrors the scholastic philosophy of intentionality, based on the ideas of Brentano and Husserl in the latter part of the twentieth century. According to them, all phenomena refer to a content and

are directed towards or at an object. Brentano (1973, p.88), as quoted in Crotty (1998, p.44), states that “in presentation something is presented, in judgment something is affirmed or denied, in love loved, in hate hated, in desire desired and so on.” The philosophy on intentionality uses intentionality as a connotation not for deliberation or intent, rather it refers to reaching out into, derived from the root of in-tend, as opposed to ex-tend, or reaching out from. This blurs the line between the subject and the object, and hence rejecting both objectivism and subjectivism in a sense, as it is the interaction between subject and object that constructs meaning.

Other concepts that have shaped the constructionist viewpoint include Fish’s contextualist theory and Lévi-Strauss’s idea of a researcher as a *bricoleur* (Crotty, 1998, Schwandt, 1998). Fish’s contextualist theory adds relativism to interpretation in the sense that reality is the result of the social processes that are deemed to be normal in specific contexts, and any claims or knowledge and facts to be ascertained from that reality must be done within that particular context of society (Crotty, 1998). The researcher as a *bricoleur* concept of Lévi-Strauss is interpreted differently by Denzin and Lincoln (1994) as suggested by Crotty (1998) than Crotty himself. While the former considers it to mean the researcher has to become a sort of jack of all trades in terms of how to approach subjects, the latter argues that the actual meaning refers to being able to make something out of the different subject positions. This then, he contends, is an invitation to reinterpretation (Crotty, 1998), while others have differentiated this individual cognitive reinterpretation as constructivism rather than constructionism (Gergen, 1999), which is believed to be closer to social constructionism (Young and Collin, 2004, Talja *et al.*, 2005).

Although an ambiguity remains in the use of constructivism and constructionism (Young and Collin, 2004), social constructionism can be seen as a linkage to the pragmatism seen in interpretivism. It is a less critical constructivist approach that derives meanings not from

individual minds, rather the world created by the social exchange between people, bringing the idea of culture into interpretation (Schwandt, 1998). It is in essence the meanings formed from a collection of the individual minds who view the world through lenses impressed upon them by the culture they reside in (Crotty, 1998). Moving away from the critical focus on individualistic meaning construction brought it closer to the general interpretive orientation towards exploring cultural meanings; and closer yet to the non-critical development of pragmatism that was on going in America post World War II. While pragmatism started out as a critical philosophy by Pierce that was a method of reflexion looking to clarify reality, it developed more into a general exploration of culture and its effects of social outcomes (Crotty, 1998). Critical theorists like Horkheimer have criticised these aspects of pragmatism as lacking critical analysis and being overly optimistic and painting culture in a progressivist vein. This leads one to the work of Mead, an associate of early pragmatist Dewey, and the development of symbolic interactionism.

Symbolic interactionism is somewhat a coming together of interpretive pragmatism and social constructionism. Mead's work was elaborated upon by Herbert Blumer and it is he who is credited with outlining the three basic assumptions of symbolic interactionism regarding meaning, communication and interpretive thought. The first principle states that humans act toward people and things based upon the meanings that they have given to those people or things. The second principle is that communication through language gives humans a means by which to negotiate meaning through symbols. The third principle of symbolic interactionism is that the meanings of these symbols are established and modified through an interpretive process (Blumer, 1969). However, symbolic interactionism is also criticised for its non-critical nature and bordering on positivistic naive realism as well as privileged approach towards "the other" (Denzin, 2001). Denzin's (2001) revision calls for an interpretive interactionism that enforces cultural criticism. In interpretive interactionism, Denzin has addressed the critical theorists' July 2013

concerns about realism and has gone on to look at how interacting individuals relate their lived experiences to the cultural beliefs about those experiences (Schwandt, 1998). When the concepts of interpretive interactionism are applied with the critical constructionist approach in building meaning, the resultant paradigm is what has come to be known as the constructivist-interpretive paradigm.

2.3.1 Constructivist-Interpretive Paradigm

The constructivist-interpretive paradigm “assumes a relativist ontology (there are multiple realities), a subjectivist epistemology (knower and respondent co-create understandings), and a naturalist (in the natural world) set of methodological procedures” (Denzin and Lincoln, 2005, p. 24). The three assumptions of the constructivist-interpretive paradigm described by Denzin and Lincoln (2005) above fit the model of this research; more specifically, it is the intended goal of this study to identify differing views of consanguinity, that is to develop a thorough understanding of consanguinity based on the analysis of literature as well as those acquired from the participants of the research, and have this study based not just on theory, but built upon the sociocultural experiences of those most closely relative to the consanguinity discourse, and the meaning they derive and apply to consanguinity within their daily context.

The constructivist-interpretive paradigm evolved from the philosophy of phenomenology and the interpretive understandings of hermeneutics and symbolic interactionism, as explained earlier, in which the lived experience and the importance of the researcher’s input and interpretation of events is held important (Mertens, 2009). There is more responsibility on the researcher to narrow the multiple subjective views of the participants into meaningful ideas that stay true to the intended meanings and lived experiences (Creswell, 2009). Hence it is important for the constructivist-interpretive researcher to gain the appropriate context in which those lived

experiences are either recorded in history or are being described by participants.

This is why it is important to ask the question when and how did consanguinity become the norm for some and a taboo for others around the world? In order to gain a better understanding of this method of thinking, and to apply a critical lens to the overall approach as suggested earlier, a closer look needs to be taken at Foucault's theory of discourse, the concept of power relationships in the sociocultural context through history and the emergence of Orientalism, all of which can perhaps be classified as critical theory but include elements that also make them part of the constructionist worldview. It is important to state though that the concepts rather than the label given to them are important in application for this research. For example, even though the paradigm being followed is a constructivist-interpretive paradigm, it has roots in the generic form of constructionism. However, if broken down epistemologically, the constructivist-interpretive paradigm in this research will involve both social constructionism of the participants in deriving their meanings through sociocultural interactions and the constructivism of the researcher in applying individual cognitive processes to apply an interpretation to those meanings. Hence, calling it an overall constructionist approach is adequate, but there is no ambiguity in the concepts being applied as explained above. Similar ambiguity also exists in the use of discourse as an analytical tool or as a theory about the derivation of knowledge, which is more in line with the constructionist views of Foucault, as explained next in applying a further critical lens to the constructivist-interpretive paradigm.

2.4 Discourse and Knowledge

One of the many branches that evolved out of the critical theory worldview was structuralism and then later poststructuralism. In brief, structuralism looks at the underlying foundations of a culture or phenomenon. It is based on the belief that there lay essential elements

which make up a culture and that can help define and understand that culture. Whereas, poststructuralism is critical of the idea that there must exist essential elements that may be unbiased in their formation or in their discovery through analysis of the researcher. One famous poststructuralist that helped shape this critical view was Michel Foucault, although he would not have limited his thoughts and reach by labelling himself as such (Eribon, 1991). Classifications aside, Foucault's philosophy put the focus on language, or discourse as he referred to it, at the centre of this idea of bias in and around underlying elements of culture and phenomena (Hughes and Sharrock, 1997).

In common language, discourse refers to passages of rational speech or debate. Foucault's use of discourse differed in that he used it to describe "a group of statements which provide a language for talking about – a way of representing the knowledge about – a particular topic at a particular historical moment" (Hall, 2001, p.72). So, for Foucault, discourse is about the use of language to formulate knowledge. Discourse is shown to be a multifaceted structure governed almost by a doctrine that directs it in terms of what to talk of, how to talk of it, and who can and cannot talk about it (Hughes and Sharrock, 1997). In fact, these separate statements, the so called doctrine that drives a discourse, work together to formulate a singular dominant opinion or propagate, develop and represent an idea and a way of thinking about the idea, which Foucault referred to as *discursive formation* (Hall, 1992). A discursive formation need not contain similar statements of agreement, but the dispute between them, the conflict of ideas must maintain regularity, a system of dispersion that defines the discourse. It is through discursive formations which are linked to historical moments and developments, power relations, that a discourse discerns itself in particular relations (LeCourt, 2004). Foucault argues that it is these discourses that have moulded and formed meaning systems that have gone on to be known as truths or

representative of the truth. These representation in turn define the social norm and marginalise alternative discourses, and give rise to sociocultural relationships of power, dominance and hegemony.

Once a discourse is formed, it can go on to build upon elements of other discourses. Moreover, others that want to deploy a discourse, must become a subject of the discourse, even if they do not believe in its meaning or reality (Hall and Gieben, 1992). An example of this in relation to this study would be to only discuss the psychological theories of incest-taboo and natural aversion in relation to consanguinity, even though the negative connotations associated with incest and aversion in society would lead to maligning and polarising the consanguinity phenomenon further, before any analysis is even done, which is contrary to constructionist approach. However, those polarising words must be used in order to discuss the discourse as it stands today, and hence it is important to realise Foucault's ideas of discourse and discursive formation, and locate perspective and context behind existent ideologies on consanguinity.

It is however not always easy to identify influenced ideologies, especially in the sociocultural realm that has already passed, for truths can be construed and reality can be formed based on the language or discourse that was deemed superior at that moment in history. This then adds another dimension to the theory of discourse, that of power and its influence over discourse and popular beliefs (Hall and Gieben, 1992). Some critics of Foucault and his approach to (theory) discourse have singled out Foucault's perceived notion that nothing exists outside of discourse. However, it is not that Foucault denies existence of real things in the natural world; in fact, it is his notion that no meaning can be drawn from such a reality without discourse. That is to state, as mentioned earlier, differentiation between reality and perceived reality. While Laclau and Mouffe have since developed discourse theory further, elements of Foucault's views

on power and its influence on derivation of knowledge through discourse have been retained, which is in slight contrast to critical discourse analysis (CDA) of Fairclough and van Dijk, where discourse is not only constituted but can also constitute power and truths through linguistics (Jørgensen and Phillips, 2002). This then presents an epistemological shift from Foucault's reluctance in substituting one 'truth' for another in his approach to discourse, to the poststructuralist CDA argument that analysis of linguistics will constitute an interpretive standpoint which can then influence future social interactions (Graham, 2005, Wetherell *et al.*, 2001). This can possibly be seen as locating a theory to define consanguinity, whereas the approach in this research is to understand and present existent meanings of consanguinity within the sociocultural context without declaring any interpretations as a dominant or novel theory of consanguinity. Applying the Foucauldian theory of discourse thus, is like entering into debates about the foundation of knowledge, how it is built up, and one's own subjectivity is then constructed whilst grasping social interactions (Wetherell *et al.*, 2001). This moulds well into the overall constructivist-interpretive paradigm, while adding critical elements like power relationships and the representation of the 'Other'.

2.5 Power Relations and the rise of the West

Discourse, in Foucauldian terms, acknowledges the existence of power relationships in the world, culture and society, not only in the present, but throughout history, which have shaped the meaning of reality as known then and as known today. This power has been crucial in the formation of modern society and what it deems as knowledge through an institutional apparatus and its techniques (Hall, 2001). This apparatus could include everything from philosophical and scientific propositions to laws and regulations. This critical approach to society by Foucault drew parallels with Marxist views on ideology and class issues and identification hidden in forms of

knowledge. However, Foucault's concerns were not focused on class differences and discovery of alternative truths like Marxism, instead he focused on the interplay between power and knowledge formation as well as conceptions about what power actually means (Hall, 2001).

Foucault uses the interplay between power and knowledge to locate hidden influences. While focusing on this interplay, more importance is given to finding these influences than any absolute facts, ones that remain true no matter the context, time, or place. It is this notion that by locating influences, absolute facts may well have become apparent themselves. However, it starts with the idea of knowledge as power. Power is more than brute force and oppression or rule over those that are in weaker positions; it is evident in more subtle things like knowledge and culture. "Knowledge when linked to power, not only assumes the authority of 'the truth' but has the power to make itself true" (Hall, 2001, p.76). This is not to say that an opposing view or knowledge does not exist.

According to Alasdair MacIntyre (1988), as cited in LeCourt (2004), within any historical moment, there may be multiple traditions of thought, where one can be dominant, another marginalised and yet another that perhaps may be in crisis. However, when speaking of and within these traditions, one must take a stand that goes for the tradition or against the tradition, which then puts one on either side of the fence dividing right and wrong. This according to Foucault is where knowledge laden with power can be crucial, in deciding which tradition gets known as right and which becomes wrong. This new "right" is the truth, but it is an influenced production rather than the absolute fact, the truth that is based on discursive formations maintaining a regime of truth (Hall, 2001). Regimes of truth exist in every society, that is to say they have accepted discourses that function as being true, and it is through these mechanisms that one distinguishes between true and false and establishes the position of those that can decide what

counts as being true (Foucault 1980, as cited in Hall, 2001, p.77).

Another notion brought forth by Foucault that distinguishes his views from classical Marxism is the idea of power as being other than just a linear force brought down from a position of authority. He argues instead that power relations are more circular in nature and that everyone from top to bottom and from bottom to top contribute to the flow of power, and in effect knowledge. Power relations filter through every level of society and power is not only repressive but it is also productive (Hall, 2001). For example, an attempt to curb youth smoking can produce a number of discourses ranging from regulation of advertisement, rise in value of nicotine substitutes, magazine articles and publications, television and radio shows, mobilisation of freedom and youth activists, public health campaigns and dinner table discussions and arguments. One can use the same example in terms of consanguinity, where if it becomes accepted as a negative influence on healthcare then it too can be regulated, or limited through advertisements, programmes, articles and publications, as well as dominate lay discussions, and by some accounts (Ahmad and Bradby, 2007, Darr *et al.*, 2013), this is already happening, but is the negative derivation of meaning accurate? This then is power circulation from very public to much localised levels, something Foucault refers to as the micro-physics of power. It is not to the intention to deny the dominating nature of power wielded by those in authority, but there exist micro level of society through which power circulates (Hall, 2001). This revelation of power, hidden in plain sight, shows the depth of the impact that discourse, power and knowledge can have on everyday life.

Going back to the more common visions of power, that of dominance over another and the feeling of self-worth, and keeping in mind the earlier discussed idea of traditions and the dominance of certain traditions over others in different periods of history, a look into current

dominant traditions and their evolution through recent history will be useful in seeing the underlying elements that form current “realities”. Without a doubt, the most dominant culture currently is that of the West. But what truly constitutes the West? It is certainly not geographically inclusive, because countries like Japan and Australia could be considered part of the Western culture, but they are quite clearly in the Eastern hemisphere. Similarly, what about Eastern Europe, is it part of the West, by being in close proximity to other European nations that are part of the West? This is a debatable point and can undoubtedly lead to discussions about political alignments that have evolved in the past century. However, it is the political and ideological alignment of the past few hundred years that has given rise to the idea of the West rather than any geographical location. The West then, has come to be defined as an industrialised, secular, capitalist and modern society (Hall, 1992). It is a discourse in its own right, and as such, it has discursive formations.

Hall (1992) describes the progression of this discourse in postcolonial terms of the expansion of Europe, through exploration and colonisation, increasing its power gradually in the world. Five main phases of European expansion and dominance are defined, starting with the early exploration where new worlds were *discovered*, new only because they were being *discovered* for the first time by Europeans. This was followed by early contact and conquests of these lands and then trading and annexing of the lands as possessions and later laying the seeds for settlement. The next phase was the permanent settlements of Europeans in these new worlds through colonialism and the beginning of capitalist voracity, stripping the new lands of their natural resources for profit. The penultimate phase is described as the peak of Imperialism and a mad grasp of available land leading up to the First World War. The final phase is how the world stands today, where the West is the economic giant of the world, a world that is now independent

and no longer colonised, yet still dependent and marginalised (Hall, 1992, p.282-283).

2.5.1 West and the Rest

A few important factors in the early phases described above are seen as events that have helped shape the European identity and thus the dominant view. One of these factors was the unification under the banner of Christendom to tackle both the social barrier posed by the rapid expansion of Islam in the latter part of the first millennium and the physical barrier posed by Muslim lands controlling key trade routes to the East. Another important development was the apparent break from Christianity towards a more secular identity, and the evolution of “Europeans” which then lead to the age of colonisation. However, true secularism was hardly achieved as encounters with other worlds only emphasised further the differences that existed between their cultures, including religion, leading to an increased sense of superiority and an ethnocentric, rather Eurocentric view of the world (Hall, 1992). Through this vision, a regime of truth was established, an effective discourse if not necessarily the truth, fully aided by rules, statements, behaviour and actions that constituted its discursive formation.

The West has become a culture of its own (Hahn and Inhorn, 2009), mostly by differentiating itself from other groups of people that were unlike them. So, to find a suitable opposite for the West, most would look to the East. However, since the West has been established here as a non-geographical entity, Hall (1992) defines the two sides as West and the Rest. Since, a discourse is constituted by dominating views, the statements, images and ideas that have come to be classified as belonging either to the West or the Rest, clearly show the scales of power are heavily in favour of the West. In a simple play of word association, Hall (1992) has shown both the polarising nature and the power dominance by one group in this discourse. The words and images associated with the West and all things Western start with developed and urban, whereas

the complete opposites are associated with anything non-western, like non-industrial, rural and under-developed. This discourse is further built upon with further polarising word association that shows the progressively increasing power of the idea of the West. The West and western have now come to imply not only developed, but good and desirable, with the non-west the opposite in being undesirable. A new and accepted form of knowledge and ideology has been created through this discourse, one that has come to clearly define the West in association to the Rest, the others.

2.6 Representing the Other

As has been alluded to earlier, the concept of the Other plays an important role in terms of identifying your own self and in the preceding context, in identifying the Western culture and the rise of the West. Continuing on with reference to the work of Stuart Hall (1991, p.16), as cited by Fine (1998, p.133), in his description of the Other, which he states is critical in forming an identity through the relationship between one's self and the Other; "only when there is an Other can you know who you are." According to Hall, racism is in fact a discourse that was created by exclusion of the Other, putting the Other away, out in the Third World. In the process of identifying its own cultures, the Eurocentric vision has come to define the Other as almost ahistorical and without a real culture, the Other is rather reduced to the images seen through the colonial lens (Giroux, 1991).

This vision of the Other is not created through the brute force authoritative power of a colonial master, but the version of power Foucault introduced (as discussed earlier), the circle of power and knowledge distribution that circulates a discourse from macro to micro societies and culture. It has been created through writings of Keynes or Friedman, policies and statements of the World Bank and the International Monetary Fund, and public debates and dinner table

discussions, all of which according to Inden (2000) act as hegemonic agents, or as Foucault might have called elements of the discursive formation behind the discourse of the Other. Examples of representation of the Other hidden in scholarly texts is seen in ethnographic studies that in maintaining objective distance fail to engage authentically and result in works describing the Other as a people that are amenable to domination or were potentially a great labour pool. These attempts to “capture” the other only result in advancing the prevailing discourse (Fine, 1998, p. 137).

2.6.1 Orientalism

One such advancement of this discourse is the idea of Orientalism, coined as such by Edward Said (1995), describing the discourses and traditions that developed an ‘other’ object to gain knowledge of, “the Orient”(Hall, 1992). Said (1995) further describes Orientalism as a method of rationalising the Orient as an exotic place in Eurocentric experiences. “The Orient is not only adjacent to Europe; it is also the place of Europe’s greatest and richest and oldest colonies, the source of its civilisations and languages, its cultural contestant, and one of its deepest and most recurring images of the Other” (Said, 1995, p.1). In Said’s (1995) description of the Orient, it is not necessarily the land and the people, it is instead the representation and objectification of the land and the people by those Western powers and institutions anointed as an authority on the subject to disseminate the true knowledge to the rest of the West and that too through a Western power with a Western consciousness. It is this image of the Orient, that which is alien and perhaps beneath, but definitely far removed and different than the West, an image of the Other, which constitutes Orientalism, the Orient as presented to the West.

Orientalism, is in fact, “a manner of regularized (or Orientalised) writing, vision, and study, dominated by imperatives, perspectives, and ideological biases ostensibly suited to the

Orient” (Said, 1995, p.202). This description of Orientalism closely resembles the discursive formation that surrounds and constitutes a discourse according to Foucault. The Other that is represented by Orientalism is the Oriental, a dehumanised stereotype that fits into the Eurocentric perspective of all that is deviant, everything that the European is not. When any specifics are presented about the Oriental, they seem to be contradicting generalisations of a male being a weak person yet strangely a viable threat to the Western women, and the female Oriental is ostracised, credulous and exotic (Said, 1995). Said (1995) explains the Orientalist discourse in terms of how the Middle East, Arabs and Muslims in general have come to be known, especially through the eyes of the French writers. Yet it is the audacious and blatant denationalisation and unification of the masses into singular opposites on either side of the Oriental discourse that is the most criticised. This singular representation of a large part of the World that was *different* than the Europeans, a representation void of any culture and meaning true to the many nations and peoples that populated these lands, instead replaced by an image that was only dominated by stereotypical differences, is the knowledge backed by power that has become engrained in the world over the last few centuries. It has also been a sort of coming of age in the formation of the Western identity, the other side of the discourse.

Critics of Orientalism and of Said in particular have taken issue with his harsh stance of generalising the racist elements in Orientalism to everyone who has ever written of the *Orient* during and since colonialism (Irwin, 2008). Moreover, othering is not a uniquely Western attribute, as the opposing view of Occidentalism, as highlighted by Buruma and Margalit (2004), exists to dehumanise the Western world. However, Occidentalism has been used to differentiate but also learn from Western ideals of modernity to develop non-Western ideals (Bonnett, 2004), which has been a positive deployment rather than the negativity apparent in Orientalism. This

characterisation may in fact make it impossible for anyone to write anything about the legitimate differences that do exist between civilisations and the need to study and intellectually understand and appreciate such differences (Crotty, 1998). However, the essence of Orientalism is to realise the existence of such a discourse and to be able to critically appraise fact from fiction. It is appropriate to talk of differences between cultures, so long as each culture is given its due share in terms of deep understanding rather than broad generalisations and stereotypes present in ethnocentric representations, leading back to the idea of categories as discussed in chapter 1 (section 1.3). In denying Orientalism altogether, certain critics have fallen prey to the power of such discourses, where the dominant view is the only view and that anyone or anything that distances itself from that view is going against the norm.

While elements of racism in Orientalism may be controversial for some, it is hard to deny its existence given the expansion of its elements in works since it was published. One such element takes on the issue of the Oriental that is from within, the immigrant imaginary, another form of representing, interacting with and handling of the Other. The inside Other, from a Eurocentric perspective, is a non-white (mostly) person in the West, who may have moved to the West, or was born in the West, or has been in the West long enough to not know that he or she is not *from* the West. However, to the West, he or she is either fully integrated, in the process of being integrated or a foreigner completely to the way of Western life and culture. “The discourse of the immigrant imaginary which explicitly or implicitly provides a lexicon through which ethnicised minorities are managed, through which their foreignness is domesticated but not eradicated” (Sayyid, 2004, p.148). The immigrant imaginary is a realisation and an expansion of the Orientalist discourse and representation of the Other, made more relevant for those minority groups living in the West as inside Others, such as the British Pakistanis.

2.6 Summary

In this chapter, a conceptual framework has been laid out for the approach to be taken in this thesis to understand consanguinity. While the overall approach is constructionist in essence, it has been refined by critical theories that are analogous and complementary. The overall approach is shown in Figure 2.1, which includes the methodology applied in later chapters, which remain

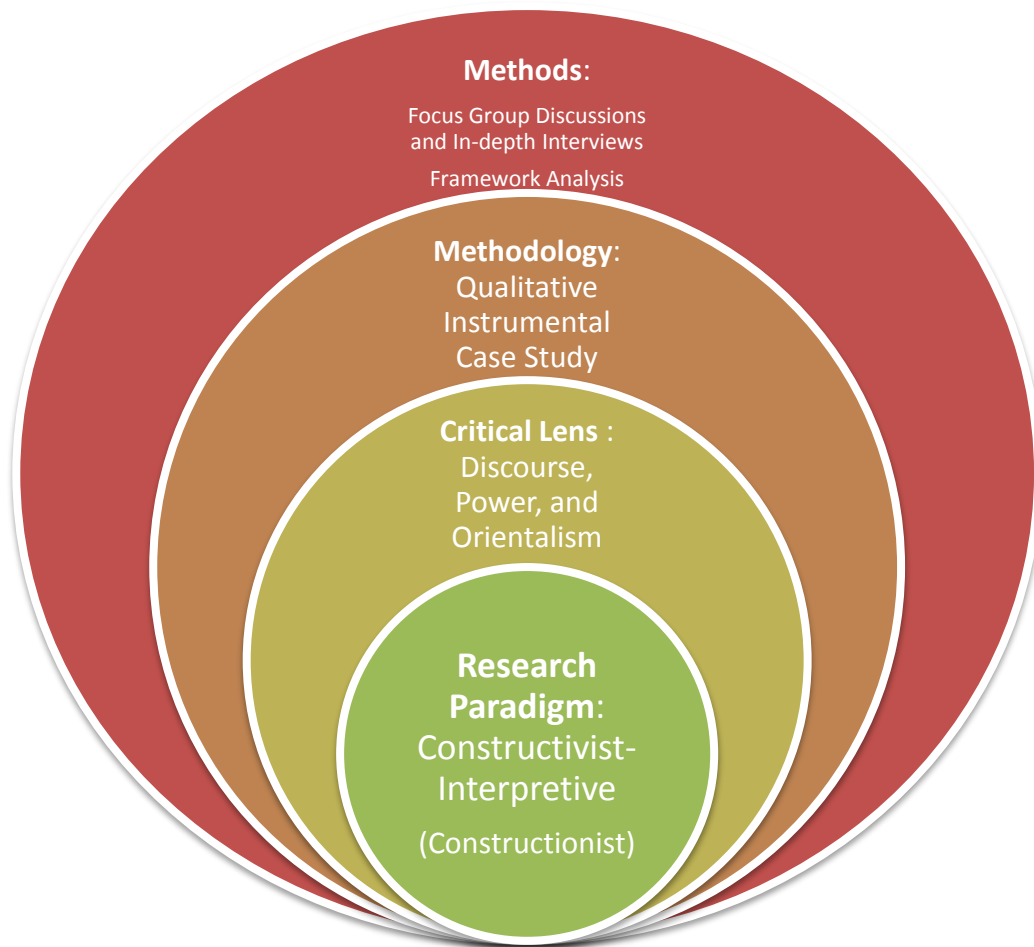


Figure 2.1 – Conceptual Framework – Conceptual framework showing the constructionist core with added layer of critical theories of discourse, power and orientalism that will guide the qualitative instrumental case study methodology and filter through to the data collection with focus group discussions and in-depth interviews, followed by framework analysis of the data. (Read Bottom to Top)

true to the core approach. This was exemplified in this chapter by describing other research paradigms through their respective developments, how they were not necessarily appropriate for a research looking into understanding consanguinity by contextualising its perceived impacts

through sociocultural elements. The constructivist interpretive paradigm, which evolved from the philosophy of phenomenology and the interpretive understandings of hermeneutics and symbolic interactionism was deemed most appropriate as an approach for this research. This approach will allow the understanding of consanguinity through not only the theories in literature but through the experiential understandings of people who are most relevant in the sociocultural context. The critical theories of knowledge through discourse and power relationships, and that of orientalism and representation of the other will allow the researcher to interpret the findings whilst understanding the influences that may have played a role on those findings. The overall approach is complementary to the constructionist school of thought. In the following chapters, this critical approach will be applied to every aspect of this research, from decoding theoretical and historical understandings of consanguinity to the methods used to collect information from study participants and to the analytical interpretation of those findings. The constructivist-interpretive paradigm, the theory of discourse, knowledge and power, using a qualitative design and an instrumental case study rather than an intrinsic case study (as discussed later in chapter 4, section 4.4); all reinforce the exploratory nature of this study, open to understanding different points of view, but one that is laden in critical analysis rather than latent naiveté. The result will be to construct a comprehensive understanding of consanguinity and through its sociocultural and healthcare impacts.

CHAPTER 3 – CONSTRUCTING CONSANGUINITY

3.1 Introduction

The focus in this chapter will be to apply the conceptual framework in examining the current understandings of consanguinity and how they have evolved over time. The basis of a constructionist approach, especially one with critical concepts of discourse, power and knowledge as a guide, calls for an understanding of consanguinity which recognises the influences over time that may have shaped the majority narratives on consanguinity and bares these influences to allow an impartial view to be developed. However, as suggested previously, the intent is not to find an origin or to define a new theory, it is merely to recognise the complexities behind presented or constructed realities (Graham, 2005). The ideas of consanguinity today are divisive, where popular narratives consider it a synonym for cousin marriage, but also deem it relative to incest, inbreeding, and forced marriage; while others may consider it as a genetic opportunity, a means to stability, family continuity, and inheritance retention. In this chapter, a genealogy of current understandings of consanguinity will be presented by examining and contextualising the major areas of knowledge which have shaped these understandings. These areas include firstly the anthropological and psychological (“anthro-psychological”) theories that have attempted to explain and predict consanguinity as a phenomenon; secondly, the knowledge of genetics as a science and development as a healthcare service that has become most relevant in both researching and treating some of the health impacts associated with consanguinity; and lastly, the sociocultural elements that constitute the understanding of consanguinity as a cultural practice. However, before examining these interpretations, it is important to briefly explain how Foucauldian concepts, discussed in the previous chapter, will be applied here, and this will first begin with the discussion on the absence of an ultimate truth or a protocol for conducting a genealogy.

3.2 A Genealogy of Consanguinity

In the words of Rorty, truth is but a creation based on the language applied to describing it, and thus believed in the plurality of standpoints (Davidson, 1984, Rorty, 1998). Truth could be existentialist and what man makes of it; it could be Cartesian or positivist or empiricist or experientialist and depend on physical observation of events; it could be nihilist and not exist at all; it could be fatalist and will occur no matter what; it could be pragmatist and be what you and others have come to make of it through repeat occurrences; or it could be Kantian and not comprehensible fully due to limits of space and time but is formable based on theory (Craig, 2005). This may not be a precise representation of the idea of truth according to each school of thought, and admittedly, the grouping of some schools of thought together as well as not including others can raise heated debates, but it is essentially a glimpse into the possible standpoints that exist or supposedly exist. Foucault has been criticised for his possibly simplistic approach in censuring existing theories. Taylor (1986) has suggested that Foucault's deconstruction of theories in light of the influence of power represents yet another truth in itself, Foucault's truth, and he questions why that should be superior to others? Foucault himself may have resisted in making such a claim about truth, hence the difference in his approach to discourse as opposed to critical discourse analysis, as explained in the previous chapter. It is, however, inevitable that the result of this research will present a viewpoint based on the findings, but this is not a dualist agenda of the research or a purposive inclination towards a relational relativity, as it is the stated objective to construct an understanding of consanguinity based on the experiences of its participants as well as current and previous research in the field, and the conceptual framework suggests to do this without privileging it as an ultimate truth or a novel theory.

This framework questions the dominant discourse on consanguinity, due to influenced realities, discursivities that have come to shape lives (Hall, 2001). Understanding that these

influences may have caused a distorted representation of the past, Foucault developed the tools of archaeology (to locate discursivities) and genealogy (to analyse the 'knowledge' presented) to develop a type of discourse analysis that attempts to impartially study or appreciate history (Kendall and Wickham, 1999). However, Foucault did not identify a specific protocol to follow in conducting a genealogy. It has been said (Graham, 2005, Diaz-Bone *et al.*, 2007) that Foucault defined his epistemological stance in *The Order of Things* (1970) and gave it methodological shape in *The Archaeology of Knowledge* (1972), however, a step-by-step approach is not only non-existent (Kendall and Wickham, 1999) but quite contrary to his ideas (Graham, 2005). This ambiguity has been criticised by some as being inaccessible and exclusionary (O'Farrell, 2005), while some have embraced the ambiguity and attempted to evolve novel methodologies from it (Harwood, 2000), and yet others have explained the lack of a well-defined methodology to Foucault's reluctance on making a proclamation, because it would just be yet another interpretation, rather than focusing on the intentions behind Foucauldian methods, which is to learn things about the current understandings that perhaps have been overshadowed either systematically or fortuitously (Graham, 2005, Kendall and Wickham, 1999). Moreover, conducting a comprehensive genealogy of a subject matter cannot always encompass everything possibly linked to the subject and the result is still not always bereft of personal interpretation, and same will be the case with this research, but acknowledging such limitations is the first step in undertaking a Foucauldian analysis.

The goal here is not to chart an origin for consanguinity; but within the context of this research and the discourse of consanguinity, there exist concepts that are used to examine, explain or understand consanguinity. These concepts may carry different weight depending on the school of thought, as discussed earlier, but their existence comes from various sources, including current research in the field, historical texts, historic and current laws, as well as religious and cultural beliefs, which can be up for debate in an academic sense as to their historic validity, but are used here because there is no doubt in the impact they have had on people's lives. In brief, to understand

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the discourse around consanguinity, this chapter takes a genealogical approach to examine the existing literature of the areas of knowledge that have shaped current understandings of consanguinity, as represented in Figure 3.1.

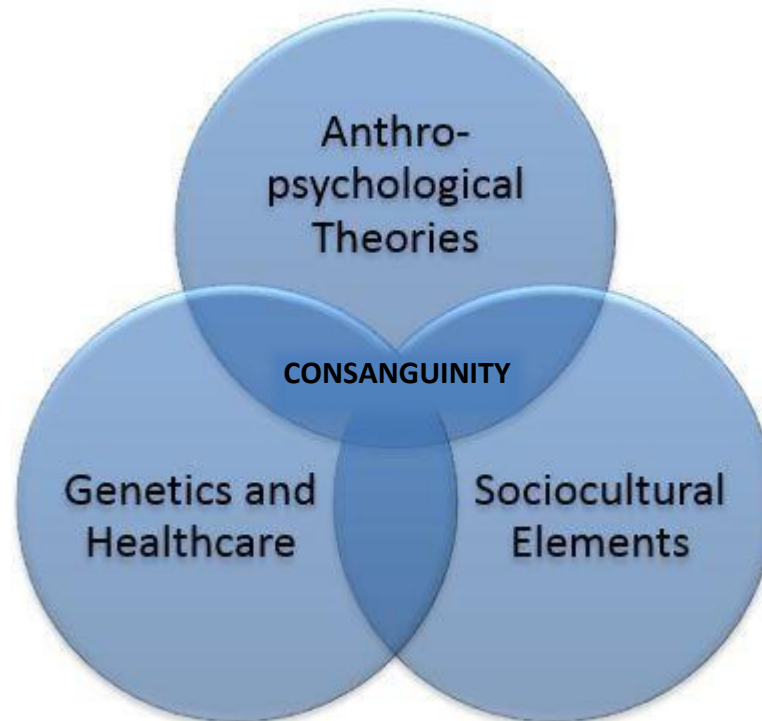


Figure 3.1 Current Understandings of Consanguinity - This figure represents the areas of knowledge that have shaped the current understandings of consanguinity

3.3 Anthro-psychological Theories

There have been attempts to understand, describe and ultimately theorise consanguinity over the years as both a social phenomenon and a health predicament. Most of these theories have evolved and intensified in literature in parallel with advancements in the social or natural sciences in the latter part of the millennium, like those from anthropology and psychology, which in turn were sometimes influenced by developments in religion. As such, the definition of consanguinity, or the bounds of consanguinity, has been debated within these disciplines, sometimes based on religious understandings. Although, in the introduction, the WHO definition was presented, as the union between close kin who are second cousins or closer (Bennett *et al.*, 2002, Bittles, 2008,

Hamamy *et al.*, 2011, Hoodfar and Teebi, 1996), the debate lies in the unstated but insinuated relations in this definition. For example, the Canon Law in Catholicism will disagree with the definition as being too lenient depending on the interpretation used to define degrees of relationship, either Roman or German (Brown, 1939), and the Aryan Hindus of North India would oppose of the definition on the similar grounds (Bittles, 2001, Kapadia, 1958). However, many others would oppose the inclusion of relationships such as brother-sister, parent-child, or uncle- niece in this same definition of consanguinity, as they primarily consider it as cousin marriage. The inclusion of relationships that are generally considered as incest can be problematic as a majority of the world's consanguineous population, and certainly in the UK, are married to their cousins; moreover, incest is not only taboo in these cultures, it is religiously prohibited as well. Perhaps it is the inclusion of these relationships that has led popular culture today to label all consanguineous relationships as incestuous, but certainly, adding incestuous relationships in this debate has made it more complex (Bennett *et al.*, 2002, Bixler, 1983, Roberts, 1967).

Although the incest taboo has existed for centuries, the relation to consanguinity evolved from the rise of Christianity and the letter by Pope Gregory to the first Archbishop of Canterbury banning consanguineous unions without special decree on the implied basis that it is incestuous (Bittles, 2009), and then given theological relevance in the work of Thomas Aquinas and his influential *Summa Theologica* in the thirteenth century (Goody, 1983). However, the reason behind this link and the subsequent ban imposed by the Pope is not quite clear. The instructions in the Bible outlined in the Book of Leviticus clearly outline the forbidden sexual (marital) relationships (Bittles, 2009, Goody, 1983, Shaw, 2009, Ottenheimer, 1996), yet Pope Gregory, in introducing a new law, cited only the first line, in which it is forbidden to uncover the nakedness of kin, and added a proclamation that the offspring of such unions cannot thrive. The reasons outlined in *Summa Theologica* seem to suggest that it was due to moral (for due respect to near ones), social (to promote out-marriage and prevent closed communities) and physiological reasons (fertility of the mother

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and health of the children) that such a distinction was made (Goody, 1983, p. 57). Considering that Thomas Aquinas was providing reasons for religious beliefs which can be controversial, especially since one of the leading figures of the Bible, Abraham himself was, by some accounts, married to his half-sister (Firestone, 1993), another possibly less contentious reasoning may be that Pope Gregory was in the midst of distancing Christianity from its Roman and Mediterranean roots. Indeed the Pope had stated that such unions only came into being because they were introduced by the pagans and Romans. In reality, the Romans were themselves confused in their allowance of such unions as laws existed preventing consanguineous unions yet they were applied and changed many times in the fourth and the fifth centuries (Goody, 1983). Another reason perhaps was the monetary compensation the Church received as dispensation for allowance of such forbidden unions, which may have further helped the establishment of the Church (Bittles, 2009, Ottenheimer, 1996). The link then, between incestuous unions and consanguineous unions turned from the word of the Pope to the word of the Bible, and later expanded¹ the ban to further degrees of relatedness and even to affinal relations through marriage (Goody, 1983, Ottenheimer, 1996). The Church of England also defined forbidden marriages in 1560 through its Table of Kindred & Affinity, which included certain affinal relationships, but removed in the revised in the twentieth century and remain as such in the last revised version of 1969 (Davis, 2011). This list, customarily found on the back of the Anglican Book of Common Prayer and displayed in all Anglican Churches however, does not forbid marriages between cousins, in one of its many departures from the Catholic Church.

¹ The differences in methods of determining degrees of relationship meant that first cousins were deemed to be second degree relatives under the Canonical Method (Roman), but were fourth degree relatives under the Civil Method (German). To avoid further confusions, Pope Innocent III placed restrictions on all relationships between third cousins or closer in 1215. Furthermore, the banning of marriages between affinal relatives was justified using scientific reasoning suggesting that marriage was like adjoining of the flesh into one and that somehow there was a physiological change that took place after marriage making the husband and wife as one blood. Hence, any affinal relative now would be considered a blood relative. And that marriage between such blood relatives was immoral to the sanctity of marriage.

Martin Ottenheimer, M. 1996. *Forbidden relatives : the American myth of cousin marriage*, Champaign, University of Illinois Press., 1996).

The link of incest with consanguinity is conceivably linked closely to the development of psychoanalysis and anthropology in the nineteenth century (Ember and Ember, 1983). Perhaps the answer lies in the apparent need for science to define a social phenomenon such as kinship and consanguinity, to find method and reason behind observable yet undefined events, so much so that science itself has been called a social phenomenon (Gould, 1996). These new sciences of the nineteenth century, much like the Church earlier, were in the midst of being established, so not only theorising but almost quantifying social phenomena was necessary to legitimise them, a slow progression away from positivism, as previously discussed. This need has perhaps been the seemingly unconscious basis of tables such as the Sequential and Knot systems from familial studies (Højrup, 1996) and the co-efficients of inbreeding and relatedness (Woods *et al.*, 2006, Bittles, 2010a), some of which while representing useful scientific measurements have also associated unconstructive words like inbreeding when studying consanguinity (Bittles, 2012), and whether intended or not, it only adds to the overall discursive formation informing consanguinity, one which equates it to inbreeding and incest. This interplay between nature and nurture and society and culture formed the basis of Levi-Strauss' take on the incest taboo in the *Elementary Structures of Kinship* (1947), in which he declares it a universal reality in *nature*; however his reasoning is based on the fact that most *cultures* are against incestuous relationships (Parker, 1976). Westermarck in his late nineteenth century work *The History of Human Marriage* (1891) meticulously outlined the marriage patterns of different cultures throughout history, and pointed to the fact that barring a few exceptions, most cultures avoided incestuous relationships and labelled it a natural evolution that did not exist in other species. Although this may have simply been a prelude to his theory of Natural Aversion that states people that are raised together develop a natural sexual aversion to each other, which makes no mention of relatedness rather points only to close quarters, and has come to be known as the Westermarck effect (Walter and Buyske, 2003). This theory of course was in direct contrast to that of Freud, one of the fathers of psychology and psychoanalysis. Freud argued that in

fact it was in the nature of close relatives to develop sexual feelings for each other, for example the Oedipus Complex where a son may develop feelings for his mother, and that it was culture that had to step in and create an incest taboo (Spain, 1987, Parker, 1976). Despite coming from different schools of thought, and arguing over the origin of the incest taboo, the works of Freud and Westermarck established a truth - that an incest taboo existed (Walter, 1990, Fraley and Marks, 2010). There have been works arguing both for (Shepher, 1971) and against (Walter, 1990) their theories, but few would question the existence of the taboo and its expansion in application to consanguinity (Bixler, 1983).

While Pope Gregory chose to cite the inbreeding theory in condemning consanguinity, a theory which developed before the advent of genetics and hereditary medicine, and one which has debatable merit (Ferraro and Andreatta, 2009, p. 211-212), others such as Levi Strauss and Malinowski have offered anthropological explanations for the incest taboo. Much like Westermarck, Levi-Strauss' take on the incest taboo in the *Elementary Structures of Kinship* (1947), as discussed earlier, is used as a build-up to introduce the Alliance Theory. The theory states that human culture had developed a method to avoid incest by marrying outside their own groups and to promote reciprocity and gift exchange between groups, where women were the gifts being exchanged (Vandenberghe, 1980). The Alliance Theory was possibly related to Strauss' structuralist school of thought, yet there were competing schools of thought for anthropology and psychology in the same era. A functionalist approach to consanguinity can be seen in the work of Malinowski and his theory of family disruption, which states that incest is avoided because it may cause confusion and conflict at home if there exists any sexual tension between family members (Ember and Ember, 1983). While both these theories have had proponents and opponents similar to Westermarck and Freud (Ferraro and Andreatta, 2009, p. 212), collectively all these works have carried forward the linkage of incest, inbreeding and consanguinity along with the words of the Pope or "the Bible". It is no surprise then to find the same being alluded to in works of fiction in July 2013

the Victorian era, like *Wuthering Heights* (1847) and *Jane Eyre* (1847), as well as popular culture today in any number of American television shows. However, the fields of psychoanalysis and anthropology were not the only sciences influencing this discourse, medical science and the advent of genetics have had major contributions in the discussion on consanguinity in more recent times.

3.4 Genetics and Healthcare

An important element in understanding the discourse of consanguinity is to examine the development of genetics as a modern science but infant discipline when compared to the basic sciences. The social influences that have given rise to genetics have also had an impact on the understandings and significance of consanguinity. The expansion of genetics and the new discoveries about the human genetic code today mirror the evolving and sometimes contradictory knowledge of consanguinity and its impact in terms of genetics. At first, genetics was just a way to study the features passed on from generation to generation, the hereditary material. In fact, this focus on heredity and inheritance patterns still dominates both the study and treatment of genetic diseases today, as seen in the successes of familial cancer care and the promising developments in Alzheimer's research (Tanzi and Bertram, 2001, Bertram and Tanzi, 2008). Although a young science, genetics has grown as a science from being mainly a research oriented discipline to one that is being implemented as a service in multiple facets of healthcare. This "new genetics", post the human genome project, is now focusing on genomic medicine, with major implications for primary healthcare (Petersen and Bunton, 2002, Finkler *et al.*, 2003), aspects of which are explored a little later. The developments in genetics have led to a greater understanding of hereditary basis of disease, and these advancements were greatly helped by studying consanguineous families, due to the presence of closely linked genes; however, much like the incest taboo theories, this also resulted in consanguinity being invariably linked to genetics. In this section, a deeper look at how the development of genetics both as a discipline and as a healthcare service have come to shape understandings of consanguinity.

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3.4.1 The rise of Genetic Science

The concept of heredity had no biological meaning or significance until the nineteenth century (Cobb, 2006b). Decoding the inheritance patterns of cousins was unimportant then, as the scientific world was attempting to breakthrough from the ovist and spermist versions of genetic inheritance and reproduction, understood to be something to do with generations at the time (Cobb, 2006a). In fact, a compilation of books and papers on marriage between near kin in the nineteenth century shows little attention was paid to consanguinity (Huth, 1879, as cited in Bittles, 2009). Europe at least, at the time, was more concerned it seems with the relations by marriage, affinal relations, and passing rulings on when and if a man could marry another from his wife's family (Bittles, 2009). Beyond the West, the Islamic World too was dominated by ideas of Hippocrates and Aristotle and the debate about reproductive methods and the role of the egg and the sperm (Cobb, 2006b); and the Chinese focused on the generative vitality rather than function of the sexes (Furth, 1999). How then has the word genetics become a concomitant to consanguinity?

Genetics evolved from social and intellectual needs and influences of the time, similar to other scientific and technological advancements through history like industrialisation in the nineteenth century to alternative energy today. At the beginning of the First World War, there was a great need for perfecting the science of blood transfusions, so that soldiers could be healed quicker and sent out to battle. This resulted in several efforts during the war period to build upon the discovery of blood groups by Karl Landsteiner, which was in 1901 (nobelprize.org, 2011). Congruently, it was the agricultural breeding community and the promise of financial gain that presented a steady hereditary model to science in the work of Robert Bakewell. However this was rejected by a prominent scientist of the eighteenth century, the president of the Royal Society, Sir Joseph Banks, as not purely scientific, rather by suspicious means. It is curious though that Banks himself was a sheep breeder was unable to replicate the results with his animals (Wood and Orel, 2001). Banks' power was such that it was not until the beginning of the nineteenth century that the impact of the agricultural

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breeding community was carried forward and in the middle of the century intrigued Gregory Mendel into conducting his own experiments with peas which have resulted in our understanding of heredity today (Cobb, 2006b). Powerful social influences first kept studies about heredity from progressing and later propelled the same studies to the forefront, showing the impact social events can have on discovering the truths of science.

The first scientific interest in consanguinity evolved after Charles Darwin expressed concern that children from a consanguineous marriage may not be viable after seeing three of his own children from a cousin marriage die at a young age, although their deaths may or may not have been linked to consanguinity (Bittles, 2009). However he requested to have relationship information collected with census data for this regard through a bill in parliament, but it was rejected and ridiculed. Later investigations by George Darwin, Charles' son, found that socio-economic status rather than consanguinity were of a greater impact in survival rates of children (Bittles, 2009). Such consideration to socio-economic status and the possible breakout of tuberculosis in the households of those less privileged was not given in the United States around the same time. There, a church clergyman, Rev. Charles Brooks, addressed the American Association for the Advancement of Science meeting calling for an incisive look into the dangers of consanguinity based on statistics of higher rate of early death in children of consanguineous marriages, which as stated earlier, failed to normalise for socio-economics and may have been skewed in its results (Ottenheimer, 1996). These events in society and science formed the basis of numerous laws (in the United States) and future studies linking cousin marriages with adverse effects. While this debate continues till today, about the possible risks associated with cousin marriages (Bittles, 2001, Bittles, 2008, Grjibovski *et al.*, 2009, Hamamy *et al.*, 2011, Hoodfar and Teebi, 1996, Stoltenberg *et al.*, 1999, Teebi and El-Shanti, 2006), the linkage of cousin marriages and genetics seemed to flourish at the turn of the century. This is because while scientists did not fully understand heredity and the structure or even existence of DNA as we know today, studying families that have had multiple consanguineous marriages

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provide a good closed circuit opportunity for geneticists to explore their hypotheses (Hu *et al.*, 1982), and in today's genetics, map specific gene loci, an essential tool in finding new cures (Walsh, 2011).

Genetics is a relatively new science, surpassed in novelty perhaps by molecular biology and nano technological science, but new nonetheless. Although a great many advancements have been made in genetics, it is nonetheless a growing science. Perhaps a clear example of this is in the fundamental dogma of genetics that gene is a functional unit of heredity, that a gene results in proteins which determine function and that is life in action (Gupta, 2007); however, even the idea of a gene being the single entity to represent the smallest unit of heredity is now being questioned as genetics grows (Gupta, 2007). There are debates in the philosophical practicality of the reductionist approach in understanding biological functions by giving importance to studying them at such a molecular level (Waters, 2008). Indeed some would suggest that most medical research today is focused in on the gene (Waters, 2008), which is possibly flawed given the debatable position of the gene as the functional unit (Kitcher, 1992). This is a more recent debate, whereas most of the previous century, the advancements in genetics have resulted in medical research that has generally been based on molecular findings, privileging perhaps studies that have a molecular and genetic basis for results.

3.4.2 Understanding Genetics

As discussed, scientific investigations had started to influence the consanguinity discourse in the nineteenth century by the likes of Mitchell and Darwin (Ottenheimer, 1996). While Mendel explored and defined laws of inheritance in the nineteenth century as well, the field of genetics only expanded in the middle of the twentieth century, with the discovery of the DNA double helix. Genetics is now a key area of knowledge in shaping the understandings of consanguinity. A commonly used argument about the negative health outcomes of consanguinity is that children of consanguineous couples are at double the risk of being affected by a genetic disease than those of a non-consanguineous couple (Darr, 1997, Bittles and Black, 2010b); however, others have argued that the actual numerical values are not so significant when taken in perspective that the risk is only

~2-3% for non-consanguineous and up to ~4-6% for consanguineous couples, leaving up to a 95% chance to have a normal baby for a consanguineous couple, barring other factors (Bennett *et al.*, 2002). These reported risks are also highly variable depending on the study and not every study ought to be equally weighted due to its imbalance in controlled parameters (Bennett *et al.*, 2002, Bittles and Black, 2010b). Furthermore, genetics is a growing science and as newer technologies develop at a rapid rate, previously held beliefs or realities about disease and inheritance may need to be revisited. In order to appreciate and understand the impact of genetics in how the world defines consanguinity, a closer look into the very basics of genetics are presented in brief. This understanding of genetics is crucial to appreciate the experience a person in a consanguineous relationship may take when told of a potential genetic risk due to the nature of their relationship, as well as understand the future role genetics may play in defining consanguinity and even healthcare.

Genetics is essentially the study of heredity and how traits are inherited (Speicher *et al.*, 2009). The cells of the human body contain a central region called nucleus, which contains the chromosomes that have the majority² of genetic material known as DNA, or deoxyribonucleic acid, which in turn contains letters of genetic code (A, C, T, G)³ which form genes. Genes then are segments of DNA that are the hereditary units which determine human traits from physical features like eye colour to non-visible features like intelligence and pre-disposition to disease, based on the functional protein for which they contain the code. There are twenty-three pairs of chromosomes in humans, including one pair of germinal or sex-related chromosomes, which determine gender, while the rest are referred to as autosomal or non-sex related chromosomes, together coding for over 21,000 genes in humans, and the total genetic code is referred to as the genome. Sometimes, genes

² Some genetic material is also stored in the mitochondria of cells, called mitochondrial DNA, mainly for cell function and is almost exclusively inherited from the mother.

³ A, C, T, G, represent the first letters of bases that form pairs linking the two strands of DNA, Adenine bonds with Thymine and Cytosine bonds with Guanine. This bases form the sequence of the DNA, which codes for genes.
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can be changed due to errors or damage, causing a change, called a mutation that alters its function, this change maybe neutral, beneficial or negative. Different sequences of the DNA, containing “good” and “bad” copies of a gene, determine the different variants of the same gene in different people, and these variants are called alleles, and humans have two copies of an allele, one from each parent. Some of the alleles may be dominant, meaning the expression of that allele will be overriding on the other allele. Other alleles may be a changed version, called recessive or non-dominant and their expression is usually only possible when the allele from the other parent is also recessive (Gupta, 2007).

3.4.2.1 Modes of Inheritance

The principles of gene expression and modes of inheritance have advanced extensively in the last few decades since the discovery of Mendelian Inheritance, causing monogenic diseases, where a mutation in a single gene can cause a disease. Having a mutation does not however, equate to having a disease, as this depends on the pattern of expression of a gene. This expression could be incomplete or have co-dominance, reduced penetrance, early or late onset expression, and X-linked mutations can also play a crucial role in determining the true nature of traits and expression (Speicher *et al.*, 2009). Moreover, mutations can also occur during development, sporadic, meaning the parents need not have had this mutation, so no history will exist. Some diseases are multifactorial or complex and result from gene and environment interactions, like diet and exercise. In addition, not all diseases are caused by inherited mutations, sometimes mutations can occur in somatic cells (i.e. non-germ or non-sex cells), cells that make up the body of an organism, and a majority of cancers occur in these non-heritable mutations. So, in short, the genetics of mutations and inheritance is complex, however, it is the autosomal recessive inheritance (and to an extent multi-factorial disease) that is mostly highlighted in the context of consanguinity (ten Kate, 2012), and this is the pattern of inheritance that is discussed in slightly more detail.

3.4.2.2 Autosomal Recessive Disease

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Certain traits require that two recessive alleles be present for them to be expressed, as is the case with some genetic disorders. These recessive or mutant alleles are thought to occur less frequently than the rest, and the genetic disorders are usually rare in the general population. When a gene has two similar alleles, it is referred to as being homozygous. Similarly, when it has two different alleles, one dominant and one recessive, then it is called heterozygous. In terms of traits and disease that require two recessive alleles to be expressed, an individual who is heterozygous for that gene is referred to as a carrier for the disease or trait, because they possess one good copy of the gene (allele) and one bad copy or allele. A person can be a carrier for a trait and never express it, but they are able to pass on the recessive allele to their children, making them carriers as well. However, if that child receives another recessive allele from the other parent for the same gene, then the child that receives both such alleles will express the trait, as shown in the Figure 3.2, referred to as a Punnet Square. The Punnet Square shows two heterozygote (carrier) parents and the possible genotypes (different types of allelic combinations as opposed to phenotype, which is the physical and visible appearance of a trait) of their children. So, with two carrier parents, there is a 1 in 4 or 25% possibility of having an affected child (shown in red) every time they conceive, in terms of an autosomal⁴ recessive disorder (Young, 2007). As mentioned above, recessive alleles are rare, and hence homozygous recessive genotypes are even rarer; however, once a recessive trait is expressed within a family, the chances of it re-appearing in successive generations increase when there is consanguinity (Bittles, 2010a). Furthermore, evidence suggests that when there are successive generations with cousin marriages, this increases the genetic risk of disease to a higher level than 5-6%, because the parents are related closer than just as first cousins and also due to the increased levels of homozygosity (Bittles, 2008, Woods *et al.*, 2006(Farmer *et al.*, 2004).

⁴ Autosomal refers to the gene being on one of the twenty-two pairs of non-sex chromosomes, as opposed to allosomal, which would indicate the gene being on one of the sex determining germinal chromosomes.

	A	a
A	AA	<u>Aa</u>
a	<u>Aa</u>	<u>aa</u>

Figure 3.2 - Punnet Square – This figure shows a cross between two parents heterozygous for a gene (called carriers), with the potential of having one of the four offspring be homozygous recessive (autosomal recessive is in red) for that particular gene.

3.4.3 Population Genetics

Given the impact of potentially lethal diseases arising from mutated alleles, an important branch of genetics, population genetics, is dedicated to analysing inheritance pattern changes and allelic frequency variations at a macro level (Speicher *et al.*, 2009). One of the basic principles of population genetics is the Hardy-Weinberg Equilibrium which predicts that allelic frequency remains equal in a randomly mating population of infinite size (Bittles, 2010a). However, there are times when this equation is a not so accurate a method in determining allelic frequencies. The exceptions come in the form of non-random or assortative mating and genetic drift among others (Young, 2007). Random mating is a concept that is poorly applied to humans, because there almost always some type of selection process involved in choosing a partner. Whether the selection is based on a particular phenotype (eye colour, height, weight) or race and ethnicity, this results in assortative mating, which has an impact on allelic distribution (Bittles, 2010a). Consanguinity is also a type of assortative mating in which a choice is made for a partner based on family background. Genetic drift, on the other hand, is the impact that chance has on allelic frequencies and is mostly evident in smaller populations, where non-random mating occurs as a matter of chance due to small selection samples (Bittles, 2010a). Hence, not only consanguinity but endogamy and population stratification can have an impact on allelic distribution, as again, mating is confined to

a select group of partners based on geographical or behavioural grounds. The result from all of the above can be the same, which is an imbalance in allelic frequencies away from the Hardy-Weinberg Law. So, in order to determine if a dangerous imbalance may occur in a population, like an increase in recessive homozygosity (two recessive alleles) that can result in increased diseases, due to any of the above factors, other methods of calculation were required.

3.4.3.1 Coefficients of Relatedness and Inbreeding

The co-efficient of relatedness (r) and the co-efficient of inbreeding (F) are used to quantify genetic relationships (Bittles, 2010a), and are used in risk assessment and diagnosis of genetic diseases. While the relatedness coefficient measures the amount of genes shared by two individuals, the inbreeding coefficient determines the proportion of gene locations (loci) where the individuals will be homozygous (Young, 2007). This is in effect a modern and more practical method of defining consanguinity and assessing any possible affects than the degrees used under the Canonic and Civil methods a thousand years ago and Table 3.1 describes the most common consanguineous

Relationship	r	F
Siblings/Parent-Child	1/2	1/4
Half Sibs/Uncle-Niece/Aunt-Nephew	1/4	1/8
First Cousins	1/8	1/16
First Cousins once removed	1/16	1/32
Second Cousins	1/32	1/64
Double First Cousins	1/4	1/8
Double Second Cousins	1/16	1/32

Table 3.1 – Common Consanguineous Relationships – This table represents the common consanguineous relationships, where r represents the co-efficient of relatedness, indicating the proportion of genes the couple will have in common, and F represents the inbreeding co-efficient, indicating the proportion of gene locations where the couple will be homozygous *recreated from (Young, 2007)

relationships. However, what is interesting to note is that the names of these scientific terms that are being associated with consanguinity are using language that can denote negative meanings of

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the phrase, such as inbreeding co-efficient. This implies that consanguinity is in fact inbreeding, which scientifically speaking it is, but in sociocultural terms, this is a very problematic association.

So, from the Table 3.1 above, it can be deduced that first cousins will share $1/8^{\text{th}}$ of their genes and will be homozygous at $1/16^{\text{th}}$ of their gene loci. This information can be used to determine the risk of genetic disorders and is broadly used as a tool in genetic counselling along with pedigree analysis, which also allows the studying of inheritance patterns (Bennett *et al.*, 2002). Another calculation used in consanguinity studies is based on the genetic load theory based on the credence that a human population is heterozygous for certain genes that if expressed could be lethal. Genetic load is a decrease in the fitness of a population due to the expression of deleterious genes that reduce population survival (Bittles, 2010a). Using a comparison of death rates in the progeny of related and non-related individuals, it is possible to determine the lethal gene levels in a community or sub-population (Bittles, 2010a), showing once again, how consanguinity has been important in expanding genetic science.

3.4.4 New Genetics and Healthcare

Given that genetic science is still growing, the impact its advancements have had in medical research has been surprisingly far reaching, like the fact that socio-psychological phenomena are now being looked through a genetic perspective (Fraser and Tobin, 1998). Those that criticise genetics as being a reductionist science would argue at the idea of defining sociocultural phenomena like consanguinity through molecular findings. This may serve as a reason why consanguinity and consanguineous families present such good models to study and present genetics, because of their visibility in terms of cases of congenital disorders and disabilities, giving prominence to an otherwise invisible molecular science. However, pragmatists would suggest that while the approach may be debatable, the findings and observations may be valid and have been useful. A prime example of this usefulness is available in the research and treatment of cancer and the advent of new genetics or genomic medicine.

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Environmental factors were given priority over others in explaining and preventing cancers before advancements in genetic research (Wilson *et al.*, 2002), possibly due again to social developments like post-industrialisation and social movements like environmentalism. However, with the rising death toll of cancer over the years, the focus shifted towards genetic research and understanding again the role of heredity in disease, now with advanced methodology. What has evolved is that almost every major cancer can have traces in family history, but the complexity exists in numerous genes being identified as oncogenes or tumour suppressor genes, expression of some and non-expression of others, respectively, can result in cancers. Nonetheless, successful identification of several such genes has yielded high success rates in treatments of some cancers of the breast, lung, prostate and colon. This has steered leaders in medical science today to call for a reformation of healthcare services to have a more genetic focus in both research and treatment (Emery *et al.*, 1999). This reformation and awareness to the new genetics or genomic medicine has been especially highlighted for primary care, given the rise in demand for genetic services at the secondary and tertiary care level (Emery and Hayflick, 2001, Emery *et al.*, 1999, Miller *et al.*, 2010). Indeed, government level initiatives emphasising the role of genetics in family medicine like the NHS' National Genetics Education and Development Centre have been setup to meet the growing needs of modernising medical care (Godfrey, 2003), and the result is an ever growing number of genetic services being offered.

3.4.5 Genetic Services

Genetic services range from simple family histories to laboratory diagnostic testing, and include predictive screening and genetic counselling. It is important to understand the genetic services that are available in healthcare because they can have implications for the choices available for patients and families, and in the case of a consanguineous couple, the implications can influence their understanding of not only the genetic disorder, services and treatment, but also consanguinity itself (Bennett *et al.*, 2002). It is also important in terms of understanding the limitations that may

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exist in terms of genetic services when it comes to consanguinity, which sometimes gets drowned in the dominant discourse.

Genetic testing and screening is used to test if a particular gene mutation is present in an individual based either on family history (testing) or ethnic or population susceptibility (screening). The process usually involves the patient, who may have been referred by a health professional, to provide a blood sample which would then be sent to a diagnostic laboratory for analysis. If the disease in question is caused by a known mutation in a gene, then the testing is usually straightforward. However, if the disease can be caused by a number of mutations in a gene, then this involves a lengthier process where the full gene will need to be sequenced. As mentioned earlier, the genetic code in genes is represented by letters A, C, T and G, which represent different bases. The pairing of these letters, when two strands of DNA come together, forms a base pair. Each single gene can contain thousands of base pairs, hence sequencing even for a single gene can be a lengthy process. This however, has advanced drastically in the last decade, and latest techniques like Next Generation Sequencing can sequence lengthy sequences within hours instead of days.

3.4.5.1 Types of Genetic Testing and Counselling

As stated above, a person can choose to have a genetic test done or a screening. Screenings are mostly done for mutations that are common at the population level, for example the sickle-cell anaemia mutation is common in people from Africa, cystic fibrosis in people of European descent and thalassaemia in people from South Asia. There are other screenings like prenatal (antenatal) and neonatal screenings for conditions like Down Syndrome and metabolic disorders as well as haemoglobinopathies (blood disorders like thalassaemia). Since screenings are done for the most common mutations at a population level, they have mostly become standardised in most health systems and the NHS offers both antenatal and neonatal screenings, however these are not mandatory services (NHS, 2012).

Genetic testing on the other hand is done when usually there is a history of a disorder in the
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family. Testing can then be done for either diagnostic reasons, when a disorder has been diagnosed but the mutation needs to be identified for better treatment; it could be predictive testing when an unaffected person gets tested to assess risk because of a presence of a disorder in the family; or carrier testing which is similar to predictive testing but the presence of a mutation does not mean the person will have the disorder, they will just be a carrier who may pass on the carrier gene to a child or the disorder to the child if they marry another carrier (Young, 2007).

Before testing has been conducted, patients are usually referred to or ask to be referred to a genetic counsellor. These are trained health professionals, usually not physicians, who can help patients understand the genetic risk, or results of their genetic tests and aid in them evaluating the probabilities using co-efficient of inbreeding as well as treatment options at length in consultation with a clinical geneticist, a consultant level physician trained in genetics. They also take detailed history, which is the first step in a genetic diagnosis or evaluation (Bennett *et al.*, 2002). This history not only helps them diagnose the patient better, but it may also identify other members of the family who may be at risk of genetic disease. Sometimes, in order to diagnose the patient, and to accurately identify the mutation, blood samples need to be taken from other family members, and those members are also offered counselling. Genetic counsellors are trained to deal with the sensitive nature of consanguineous relationships and are advised to reduce anxiety in the patients (Bennett *et al.*, 2002). They also have the option to refer patients to psychiatrists if the need arises. Once all the information has been provided, patients can then agree or disagree to have testing done, through informed choice.

3.4.5.2 Limitations of Genetic Testing and Emerging Technologies

Genetic testing is usually only useful when there is a history of a disorder in the family. Even then, not every mutation of a gene is known and sometimes diseases can be caused by multiple genes, and testing for complex diseases is limited at best. Sometimes testing also may not provide a clinically relevant diagnosis for rare variants. There are rarely definitive positive or negative

results, all results are probabilistic and are a risk assessment, and sometimes the tests may also be inconclusive. Interpretation of these results can therefore sometimes be overwhelming for patients who would much rather have definitive answers.

However, testing procedures have greatly improved and since the human genome project was completed, thousands of new genes have been identified and there are a greater number of known mutations. Testing is also done at a larger and faster scale, and it is more affordable. There are now genome wide association studies being conducted which assist in locating genetic variants, increasing the potential to map more mutations (Beals, 2010). Furthermore, next-generation sequencing techniques like exome-sequencing have now increased the probability of mapping rare variants, which would aim to limit the inconclusive results of genetic testing (Ku *et al.*, 2012). Although availability of these latest techniques as diagnostic services is still limited. Most genetic screenings still use profiles of the most common mutations, therefore limiting their applicability for rare variants, such as the ones that are most common in consanguineous relationships (Choi *et al.*, 2009).

Genetically speaking, consanguinity increases the likelihood that both members of a couple may carry a recessive allele, as they will have had a previous recent ancestor (grandparent in first cousins) in common, increasing the chances of one of their children being born with an autosomal recessive disorder (Modell and Darr, 2002b, Bittles, 2008). As a result of such risks, and reports such as the one discussed in Chapter 1 on infant deaths, sometimes healthcare systems focus on reduction of consanguinity as a way to improve overall health profiles (Darr *et al.*, 2013), this has been met with limited success and instead led to alienation and barriers to health services (Ahmad, 1994). The genetic basis for increased risk in consanguinity exists, but the impact has been reported to be highly variable (Bittles, 2012). Furthermore, due to limitations of genetic testing and diagnosis, patients do not always have a definitive answer either for disease aetiology of future risk, causing confusion, frustration and sometimes rejection of results and future treatment. There is also

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the issue of patients who get identified as carriers, dealing with the stigma associated with being not just a carrier (Miringoff, 1998), but an ethnic carrier (Atkin, 2003). As suggested in Section 1.3 under social categorisation and the example of haemoglobinopathies, the labelling of carrier status often gets linked along racial and ethnic lines (Dyson and Atkin, 2011), further limiting the genetic testing services in terms of the hesitation people will face, especially from ethnic minority groups, in accessing these services for fear of discrimination. Genetics thus, in terms of understanding consanguinity, needs to be taken in perspective of the relative risk versus both the limitation of genetic services and the social benefits that are perceived by the populations that traditionally marry within family (Bennett *et al.*, 2002, Bittles, 2012, Hamamy *et al.*, 2011).

3.5 Sociocultural Elements

The third area of knowledge that informs current understandings of consanguinity are the sociocultural elements, which include issues related to social norms, cultural and religious customs around marriage and sexual relationships, as well as sociocultural responses to differences in ethnicity. The subject of marriage is significant in terms of the sociocultural understandings of consanguinity, not only in terms of how it is defined, but also in terms of how consanguinity gets linked to other sociocultural elements like cultural traditions, social classification, immigration laws and even ethnic strife. As discussed earlier, the definition of consanguinity includes relationships deemed incestuous, which may play a role in ascribing that label to all consanguineous relationships (Katon and Kleinman, 1981). However, consanguinity in the public domain, especially in the UK, is mostly synonymous with cousin marriage, which then excludes relationships generally considered as incest. In chapter one, it was discussed how consanguinity is associated with certain ethnic groups, like the British Pakistanis. Since the cultural and religious traditions of British Pakistanis forbid incest, consanguinity in this ethnicity is limited to cousin marriages. So, while consanguinity could be applicable to multiple ethnic groups, including Western ethnicities, cousin

marriage gets associated mostly with only non-Western ethnic groups, or “traditional” societies, and all the public debates on consanguinity then focus on cousin marriage and these non-Western ethnic groups. As discussed earlier, the issues these groups face, in terms of being a visible minority, then get exasperated by inclusion of another factor that makes them the others. This more subtle form of discrimination feeds into discursive formations that continue to inform current understandings of consanguinity. Thus, making consanguinity into an “ethnic” condition, associated mainly with certain cultures (Ahmad and Bradby, 2007). While acknowledging that the use of such language, like cousin marriage and co-efficient of inbreeding, feeds into the dominant discourse, it will be used throughout this research as it is currently an accepted part of either common or scientific language used to describe consanguinity; however, as part of the constructionist approach, the context behind its use and evolution has been stated. Marriage then, is another important aspect in looking at how consanguinity has come to be understood. Much like the anthro-psychological theories and genetic sciences and services evolved in parallel to the shaping of consanguinity as a phenomenon, the growing role and interpretation of marriage have had an impact on consanguinity.

Marriage has played a role in shaping societies from agricultural times to industrial and even in “modern” society. In between, marriage has been defined and has defined religious edicts and splits, civil laws, social ideologies, and cultural divides. All of which have in turn had an impact in the understanding and opinion about consanguinity. While the debate about defining consanguinity has been discussed already, and the links of cousin marriages to specific cultures and ethnicities withstanding, cousin marriage is perhaps a term and practice comes into a relatively lesser scrutiny than incest or non-marital illicit relations between family members, which remain strictly taboo (Bennett *et al.*, 2002). Cousin marriage may well still be a civilised sociocultural phenomenon that although debated, is generally acceptable, whereas incest is mostly regarded as, and has for centuries, a savage and immoral act and is a criminal offense in many countries. This however, has
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not always been the case as many civilisations from the Aborigines of Alaska, the Kaniagmuts to the traveling gypsies to the ruling dynasty of Roman Egypt, the Ptolemies, all allowed marital/sexual relations between brothers and sisters and even parents and children (Goody, 1983). The castigation of incest may well have begun many centuries ago, and may even have been implicit in nature (Goody, 1983), but the idea of the sanctity of marriage has evolved through developments and influences of religion, as previously discussed, and through other sociocultural developments.

Westermarck (1891) attempted to chart the origin of marriage in his *The History of Human Marriage*, although the sources are the earliest written or spoken records and may not indicate a true origin. It is suffice to say that earlier societies did not give credence to marriage or even monogamy as both genders in some societies tended to mate non-exclusively and the resulting children would rarely know their biological fathers (Westermarck, 1891). The emergence of a family in fact may have given rise to the idea of marriage, as mother and father obtained a sense of responsibility towards their children, giving shape not only to a family but also the idea of a commitment and a type of marriage (Goody, 1983). As discussed earlier, this work by Westermarck may have been used to setup his theory on natural aversion, the evidence presented charts a development of the idea of marriage, which continue to influence the understandings of consanguinity. The importance of the family in marriage might have been mentioned in passing but it is relatable to the reasons given by some today in wanting to maintain and indeed undertake consanguineous marriages to appease family (Charsley, 2007, Darr and Modell, 1988).

Settled agricultural societies further enhanced the role of marriage shaped around the inheritance of property and gender roles (Shaw, 2009). Tillion (1983) has suggested that the patriarchal nature of these societies augmented not only the roles of women and the inheritance patterns, but also the preference for marrying within close kin. It was through marriage within their children that bonds were made stronger between kindred who shared common land. While there was not an issue of land inheritance through women, this changed ironically with the arrival of
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Islam, and the enhanced rights of women. Contrary to popular representations today, women under Islam had the right to inherit property from husbands, brothers and sons, well before it was allowed under Western cultures which mostly followed primogeniture customs of inheritance, where land and property was transferred to the first born son (Hrdy and Judge, 1993). This inheritance right made it even more important to then marry within kindred to ensure land stayed within the family (Tillion, 1983), a practice stipulated even in some Jewish customs, that if there are no sons, and the property is inherited by a daughter, then she must marry within her father's tribe lest the property be transferred to the tribe of a man she marries from outside⁵. This emancipation of sorts for women in Islam, with regards to inheritance, is in contrast to the rest of Tillion's own work, which takes an arguably orientalist look at the oppression of women in Mediterranean society and suggests this as the beginnings of cousin marriage as it is known today. However, Shaw (2009) has decorously pointed out that this view ignores other factors in the development of cousin marriage as well as fails to account for the practices of several other cultures of the time. Nonetheless, the importance of keeping land, property or businesses within the family has been cited as key motivations for preference of cousin marriage even in recent times (Hussain, 1999, Khanum, 2008, Shaw, 2006). Bertochi (2006) argues that inheritance patterns evolve from primogeniture to equal partition, as the economics and the politics of a society grow from agrarian and aristocratic political systems to industrialised democracies. This theory however is somewhat complicated for the British Pakistanis by elements of transnational marriages, institutional policies towards migrants and religious influences (Shaw, 2009). Marx called the concept of private property and its ownership and inheritance central concepts in the rising Western ideals of Capitalism (MacFarlane, 1998), and it

⁵ Book of Numbers, Chapter 4, verses 6-7: This is the thing which the Lord hath commanded concerning the daughters of Zelophehad, saying: Let them be married to whom they think best; only into the family of the tribe of their father shall they be married. So shall no inheritance of the children of Israel remove from tribe to tribe; for the children of Israel shall cleave every one to the inheritance of the tribe of his fathers.

Online at: <http://www.mechon-mamre.org/p/pt/pt0436.htm#1>

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seems Trillion (1983) has extended this dichotomy in labelling the opposite of the modern Western concepts, which have evolved out of the tribal, ancient, and feudal systems to capitalist ones, as simply a patriarchal society enforcing cousin marriages. The further development of marriage customs is of more importance in Trillion's work here rather than focusing on the orientalist tracing of the origin of cousin marriage or discussing the cultural oppression of women.

Another aspect of marriage customs that plays a major role in cousin marriages and has developed through centuries and across cultural and religious lines is the concept of bride-price and dowry (Modell, 1991, Wahab and Ahmad, 1996). Both bride-price, paid by the groom's family to the bride's, as well as dowry, paid on behalf of the bride to the groom's family, have promoted the idea of tying economics to a marital contract. The economic consequences of these practices have been explored and been found to be a significant determinant of social class, women's rights and even consanguinity (Do *et al.*, 2006). The relationship between the rising costs of dowry payments and increase in consanguinity points to the fact that by marrying within family, the payment of dowry while not negated will at least be reduced and it may even be possible to make payments in instalments as opposed to paying two to three times the household income in one payment for marriage (Do *et al.*, 2006). A further consequence of these customs has been the subjugation of women further as property or items of possession. Women do also play an important role in the continuance of consanguinity within families, usually as a means to attaining or maintaining power in their new families through marriage. This power, or ascendancy in power relationships is done through influence on future generations to marry from their side of the family giving them ownership of property and thus more influence that may or may not have been with them when they married into the family (Darr, 1997).

The exchange of women as possessions is analogous to the aforementioned, and more recent, Alliance Theory of Levi-Strauss (1969). Contemporary concepts of marriage and consanguinity are not far removed from historical practices and developments of cultures; however
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there has been a shift in portrayal of these practices as being primitive and suppressive. This linkage of pre-industrial practices as primitive and inferior to the modern concepts was propagated by Lewis Morgan (Morgan, 1877, as cited in Shaw, 2009), a prominent American Lawyer, which served to further advancing American lawmakers resentment towards endogamy (mating within a closed group) and consanguinity. However, Morgan himself was married to his cousin, and the idea of marrying outside one's family to him meant to marry outside the direct lineage which carried from the father. This definition of consanguinity is still held true in some cultures, like the Chinese Han (Bittles, 1994). In essence, marrying maternal cousins or through non-male family members did not constitute endogamy or indeed promiscuity and primitiveness. While promiscuity may no longer be associated with primitiveness in anthropology (Shaw, 2009), the links of modernisation to restrictions and advancement of marriage laws has progressed. In Westermarck's *History of Marriage*, he points out that although modernity did not have exclusive ownership of restrictions on marriage, and cousin marriage was not illegal in most of Europe, it was still mainly seen in "Mohammedans and several uncivilized peoples (sic)" (Westermarck, 1891, p. 298).

The dominance of Eurocentric views and the West in the formation of concepts of modernity (Hall, 1992) have been discussed in section 2.5. It has been the emergence of marriage concepts and restrictions of marriage laws that have shaped contemporary Western concepts of marriage towards secularism and economic realities that remain in contrast to an extent with other more traditional views that persist in many other parts of the world. In the current age of immigration to the West rather than mass migrations and colonisation, convergence and dissonance of different cultures has become more common. While individual cultures may be internally coherent systems, as suggested before, they transcend international boundaries, making them less autonomous and more connected to international circumstances and events (Hahn and Inhorn, 2009). As seen with the migration and settlement of the British Pakistanis, immigration laws of their adopted country have evolved based on economic and perhaps ethnic realities, which directly impacted an increase

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in transnational consanguineous marriages to bypass these stricter immigration rules (Shaw, 2006). As discussed earlier in section 1.2, the first large scale migration of Pakistanis to the UK was initially related to the shortage of labour in the UK. Later waves of migration involved largely, families, nuclear and extended families of the initial migrants, as well as some skilled workers, especially doctors coming to work for the National Health Service (Werbner, 2005). However, immigration laws progressively tightened where now “marriage is a loophole enabling migration to the United Kingdom despite strict immigration controls” (Werbner, p.479, 2005). The incidence of these transnational marriages has increased since the “primary purpose” rule in 1997, the intention of which was to reduce the number of “sham” marriages, conducted for the sole purpose of immigration to the UK (Cameron, 2006). While others saw this and other restricting immigration legislations as a way to police the South Asian others, who are often stereotyped for their marriage customs (Wilson, 2007, Chantler *et al.*, 2009). Transnationalism can be seen as sustained contacts and activities between two countries through a large proportion of the immigrant community (Portes, 2000). Cameron (2006) suggests that in the South Asian (including British Pakistanis) context, transnationalism is strengthened through strong kinship networks and inter-marriage. Charsley (2007) also agrees that kinship obligations and strategic considerations like circumventing strict immigration rules play important roles in transnational marriages, however, elements of risk negotiation (Shaw, 2009) relevant to marriage and migration at individual level also play a large role. The strong links formed through kinship networks, often called *biraderi/qaum/zaat* (or *jat* in Indian Punjabi), marriages within the family or the *biraderi*, help to negate risks associated with marrying an outsider who may not value the family’s customs, or may not have the *dard* (altruistic feelings, literally meaning pain) that family or kin have towards one another (Ahmed, 2005, Jeon and Buss, 2007), or may demand a large dowry (Nadvi, 1998, Zaman, 2008), or perhaps may be undertaking a “sham” marriage for the purposes of attaining immigration (Cameron, 2006). The obligation to maintain these links within kin or *biraderi* are deemed a matter of *izzat* (honour),

making their influence on marriage choices even stronger (Brah, 1978, Ballard, 1994). However, focusing on issues of *izzat* (honour) and “sham” marriages, only through the mirror of honour killings and immigration fraud, and then associating them with cousin marriage and “traditional” customs, without providing the context of the sociocultural developments throughout the Pakistani experience of migration to the UK, serves only to extend stereotypes and perpetuate existing discursive formations. Consanguinity thus has now become a contentious issue in this “modern” globalised society, where cultural norms, ethnic strife and immigration patterns have added a geopolitical significance to this discourse.

3.6 Summary

This chapter has presented a discussion of the debates that have informed current understandings of consanguinity. Constructionism provided the framework to understand the way in which the discourse around consanguinity has developed and it helps to understand current positions on the practice. Several parallel historical developments may have had an influence on the direction and impact of these viewpoints. As suggested by Figure 3.1, these areas of knowledge were centred around anthro-psychological theories used to define and predict consanguinity, the developments in the knowledge of genetics as a discipline and as a service into becoming the dominant perspective of healthcare on consanguinity, and the sociocultural elements of cousin marriage that have systematically evolved and have been reinterpreted into making consanguinity an ethnic condition. The impact of the hidden influences within these areas of knowledge has been a blanketing of contradictory issues such as competing social and biological theories, differences in incest and cousin marriage, limitations in genetic science and healthcare services, and the changing sociocultural realities within a postcolonial and globalised political landscape, which have all resulted in constructing the dominant twenty-first century understanding of consanguinity. In the next chapter, a methodology will be devised to explore these viewpoints further, and the findings from the fieldwork may defy, accept or add to these current understandings.

CHAPTER 4 - METHODOLOGY

4.1 Introduction

The previous chapters have set the stage for taking a look into consanguinity, discussed the theoretical underpinnings of this research and presented a critical literature review, in the form of a discussion of the current understandings of consanguinity through anthro-psychological theories, genetics and healthcare, and the sociocultural elements of cousin marriage. In this chapter, the focus shifts towards the methodology used to help examine these and perhaps alternative viewpoints of consanguinity through fieldwork and then interpretation of the findings in light of the conceptual framework discussed earlier. As such, the appropriateness of the chosen methodology to the overall constructionist framework will be discussed first, exploring other methodological approaches which were considered, the specifics of the methodological protocols and tools, ethical compliance and later the details of the issues encountered during fieldwork and lastly the analytical approach. The organisation of this chapter could be seen in two parts, highlighting the journey taken in planning and applying the methodology. A large part of the chapter is based on the proposed methodology indicated by the future tense applied in planning for the research to go in a particular way, while the data collection section represents the actual application of the methodology and the descriptions in that section will detail fieldwork which was completed by that stage. However, first, the overall methodology used for this research is presented.

4.2 Research Methodology

As alluded to earlier in Figure 2.1, this research utilises a constructionist qualitative approach using an instrumental case study of the British Pakistanis and local service providers in Luton, through focus group discussions and in depth interviews, using the framework method to analyse the findings. While the choice to use a qualitative rather than a quantitative approach was

made simpler due to the constructionist framework, as discussed below, the choice to go with a case study approach rather than a phenomenology or an ethnography was complicated. Eventually, a hybridised instrumental case study approach was deemed most suitable, which employed a triangulation strategy that included elements of both phenomenology and ethnography. The instrumental case study approach allows the flexibility to utilise concepts of ethnomethodological research while keeping focus on consanguinity as a local, national and global phenomenon and attaining perspectives from multiple sites and sources in constructing an understanding. This perspective will ensure that consanguinity remains the focus, through an in depth look into how it is lived and experienced by the Pakistani community in Luton and the healthcare and service providers directly associated with the community and in turn consanguinity, in Luton. The triangulation in approach, by combining methods, will also be evident in data collection through multiple tools and sources, and will lead to a more rigorous study.

Triangulation in a positivist approach may refer to the use of multiple methods to generate more confidence, or gain validity in the collected data. However, triangulation in terms of the constructivist-interpretive paradigm, where reality is relative, is more aptly used to attain completeness in data, or adding depth and value to understanding (Ritchie, 2003). This type of triangulation can be within-method, where different methodological tools are used, or across-method, where different methodological approaches are applied (Denzin, 2009). This across-method means of triangulation is sometimes referred to as mixed-method research, however, it usually implies mixing qualitative and quantitative methodologies. In this research study, across method triangulation will be applied in combining different qualitative approaches, by combining elements of ethnography with phenomenology, while following a case study research protocol. Maggs-Rapport (2000) defends this novel approach in combining ethnography and phenomenology, arguing that not only does it give a more wholesome outlook, it encourages triangulation in methodological tools and approach, as well as allowing both the researcher and the

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subjects to play important roles in the research, which is crucial for the constructivist- interpretive approach of this research. While combining methodological approaches for the purposes of completeness is novel (Casey and Murphy, 2009), it is not without precedent. Conway (1998) combined ethnography and phenomenology to understand the development of expertise in nursing, using phenomenology to gain an emic perspective and ethnography for an etic perspective, and to develop a theory, using elements of grounded theory. Mixing methodologies as such has been criticised as method slurring, however, as Conway (1998) points out that there is a lack of clarity in methodological approaches in literature, and often it is left ambiguous, thus avoiding both slurring and defining approaches. The benefit in using a combined approach for Conway (1998) was evident in the results when it appeared that nurses did not actually do what they thought they had done, hence adding clarity and precision to her data by combining both phenomenological data with observation. Others too have combined both phenomenology and ethnography (Lackey and Gates, 1997, Swanson-Kauffman, 1986, Hocking, 2007) and even case study approach (Khanum, 2008) in attaining triangulation. While criticisms are raised in using triangulation for purposes of validity, it is generally accepted as a means of adding richness to research (Ritchie, 2003).

This research will also use an approach combining qualitative methods to obtain an understanding of consanguinity in line with the underlying conceptual framework, the overall research study design is visualised in Figure 4.1. As stated above, it will be a constructionist approach using an instrumental case study (Stake, 1995), used to understand consanguinity through the lives of Luton's Pakistani community, followed by framework analysis done with the data management assistance of the software package, QSR Nvivo v10. Not unlike an instrumental case study, there will be topical information questions (Stake, 1995) that will be answered through a genealogical literature review. As well, issue questions (Stake, 1995) will be generated from the literature review that will be answered through data collection from multiple sources within the study population. Owing to the approach taken so far in this research, the selection of an appropriate

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methodology to compliment the theoretical framework will be outlined by briefly discussing the developmental journeys of the various methodologies considered, providing context to the choice of methodology, beginning first with the reasons to go with a qualitative approach.

4.3 Qualitative Study

Qualitative research can be used to describe the true nature of situations, processes, programmes and people. It can be used to comprehend new insights, develop new perspectives, or highlight problems within a phenomenon. Qualitative research can also allow for the researcher to verify the perspectives within the real-world context and further evaluate the effectiveness of existing policies and practices (Peshkin, 1993, Leedy and Ormrod, 2005). The words “can be used to” or “can allow” are indicative of the openness of qualitative research. It is this lack of rigidity that is one of the distinguishing features of qualitative research that allows for exploration of concepts in the real world rather than in plain theory or for the purpose of hypothesis testing. It is often criticised for its lack of generalizability, however, it is the richness of the content and its context that define the need and importance of qualitative research. The purpose of qualitative research is not to highlight a cause and effect relationship; hence it need not follow rigid protocols and calls for reproducibility. This does not mean that qualitative research is without definition and procedure; in fact, qualitative research has come to be well defined and continues to grow in its approaches and methodological protocols.

Paradigms, as discussed earlier, broadly guide the researcher’s approach in terms of epistemology, ontology and methodology (Denzin and Lincoln, 2005). Qualitative research has been defined through a prism of different paradigms, such as the critical theory perspectives, structuralism and post-structuralism, semiotics, post-modernism and post-colonialism. It has also been defined as interpretive research that can be used to understand and construct theories about

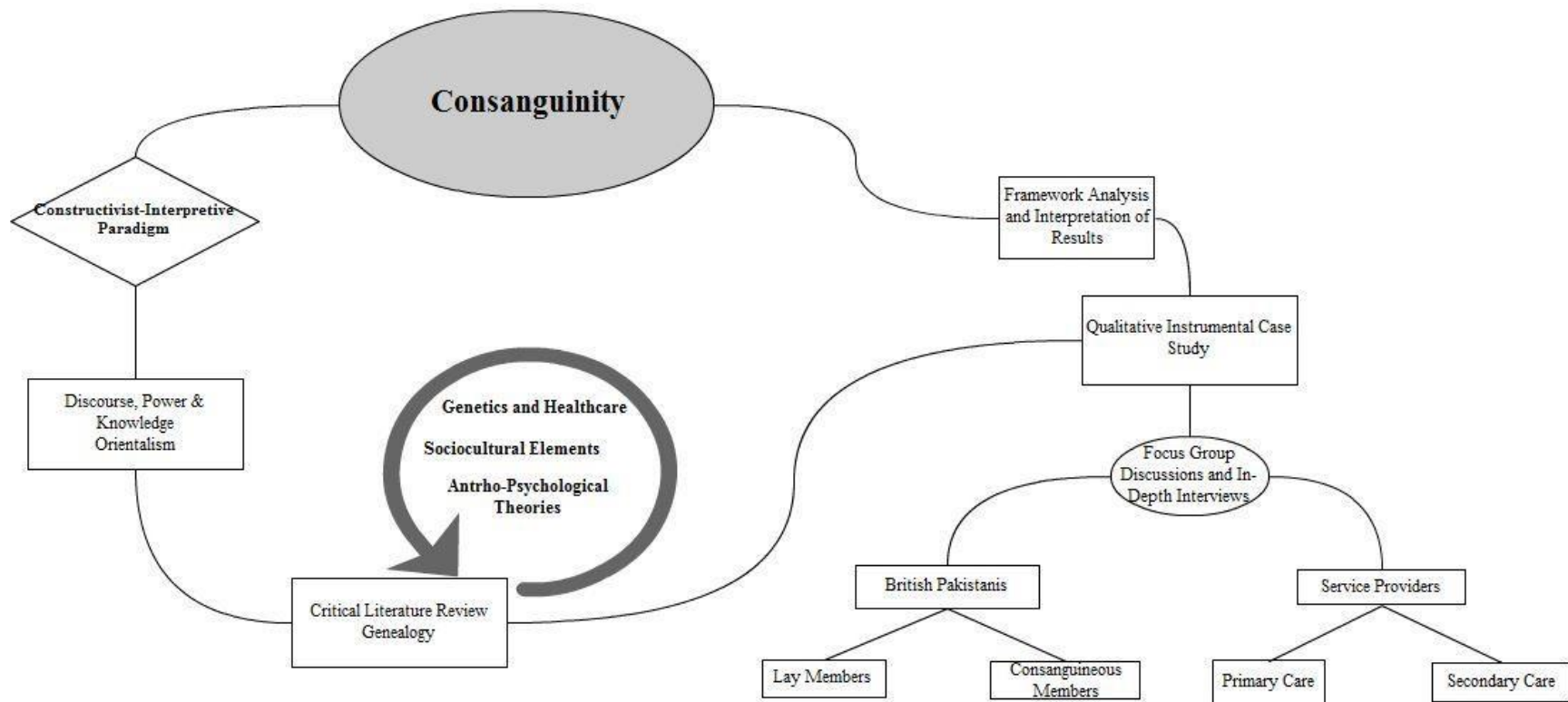


Figure 4.1 – Research Design – The overall research design is represented here, starting anti-clockwise from the subject, consanguinity, the conceptual framework is represented by the constructivist-interpretive paradigm and the critical theories of discourse, power and knowledge, and orientalism, followed by the literature review which was conducted through a genealogy of current understandings of consanguinity through three main areas of knowledge, which then informed the issues to examine further in the qualitative instrumental case study, through focus group discussions and in-depth interviews with the local Pakistani community and the Service Providers, which were both broken down into sub-groups. The analysis was conducted using the framework method, resulting in a suggested impartial understanding of consanguinity.

phenomenon, people, programmes, behaviours and processes (Hennink *et al.*, 2011). This definition purposively fits in well with the constructivist-interpretive paradigm that is to guide this particular piece of research. While the paradigms generally guide qualitative research, it is the methods specific to research design that have come to be defined in qualitative research that determine the tools to be used for data collection and analysis, as well as how to go about using those tools. In order to maintain transparency and context, it is important to understand some of the relevant methodologies that exist within qualitative research, the common factors that exist in these methodologies to reveal the true nature of processes and phenomenon, and indeed relate to the overall constructionist approach.

Besides the common defining features of qualitative research that have been discussed earlier, it would be helpful, in terms of the constructivist-interpretive paradigm in particular, to recognise the concepts of understanding and *Verstehen*, a concept previously introduced in chapter 2, as well as, the emic and etic perspectives within qualitative research methodologies. While understanding a phenomenon, process, population or idea is vital to any qualitative research, the concept of understanding itself can be taken in one of two ways. One way is to understand from a researcher's own perspective, using a set of available frameworks of reference on an issue or subject matter. This is referred to as *understanding*, conversely, understanding the issue through the perspective of the study population is referred to as *Verstehen* (Hennink *et al.*, 2011). If qualitative research is to be interpretive, it is vital to gain an understanding that people attach to their views and experiences, to gain an understanding that is *Verstehen*. Similarly, the emic and etic perspectives are used to describe the insider's and outsider's points of views, respectively (Hennink *et al.*, 2011). While the emic perspective is closely associated with *Verstehen*, the etic perspective can also be relevant, especially when it comes to the differences in the actions of what people say as opposed to what they may actually do (Morse, 1994a). In a constructivist- interpretive paradigm, it becomes important to allow the emic perspective to construct an explanation, but it is also

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important to have an etic perspective to interpret the explanation. So choosing an appropriate qualitative methodology for this research will mean identifying an acquiescent methodology that allows using both emic and etic perspectives in achieving the study objectives through a constructionist approach. Choosing an appropriate methodology begins with identifying, and in keeping with the conceptual framework, contextualising the various approaches available in the realm of qualitative research. There is not a definite number of approaches listed that one can emulate or eliminate when it comes to qualitative research, but there are certain approaches that have been more commonly used, developed and critiqued. The four approaches presented here in their least prescriptive sense, are phenomenology, grounded theory, ethnography, and finally case study, which as previously mentioned was deemed to be best suited.

4.3.1 Phenomenology

Phenomenology is used to study the shared meaning of experience of a phenomenon for several individuals and attempts to understand people's perceptions and understandings of a particular situation (Leedy and Ormrod, 2005, McCaslin and Scott, 2003). "The understanding of meaningful concrete relations implicit in the original description of experience in the context of a particular situation is the primary target of phenomenological knowledge" (Moustakas, 1994, p.14). Creswell (2009) alludes to the emic nature of phenomenological approaches in that the researcher sets aside his or her own perspective, called bracketing, on the subject being researched in order to only focus on the perspective of the study population. Historically, phenomenology was initiated by Husserl, re-theorised by Heidegger, and then formalised by the likes of Giorgi and others in the Duquesne Circle in the 1970s, and throughout the main focus has remained on the essence of the *life world*, which comprises of the world around, as perceived and experienced by oneself (Finlay, 2003). The researcher attempts to derive the essence of the experience. Though, in order to extract these experiences and understand their meanings, the role of the researcher becomes very important, as in most qualitative research where the researcher himself or herself is also a tool of the research (Leedy July 2013

and Ormrod, 2005), and in a constructionist way, a researcher bricoleur (Crotty, 1998), as previously discussed. It is in the manner the researcher poses questions and the types of questions to help subjects describe and give meaning to their experiences that also drives the research. As phenomenology has developed over the years, many variants have taken shape, and have mostly focused on enhancing either the aspect of the meaning of *life world* or the role of the researcher(s) in approach and in interpretation (Corbetta, 2003, Giorgi and Giorgi, 2003). Phenomenology has been used in deriving the meaning of a lived experience, however, the aspect of bracketing researcher's own views and obtaining a shared meaning from several different experiences while leaving out details of outside sources is counterproductive for this constructionist study. Even though further classifications of phenomenology like IPA (Interpretive Phenomenological Analysis) have answered some of these queries to an extent, they are not appropriate for this study as they require input from several researchers, which is not possible for this thesis.

4.3.2 Grounded Theory

When existing theories and understandings about a phenomenon are not well defined or are lacking or are possibly not present or wrong in general, a grounded theory approach is very useful, as it aims to develop a theory rather than dissect existing ones (Leedy and Ormrod, 2005). "In grounded theory, the researcher generates an abstract analytical schema of a phenomenon, a theory that explains some action, interaction, or process" (McCaslin and Scott, 2003, p. 449). The analysis is generated from collection of interview data, theoretical sampling by way of making several field visits, category formation and interrelation through constant comparison, and creating a theoretical model that is functional or context-specific (Corbin and Strauss, 1990). The name grounded theory emerges from the fact that the theory that is formed through this type of research is rooted or grounded in the data that is collected whilst doing the research (Leedy and Ormrod, 2005). According to Creswell (2009), the primary characteristics of grounded theory research are the theoretical sampling and constant comparison. The constant comparison refers to comparing the

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collected data in the research with emerging categories, thus constantly developing and redeveloping the theory that will eventually result from this analysis. Moreover, the aim of theoretical sampling is to attain information from different groups to saturate the similarities and differences in information (Creswell, 2009). In grounded theory, the researcher usually collects data using interviews that are unstructured as well as observing research participants in their daily lives. The underlying assumptions of symbolic interactionism set the stage for the examining process, and for clarifying stages and phases in the participants' experience. Developed from the thoughts of Mead and Blumer, as previously discussed in chapter 2, symbolic interactionism posits that meaning is constructed in a social context, negotiated through the interactions one has with his or her surroundings, and then changes over time and is conveyed through the interpretation of the participant (Crotty, 1998). Glaser and Strauss who co-authored *The Discovery of Grounded Theory* (1967) kept true to the basis of symbolic interactionism in describing the grounded theory approach. While Strauss later developed a more practical guide to doing grounded theory research (Corbin and Strauss, 1990), Glaser maintained the empirical formula of letting the theories emerge on their own was the only real way to do grounded theory (Glaser, 1992), arguing as other critics have that a formulated method may predispose the researcher towards identifying categories prematurely (Leedy and Ormrod, 2005). Nonetheless, the interview process in grounded theory seeks to elicit a participant's story, and this story is told sequentially as the events being reported unfolded. Comprehension is reached when the researcher has interviewed enough participants, through theoretic sampling, to obtain an in-depth understanding (Morse, 1994b). This understanding would more appropriately be termed *Verstehen*, due to the emic nature of the data collected. So, if the theory is developed using Strauss' formulated method or it is allowed to emerge using Glaser's empirical method, it is based fully on the data collected. While the rigorous data collection and constant analysis would propose impartial findings, as discussed earlier, it is not the goal of this constructionist research which utilises Foucauldian methods, to develop a new theory about

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consanguinity, which makes grounded theory an unsuitable methodological choice.

4.3.3 Ethnography

Unlike phenomenology and grounded theory, in ethnography, existing theories are neither completely bracketed nor altogether disregarded. Ethnography involves the studying, through observation and extensive time spent in the field, of an intact culture, social group, or even an individual(s) within a group (Creswell, 2009). Ethnography was initially used mostly in cultural anthropology, and it literally means to describe an ethnic group (Hennink *et al.*, 2011); it is however used in research other than anthropology, like sociology, psychology, education and health. At the heart of ethnography is the need to learn the meanings of actions and events to a study population. Understanding these meaning systems is the key to understanding their behaviours and their way of life. It is these meaning systems that constitute a culture they have built for themselves to live within, and an ethnographic study would aim to understand and possibly theorise this culture (Spradley, 1979). An ethnographer would not just focus on behaviour to study a culture, but would encompass an understanding of the economic, social and cultural context of the community being studied (Hennink *et al.*, 2011), all of which would be quite useful in this study. There is a need to study the group in their natural setting, and observations of and interactions with the community over a period of time, which are often lengthy (Leedy and Ormrod, 2005). Previous works related to consanguinity, especially pertaining to the Pakistani community either in the United Kingdom or in Pakistan, could be classified as either empirical ethnographies (Darr, 1990, Shaw, 2009, Shaw, 2000) or as being ethnographic in nature (Hussain, 1999, Ali *et al.*, 2008, Hasan, 2009). Certainly, some of the recent guidelines provided by Hennink, Hutter and Bailey (2011), for choosing to do an ethnography are relevant in this study, like the need to understand a community whilst getting a holistic view of the situation, gaining deep insights into the lives of the study population and the meaning they attach to the research issues, hence gaining an emic perspective while also maintaining an underlying theory of culture (Hennink *et al.*, 2011, p.47). However, focusing purely

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on the actions and lives of the Pakistani community, or even the town of Luton in general, may in fact limit the scope of this research in terms of understanding the phenomenon of consanguinity. Critics of empirical or holistic ethnographies have also argued that focus on the actions of a study population lacks reflexivity in research and increases subjective bias (Iszatt White *et al.*, 2004). Ethnomethodology or ethnomethodologically informed ethnographies are a compromise of sorts that introduce elements of phenomenology and grounded theory into ethnographies. The focus in ethnomethodology is on how people make sense of their actions rather than the actions themselves and the source is limited to only the data collected, limiting the subjective bias a researcher may attribute to the actions he or she observes. The argument against using this methodology would be that ethnomethodology tries to go too far away from subjectivity and constructivism-interpretivism, and possibly in the direction of objectivity and positivism. While this criticism has been defended feverishly (Sharrock (1995) as cited in Iszatt White *et al.*, 2004, Garfinkel and Weider, 1992) as either a move towards realism or away from an objective/subjective dichotomy, questions remain regarding ethnomethodology's stance towards the role of the researcher in an ethnography. Ethnography would have been more appropriate if the objective was to gain an understanding of only the Pakistani experience of consanguinity, but that would only be a part of the study. It is useful, however, in observing a poorly understood group of people, their behaviour and beliefs, sensitive issues and an in-depth exploration of communities. Even though ethnomethodology provides a link between phenomenology and ethnography, it would still focus on the phenomenon of consanguinity as it is experienced and lived by the particular group alone, whereas the strategy here is to incorporate both the understandings of the study participants, which includes different sub-groups, and those prevalent in the literature form a global perspective.

4.3.4 Case Study

Case studies are common in both quantitative studies and also in qualitative studies. The case study approach has also been used as an overall methodology, as well as a tool to supplement

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a wider piece of research that implements a different overall approach. Here, case studies will be discussed as an overall methodology rather than a methodological tool. In a case study, a programme, phenomenon, individual or a group of individuals are studied in depth over a period of time or limited through another defining feature (Leedy and Ormrod, 2005). Case studies in qualitative research thus are an in-depth analysis of systems that are bounded, where the focus may lie with the uniqueness of the case itself (*intrinsic*) or an issue that is highlighted by the case or cases (*instrumental*) (Stake, 1995). The case study is an investigation into this system, and relies on collection of data from different and dynamic sources. The role of the researcher is to “situate this system within its larger ‘context’ or setting” (McCaslin and Scott, 2003, p. 449). The researcher has the freedom to explore single cases of individuals or of whole organizations, interventions that can be simple or compound, as well as relationships, communities, or programmes (Yin, 2003). Phenomena can be deconstructed and later reconstructed, within context, using the qualitative case study research methodology (Baxter and Jack, 2008). However, much like other forms of qualitative research, the question of generalizability is often raised in connection with case studies as a criticism, especially single case studies as opposed to multiple or collective case studies (Leedy and Ormrod, 2005). Thomas (2011) uses Foucault’s idea of a ‘polyhedron of intelligibility’ to partially answer this criticism. According to Foucault, social sciences needed to be more multi-dimensional in nature and look at a subject matter from several different directions, to give a more thorough insight. This according to Thomas (2011) is an advantage of case studies, the ability to utilise multiple sources of information for a deep analysis of a subject that surpasses the need to look at multiple loci for the same subject to attain a generalizable assessment. Another advantage is the duality in nature of case studies that they are both flexible and rigorous at the same time (Baxter and Jack, 2008). They are flexible in the sense that the data can be collected in various ways, and as mentioned before, from multiple sources. They are also rigorous, however, in that the collected data must be analysed as a whole, rather than individually, to understand the overall context within

which the phenomenon is being studied. Moreover, there are well defined protocols that can be followed (Stake, 1995, Yin, 2003) in conducting a case study. Both protocols, Yin's and Stake's, provide a means to conduct a successful case study, but provide enough flexibility in process that different types of qualitative studies can fit into its overall mould. This flexibility then, along with the focus on understanding the issue, or system, within the context of its setting, is the reason why the case study approach is best suited for this research. The flexibility in protocol allows the incorporation of both phenomenological and ethnomethodological elements for rigour and adding richness to the findings through triangulation in methods, as previously discussed. By combining elements of phenomenology, in devising questions that best allow the participants to describe their lived experience (Leedy and Ormrod, 2005), with ethnography and ethnomethodology, in observing the meanings that the participants apply to their actions (Silverman, 2010), this case study protocol allows both the co-construction of meanings and interpretation of findings as stipulated by the underlying conceptual framework of the research.

So, this constructionist study presents a genealogy of consanguinity, through a critical literature review underpinned by the theory of discourse and orientalism, searching for underlying truths behind the discursive formations that have so far shaped the current understandings of consanguinity. These understandings are further examined and interpreted through the lives and experiences of Luton's Pakistani community and service providers, understanding consanguinity through its role in present day health and society. The overall approach is constructionist, using a qualitative instrumental case study methodology.

4.4 Research Strategy

This section will outline the research strategy taken, including details of the sample selection, study population and participants, the methodological tools, recruitment, analysis and possible limiting factors of the methodology and research.

4.4.1 Sample Selection

It is not always possible to get the view of every stakeholder, so there is a need to limit the sample to a manageable size (Miles and Huberman, 1994, Leedy and Ormrod, 2005). This is true for both quantitative and qualitative studies; though, the definition or assertion of manageable size may differ in quantitative studies versus qualitative ones. This is mostly due to the need for quantitative data to be generalizable, as well as attain certain significance levels in data collected (Hennink *et al.*, 2011). Sample selection usually involves first identifying the study population and then narrowing down the sample frame or study participants.

Qualitative studies must rely mostly on non-random sampling rather than random sampling, as in with large study populations and sample sizes in quantitative studies (Leedy and Ormrod, 2005). More specifically, qualitative studies involve purposive sampling (Miles and Huberman, 1994, Babbie, 2008, Leedy and Ormrod, 2005), due mostly to the logic and inference of social research that can be lost in randomisation (Miles and Huberman, 1994). Moreover, randomising can become biased in a small sample size of a qualitative study. However, when the sample size is large enough, a randomised purposive sampling strategy is indeed possible (Miles and Huberman, 1994). Also, purposive sampling should not be deemed to be haphazard or without method, as there are defined purposive sampling methods and principles that guide sampling (Hennink *et al.*, 2011). The sampling strategy must also align well with the overall conceptual framework of the research study. Lastly, the sampling strategy must be able to set a boundary encompassing the study population with the research means and creating a frame of participants that will best assist in uncovering elements under research, without saturation (Miles and Huberman, 1994, Hennink *et al.*, 2011). In this particular study, sampling strategy entails choosing Luton and the Pakistani community in Luton as the study population first, and then identifying the study participants.

4.4.2 Study Population and Rationale

In studying consanguinity, it becomes important to identify a study population that would
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allow exploration of the areas of knowledge that have formed the current understandings of consanguinity and examine further the sociocultural impacts and healthcare implications of this debate. Although consanguinity has been a global phenomenon, today, it is most common in North Africa, Middle East and South Asia (Bittles, 2001, Bittles, 2008). As discussed earlier in the Thesis Introduction, some of the highest rates of consanguineous marriages takes place in Pakistan, where the rates are reported as high as 77.1%, as well as up to 62.5% first cousin marriage rates (Bittles, 2001, Hussain, 1999). This tradition or trend or practice of consanguineous marriages is also evident in recent migrants from Pakistan or communities with origins from Pakistan, in Britain (Hasan, 2009, Modell and Darr, 2002b, Shaw, 2006). In contrast to other European countries like Norway, where studies suggest that there has been a successive decline in the numbers of consanguineous marriages from generation to generation, possibly due to increasing levels of education amongst the Pakistani ethnic group (Stoltenberg *et al.*, 1997, Stoltenberg, 2009, Grjibovski *et al.*, 2009), research suggests that consanguinity is on the rise in Britain in successive generations of Pakistani communities (Darr and Modell, 1988, Shaw, 2001, Hasan, 2009). In Luton, the British Pakistanis are the largest ethnic minority group (Office of National Statistics, 2004, Khanum, 2008, Office of National Statistics, 2011). This sets a good boundary for the study population, in terms of case study research protocol (Stake, 1995), that a community exists locally which traditionally practices consanguinity in a town with apt healthcare infrastructure which will allow the researcher the means to explore all facets of the study in a manageable way. Previous studies on consanguinity in the UK have been mainly conducted in areas with high Pakistani populations like Bradford, Birmingham, Manchester, Leicester and areas of London. These studies focused either on an anthropological perspective on the life, migration and settlement of Pakistanis in the UK (Rex and Moore, 1967, Dahya, 1974, Anwar, 1979, Lewis, 1994, Werbner, 2002a, Shaw, 2009) or on genetic associations of consanguinity with congenital malformations, disorders and haemoglobinopathies (Sinha *et al.*, 1997, Davies *et al.*, 2000, Sanderson *et al.*, 2006, Ravenscroft *et al.*, 2011), while some were

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ethnographies focusing on specific aspects of the experiences, opinions and attitudes of Pakistanis in varying cities and towns in the UK (Darr, 1990, Basit, 1997, Kalra, 2000, Ali, 2008, Hasan, 2009). All of these studies, as well as many others which have been cited throughout this thesis, have contributed greatly to understanding the varying perspectives on consanguinity. However, most, if not all of these works did not have consanguinity as the main focus of the study, it was only an aspect of the study or the issues discussed in the studies were relevant to the consanguinity discourse. Rex and Moore (1967), as cited earlier section 1.2, looked into the compartmentalisation of housing allotment by institutions according to social class, where the early migrants occupied the lowest classes, while Dahya (1974) suggested the behaviour patterns of these early migrants was driven by the economic nature of their migration, as they chose to send most of their money back “home.” This concept of back home was explored further in Anwar’s work on the myth of return (1979), where he suggested the idea of going back home to Pakistan was dissipating for these migrants, as they became settlers with established lives in the UK. Lewis (1994) focused on the emerging Islamic identity of the British Pakistanis in Bradford, as did Werbner’s (2002a) work with Pakistanis in Manchester. The issue of identity and settler evolution of the Pakistani/Kashmiri community was the focus of Ali’s (1999) thesis in Luton, while her later work focused on the differences in inter-generational attitudes of Pakistanis in Birmingham on consanguineous marriages (2008). Shaw’s *Negotiating Risk* (2009) focused on the idea of risk, as discussed earlier in section 3.5, in terms of marriage preferences in the Pakistani communities, while Hasan (2009) balances the medical and social costs of cousin marriages against the social benefits of family cohesion, value formation and liberty she found in the Pakistani/Kashmiri communities of Bradford and Birmingham. Studies that have looked to associate genetic outcomes with consanguinity in the UK (Sinha *et al.*, 1997, Davies *et al.*, 2000, Sanderson *et al.*, 2006, Ravenscroft *et al.*, 2011), have rarely addressed the social aspects of its participants, which was appropriate for the purposes of their mostly quantitative studies, which were to establish a link or association of consanguinity with

genetic/health outcomes. As stated above, all of these works add to the growing understanding of consanguinity and factors that have influenced the British Pakistani experience of consanguinity, however, none of them focus solely on understanding consanguinity, and all but one (Ali, 1999) have been based outside of Luton.

The reason why Luton has been chosen for this study rather than these other locations is due to a combination of reasons. Luton is a smaller town compared to the other cities mentioned above, and as such the populace is situated closer together, making it easier to do community based research in terms of logistics, geography and socio-economic dynamics. Moreover, Luton has enough similarities in terms of the history of the British Pakistanis and their migration, as well as their composition, with the bigger centres that a study conducted in Luton, acting as a microcosm of these other areas, will possibly have relevance elsewhere in the country. Also, there have been a number of studies already conducted in the other locations and there may be a case made for the over-studying or at least the feeling of being over-studied, within the Pakistani diaspora in those regions (Githens-Mazer *et al.*, 2010, Henderson, 2010), whereas previous studies in Luton (Ali, 1999, Kaur-Bola, 2009, Khanum, 2008), are relatively fewer in number, highlighting the need for further research in this subject area. As well, with the local focus on consanguinity increasing due to recent health reports (Taylor and Whiterod, 2011, Taylor, 2011), this work would benefit the local public health administrators by adding sociocultural context and further depth to the genetics and health findings. Furthermore, it is appropriate for practical purposes as the researcher is linked with the local university and is also accustomed to the language and culture of the study population, making it easier in certain situations to connect with the community participants (Darr, 1990).

4.4.3 Sample Frame (Study Participants)

The participant selection process in qualitative studies is usually guided by the principle of saturation (Hennink *et al.*, 2011). Simply stated, the principle of saturation refers to the repetition of information a researcher begins to receive from participants as no new ideas tend to emerge after

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successive interviews within a participant subgroup. The identification of the saturation point determines the number of participants required for a given research. The participant saturation may occur by population subgroup or subject matter. In studying consanguinity or studies related to the subject of consanguinity, there have been studies that have used large numbers of randomised study participants (Hussain, 1999, Al-Gazali *et al.*, 1997, Khlat *et al.*, 1986) and there have been others that have used relatively smaller participant sizes (Khanum, 2008, Croot *et al.*, 2008, Ali *et al.*, 2008). Amongst these studies, participants were not limited to only those that were in consanguineous marriages, opinions of lay members of the public, defined here as those members of the Pakistani community that were not married to their cousins, were also taken, and there was an effort made to include opinions from both genders and multiple age groups, for better overall demographic coverage (Ritchie *et al.*, 2003). Inclusion of sub-groups within a participant population increases the heterogeneity of the sample and thus increases the number needed to reach saturation overall, whilst reducing the sub-group saturation numbers (Mason, 2010). A major criticism of research into consanguinity has been the lack of attention paid to the homogeneity of selected sample (Bittles, 2010b). When reporting on findings of a consanguinity study, it is important to account for the difference in the demographics and socioeconomics of the study population (Hamamy *et al.*, 2011). A literature review of relevant studies, relevant in terms of the study design or to the subject matter, is shown in Appendix 1, the purpose of which was to assist not only in selecting an appropriate sample frame based on relevant, recent and well cited studies, but also to shed light on the recruitment strategy, data collection and data analysis tools most appropriate for this type of research. The studies included in the literature review were almost exclusively qualitative in nature, and most were ethnographies, yet there were some that were just generic qualitative studies with interviews and focus groups without a definitive sub-classification (Shiloh *et al.*, 1995, Rhodes *et al.*, 2008, Bywaters *et al.*, 2003, Khlat *et al.*, 1986). In order to understand (Verstehen) consanguinity, it is important to choose a study population that knows and

understands consanguinity as a daily part of their lives, rather than simply taking an expert's opinion alone (Entwistle *et al.*, 1998). However, there is an internal division within the study population, that of those that are in consanguineous marriages and those that are not, and it is vital to get the complete perspective to fully understand the in-group and out-group dynamics that form a community's identity and in-turn on the meanings they hold towards a phenomenon (Wilder and Shapiro, 1984). Indeed, studies about consanguinity have used both groups in their study population (Hussain, 1999, Ali *et al.*, 2008, Shiloh *et al.*, 1995, Khat *et al.*, 1986), and so have similar studies looking at other social and health areas of interest (Kaur-Bola, 2009, Rhodes *et al.*, 2008, Greenhalgh *et al.*, 1998, Williams and Healy, 2001). Gender differences and age-groups have also been used as further sub-groups of the sample frame. While Shiloh *et al.* (1995) reported no major difference in responses of male and female participants, and thus did not separate their findings, other studies have stressed the importance of obtaining views from both males and females in single and group interviews (Ali *et al.*, 2008, Rhodes *et al.*, 2008). Moreover, it is preferable to conduct these interviews separately when it comes to issues considered to be sensitive like consanguinity, owing to the hesitance of talking openly in a cross gender audience in the Pakistani society (Darr, 1990, Ali *et al.*, 2008). Selecting different age-groups, ranging from the age of consent up to retirement age, to account for differences in opinion, outlook and actions based on inter-generational gaps and waves of migration in the case of ethnic minorities (discussed in further detail in chapter 1) is also used to sub-classify sample populations (Ali *et al.*, 2008, Darr, 1990, Rhodes *et al.*, 2008). There have been other criteria used for either group selection and sub- classification or have been accounted for as differences within groups, like ethnicity (Atkin and Ahmad, 2001), level of education (Shiloh *et al.*, 1995) and economic status (Ritchie *et al.*, 1994). Although generalizability is not important in qualitative studies, the validity is crucial, which is why the group composition must be well defined and well represented in order for the results to hold meaning (Bittles, 2010b). From the above, it would seem that the sample frame for this study should include

members of Luton's Pakistani community that are in consanguineous relationships, and those that are not, as well as the expert opinions of service providers in health and social care. The inclusion of service providers in this study is important because in order to ascertain the perceived impact of consanguinity on healthcare, those providing this care must be consulted along with those that use this care, and indeed understanding the impact of their interactions on the consanguinity discourse. As such service providers from both primary care and secondary care are recruited to participate in discussions. Primary care here is used to describe the first point of entry to a health care system, usually through a GP or a family doctor, who provide person-focused care over time for most conditions and co-ordinate with other specialists as and when needed, while the secondary care refers mainly to the specialist consultants and non-accident and emergency hospital care, or referrals at specialist clinics, including social workers, psychiatrists and genetic counsellors (Akbari *et al.*, 2008, Gibbons *et al.*, 2012). Moreover, having accounted for ethnicity in the sample by recruiting only British Pakistanis, other criteria to include will be age group, gender, education level and economic status, to constitute a possibly well balanced sample. As discussed in chapter 1, according to two recent reports by the Luton town council, the economic status of the residents of Luton is below the national average and is fairly similar specifically in and around the Bury Park postal codes (Luton Borough Council Council, 2004, Council, 2011), which is where the majority of the Pakistani community resides, making it fairly homogeneous for economic status. The proposed selection criteria for the sample frame are shown in Table 4.1. However, it is not always possible to recruit participants based on all the criteria, which is permissible, as long as such limitations are acknowledged and the chosen sample falls short of the criteria goals (Garg, 2008). In this case, the level of education then was deemed as a secondary criterion, as fewer studies have listed it as a selection criterion, rather noting it as a difference in the groups and a possible factor in some responses, which turned out to be the instance in this study, discussed at length in the findings sections. The final list of study participants is listed under section 4.6.2.2 of data collection and July 2013

analysis.

Selection Criteria	
<i>Primary</i>	<i>Secondary</i>
Consanguinity status	Education Level
Age	Economic Status
Gender	

Table 4.1 - Selection Criteria

4.4.3.1 Methodological Tools

Both in-depth interviews and focus group discussions (or group interviews as they are sometimes called (Leedy and Ormrod, 2005)) are valuable tools of qualitative research, and have been the general data collection tools used throughout literature. They are ideally suited for particular types of qualitative studies, dependent on the study objectives (Hennink *et al.*, 2011). Independently, in-depth interviews are best suited when attempting to identify personal accounts, attain individual perspectives and beliefs, and exploring issues in detail. Similarly, focus groups are best utilised when trying to retrieve a range of opinions on a specific issue, or obtain a social context for how people talk about an issue, and how group interaction may shape responses (Hennink *et al.*, 2011, Lewis, 2003). Other dynamics, like the discussion of a sensitive topic can have varied results. On one hand, in-depth interviews can provide a secluded environment and confidentiality that may allow participants to discuss sensitive topics, as has been noted by Ali *et al.* (2008) and Darr (1990). However, focus group discussions can also provide participants with a cathartic feeling to discuss a sensitive topic, as others are also doing a similar act. There are also disadvantages to using each technique as opposed to the other, in that interviews may lack interaction and feedback from others and multiple interviews may be needed to obtain a range of issues, yet focus groups may lack depth in information and may be less suitable for personal experiences (Hennink *et al.*, 2011).

There are instances when both in-depth interviews and focus groups can be used together to

maximise the benefits of both. The objective here is not to obtain the same information through different mediums, rather it is to utilise the unique benefits of each to understand a phenomenon, consanguinity in this study, while counteracting the possible disadvantages of each method. Both in-depth interviews and focus groups can be used in the same study to explore a range of issues within a community through focus groups, identifying key areas of discussion, and then using in-depth interviews to gain individual experiences. Similarly, focus groups can be used after in-depth interviews to attain strategic information about issues identified by the interviews, choosing to focus on underlying factors and possible solutions (Lewis, 2003, Hennink *et al.*, 2011). It is however the sample frame, the subjects to be interviewed that will determine if solo interviews or group interviews will work best. The literature review in Appendix 1 shows that some recent studies have approached sensitive topics such as personal consanguineous relationships through individual interviews and obtained the lay perspective through the group medium (Ali *et al.*, 2008, Rhodes *et al.*, 2008, Khanum, 2008, Kaur-Bola, 2009), and it is this approach which is applied in this research. The collection of data from multiple sources works well with the case study methodology, and also provides triangulation of data collected, beneficial for a detailed analysis.

Coming back to the principle of saturation, it is usually difficult to set a number for the saturation point in a sample, however Hennink *et al.* (2011) infer that 2-4 interviews are usually enough to reach saturation in participant sub-groups. Moreover, 6-10 members in a group discussion have been described as suitable for managing group interactions and dynamics (Hennink, 2007) and have also been the average numbers used in recent studies. This may vary based on factors of the actual point of saturation as determined by the researcher, progressive focusing of interview questions and focus group topic guides. Actual sample sizes may be higher or lower based on the researcher's determination of saturation point. The sample size may also be dependent on the ground reality of participant recruitment, which can fall short of anticipated levels, especially whilst discussing sensitive topics (Garg, 2008), as such, the final sample frame is presented in the data
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collection section (Figure 4.4), showing the adjustments that had to be made to the initial proposed recruitment numbers.

As discussed above, the sub-groups were divided by age and gender. An advantage of dividing the groups by age is to gain dynamic perspectives from groups that are fairly new to consanguineous relationships, those that have been in one for a while and now have children from this union, and the older generation which may hold different values and possibly have different perspectives to the younger generation. While a little heterogeneity for the purposes of sparking a conversation is an important factor in group composition (Finch and Lewis, 2003), one of the reasons to attain similarity in group composition is to keep the focus on the questions being asked rather than individual differences and power relationships of the sample (Ali *et al.*, 2008). So the focus groups are also divided by gender and age group as well, consistent with the sub-group divisions in the consanguineous sample chosen for in-depth interviews. Overall, the sampling approach that this study uses is stratified purposive sampling, in which different sub-groups have been selected to display variation in terms of consanguinity, but they are fairly homogenous within the sub-groups, and participants took part in either focus group discussions or in-depth interviews, depending on the strategy discussed above (Ritchie *et al.*, 2003).

4.4.4 Participant Recruitment

This study required the recruitment of three different population sub-groups, members of Luton's Pakistani community that are in a consanguineous relationship and those that are not, as well as local service providers like general practitioners, specialist consultants, nurses, genetic counsellors, and social workers. Most successful recruitment strategies utilise multiple approaches in recruiting participants (as seen in Appendix 1), such as using gatekeepers, formal and social networks, snowballing, advertisements and opportunistic recruitment among other strategies. Moreover, different approaches are suitable for different types of groups, like gatekeepers are most

useful in identifying lay members of a community and formal social networks, registered charities and snowballing are best utilised to recruit participants with specific characteristics (Hennink *et al.*, 2011). This study also uses multiple recruitment strategies and sites for the above mentioned sample frame. Local mosque imams were approached as gatekeepers, in order to assist in lay participant recruitment from the mainly Muslim Pakistani community, with careful attention given to avoiding selection bias, a usual critique of this approach (Phillips *et al.*, 2004, Valdez and Kaplan, 1998). Registered organisations like *Friends of Bright Eyes and Disability Resource Centre* (run by the local council) were used to gain access to potential consanguineous couples, who were asked to possibly recommend others who might like to participate in the study (snowball). Snowballing can be particularly helpful in a close knit community, especially in the Pakistani community where strong links in the *biraderi* form social networks that are strong as well as vast (Shaw, 2009). Besides these social networks within the community, there are formalised networks within different community centres, which also assisted in recruitment. Service providers were approached directly at local GP Surgeries and at the Luton and Dunstable Hospital's various departments that have relevance to genetic disorders. Recruitment conducted at a local genetic counselling clinic run on the grounds of the Luton and Dunstable Hospital required site-specific NHS Ethics' approval, which was applied for and approved, as discussed in detail in section 4.5.1.

Recruitment of consanguineous couples at either the hospital or disability centres did not involve access to confidential patient databases; rather potential participants were invited to participate directly by the researcher or through flyers. Advertisements in the form of flyers were placed around mosques, local surgeries and shops and around the university campus to recruit younger participants. Some studies have used monetary compensation to recruit participants (Ali *et al.*, 2008), and this option was utilised for the community groups with care given (in formulation of advertisement flyers that did not overtly emphasize the compensation and a detailed information sheet which stressed the importance of the research as well as informed consent) to prevent elements

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of coercion. While the list of all recruitment sites was provided to relevant ethics committees for approval, they are not be identified by name within the thesis to preserve their anonymity. The names already identified above provided specific permission to have the facility name be used but not the individual participants. The recruitments sites included all of the above mentioned places and have been mapped out and represented in Figure 4.3, under the data collection section.

4.4.5 Issues Explored

After the literature review into current consanguinity understandings, two different topic guides were formulated (see Appendix 2), one to be used for discussions with the service providers and the other for the local community, both consanguineous and lay community, although some questions are specifically reserved for only the consanguineous members of the local community. The research questions addressed in the guides are based on current and newly identified issues from the literature review and the goal is to get participants to elaborate on these issues through their lived experiences (incorporating phenomenology) and help the researcher develop an overall understanding of consanguinity through their responses as well as observation of the participants' actions in their natural settings (incorporating ethnography), and interpretation of all literature in this regard to complete the study objectives (full list of research questions in Research Protocol, Appendix 3). The community topic guide questions were also designed in a manner to assess overall health behaviour, as per the previously discussed Health Belief Model (Champion and Skinner, 2008, Skolnik, 2012), to determine the perceived risks, benefits and barriers for consanguinity in the community and what they believed to be the cues to action that would enable health promotion and bring about possible behavioural change. The depth and range of knowledge about consanguinity were asked of both the service providers in order to not only gain knowledge about health behaviours but also assess the efficiency and appropriateness of service provision (Bywaters *et al.*, 2003). This was further explored in asking questions about service use and the possible impacts on service provision due to consanguinity and a higher consanguineous population,

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as suggested by earlier work (Hoodfar and Teebi, 1996). More generic questions were asked in terms of knowledge about genetics, keeping in mind that some of the participants may actually be hearing the word for the very first time; however, more detailed questions with regards to risks associated with autosomal recessive disorders and modes of inheritance were asked if participants showed enough basic knowledge. Even the phrase consanguinity was reduced to only cousin marriage in the topic guide for the local community, as previously discussed, most people in the general public equate consanguinity with cousin marriage only. A distinction was sought between ideas of incest and consanguinity, by asking the exact nature of relationship respondents feel are part of this discussion. In a bid to answer the ‘why’ behind the consanguinity phenomenon and as a way of exploring some of the anthro-psychological theories about consanguinity (see Incest Taboo, Natural Aversion, etc., discussed in more detail in section 3.3), motivations for marriage are explored often with the alternative options to be probed for by the interviewer. The depth and range of knowledge about sociocultural elements like the local community dynamics, cultural and religious beliefs and practices are explored to see the service providers’ level of cultural competency (Owens and Randhawa, 2004) and consideration for health equity and sociocultural health determinants (Collins and Johnson, 2009, Marmot, 2010) as well as the community’s interpretation of their own sociocultural views (Croot *et al.*, 2008, Greenhalgh *et al.*, 1998, Rhodes *et al.*, 2008). The respondents’ views were pursued in terms of the geo-political scene within Luton, to see if there was any impact in their minds, health behaviours or indeed outcomes. Finally, strategies to overcome perceived and real barriers to service use were discussed with both the service providers and the local community (Greenhalgh *et al.*, 1998, Hussain-Gambles, 2004, Raghavan, 2009).

4.4.6 Analysis

The analysis of this qualitative research needed to be complementary to this study’s theoretical grounding and research strategy, based on a constructivist-interpretive paradigm, which

is following a hybridised instrumental case study approach with elements of both phenomenology and ethnography in its design. So, the analysis required the focus to be on the setting and situation, the participant and their responses, analysing data as it came in as well as a whole data set, all the while interpreting and leading to the eventually constructed understanding. This analytical approach constitutes knowledge that is informed directly from the data (Harling, 2002). The constructivist-interpretive ontology assumes multiple realities, meaning that knowledge is experimental and individually determined (Denzin and Lincoln, 2005). While every informant may have a unique reality, not every reality is real or relevant. It is the researcher who interprets results to find the most common and relative data to help construct meaning. This collective and constructive meaning is derived from the data.

Most case study protocols loosely define the data analysis as a generic form of thematic analysis which has been described by many as either a method or concept that can be applied generically to all qualitative analysis. This analysis involves transcription, coding, categorising, conceptualising and theme formation. It has been called narrative analysis, thematic analysis, or simply qualitative analysis (Silverman, 2010, Miles and Huberman, 1994, Stake, 1995). Framework analysis is more structured (Ritchie and Spencer, 1994), following the same ideas as thematic analysis but with a defined process, adding consistency and reliability and even validity if peer-review of data through the same process results in similar interpretation. Similar to thematic analysis, framework analysis (see Figure 4.2) involves identifying themes, but it goes beyond theme formation with indexing and charting that organise data, giving structure and making it easier for interpretation and congruence (Ritchie *et al.*, 2003), and this is the data analysis method used in this research. All discussions were tape-recorded with the participants' permission and later transcribed using Express Scribe by NCH software and later analysed using QSR Nvivo version 10 software, essential for data management. Other computer assisted software were considered for analysis, including Nudist and Atlas.ti version 6, which are excellent tools for data analysis assistance, but
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Nvivo, and specifically version 10 was chosen because of the ability to incorporate the framework analysis concepts of indexing and charting. This would be possible in both Nudist and Atlast.ti, but would require the use of Excel spreadsheets as well to organise the framework matrices. The advantage of Nvivo for this research, which has a large amount of data collected from various sources, lay in its ability to centralise the data management to one location, allowing for easier interpretation by the researcher. It would be important to note that none of the computer assisted software automated the data analysis, since this is all qualitative data. The function of computer assisted data analysis in qualitative studies is limited to data management and organisation, the interpretation and actual analysis is conducted by the researcher, a feature of qualitative research and a requirement in this constructionist approach.

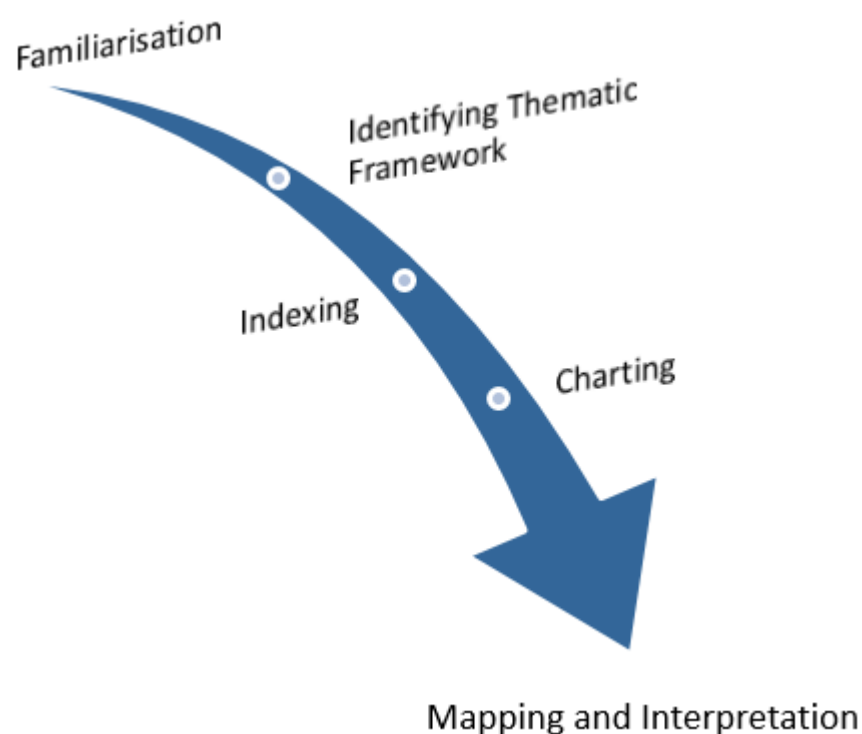


Figure 4.2 - Framework Analysis – Framework analysis method, presenting a more structured thematic analysis approach, including all similar elements of transcription, coding, categorising, conceptualising and theme formation. The framework method however goes beyond theme formation with indexing and charting that organise data, giving structure and making it easier for interpretation and congruence (Ritchie et al., 2003)

4.4.7 Possible Limiting Factors and Concerns

4.4.7.1 Insider Researcher

As mentioned earlier (section 4.4.2), one of the advantages of choosing the Pakistani community as a study population is that the researcher also has origins in Pakistan and can converse in Urdu and Punjabi. The benefits of an insider researcher include better trust, lack of exclusion, and ability to see empirical natural setting rather than what the participants would want an outsider to see (Zinn, 1979). Moreover, the researcher also has a background in genetics and medical studies, which may be useful in interviewing healthcare professionals. As an insider researcher, there are also concerns regarding ethics and subjectivity. Issues of subjectivity are always of concern in qualitative research, but as previously discussed, the researcher is also part of the study, especially in a constructivist-interpretive approach. However, recent research suggests that the concept of insider researcher based on ethnicity may be shifting, as groups tend to identify with researchers based on other characteristics including social class, education level and community membership in terms of geography (Culley *et al.*, 2007). Ethically, it is important for the researcher to maintain professionalism in research, which is needed to ask sometimes difficult questions, and to avoid taking undue advantage of participants and vice versa on the basis of insider researcher (Darr, 1990, Zinn, 1979). However, it is equally important to build rapport with participants, and when a researcher shares the ethnicity with his or her participants, then that may encourage the participants to share more of their experiences with the researcher (Ochieng, 2010). It then becomes a challenge for the researcher to balance the interchange with the participants by taking advantage of the rapport built as an insider researcher, while still maintaining the professionalism and line of inquiry, as not to effect the quality of the information being received (Seidman, 2012).

4.4.7.2 Access to female participants

Previous research has shown that it may sometimes be difficult for participants to address sensitive topics regarding marriage, children and disease with an opposite gender (Darr, 1990),
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especially in certain cultures based on cultural norms of communication between genders (Scupin, 2011). This may be seen as a barrier to recruiting female participants; in fact, Hussain-Gambles (2004) found in her research with South Asian patients that the female participants indeed considered the lack of a female health professional as a barrier to their participation in research. More specifically, Qureshi (1997) notes the same requirement of South Asian female participants to ask for a female presence for genetic counselling. Darr (1990) found it beneficial in her dissertation research that she gained much more access to the families because of her gender and was able to ask very personal questions that female participants, especially in cases of deeply conservative families, would be hesitant to answer or even be asked by a male researcher. Darr also found that the opposite was true when she had to ask such personal questions of male participants, finding that her access may have been limited due to the opposite gender. Although it can also be advantageous in addressing male participants' views (Lavin, 2010, Zinn, 1979), the researcher's gender in this study may present as a difficulty in recruiting and dealing with female participants (Zinn, 1979), and may require the use of a female proxy interviewer, who may have to be requested for from within the research team at the researcher's institute.

4.4.7.3 Interviewing Consanguineous Couples

The reason why consanguineous couples were chosen to be individually interviewed rather than be part of a focus group was due to the sensitive nature of the topic and the need to maintain confidentiality. This need of confidentiality and protection of the research subject becomes even more important when members of the same family are to be interviewed (Punch, 2007). The first decision for the researcher to consider is if multiple members of the family should be chosen for the same research study, and then to consider if they ought to be interviewed together, separately or both, and this also has an impact on how to recruit such participants and whether or not they can be recruited at all if one member of the family is chosen and another is not chosen (McGrath *et al.*, 2010). According to Beitin (2008), in discussing family therapeutics, particularly interviewing
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married couples, it is dependent on the epistemology of the researcher whether or not both members of the couple are selected for an interview or not. In social constructionism, it can be very important to obtain possible differing views to similar situations, adding richness of social interactionism into the research (Beitin, 2008). If both members are chosen to be interviewed, there are advantages in interviewing the couple together in that most of their answers will emerge after a discussion and the interaction gives ample material for research. However, the potential pitfalls in interviewing couples together can lie in the power relationships that may exist in couples where one gets overshadowed by the dominating partner, mostly male, although not necessarily (Lavin, 2010). This becomes especially important when discussing sensitive topics, as it can lead to incomplete answers due to the presence of the other member as well as tensions within the couple after the interview has been finished, and it is thus suggested that couples be interviewed separately for such issues (Hertz, 1995, Tecimer *et al.*, 2011, Valentine, 1999). However, there are also disadvantages of interviewing couples separately such as the aura of distrust that may develop where one member of the couple will wonder how and what their partner had replied to the interview questions, skewing possible answers and again creating discord in the couple afterwards (Tecimer *et al.*, 2011). These gender dynamics become even more exasperated when dealing with couples that are related and also living in joint households where multiple power relationships may exist (Darr, 1990). Hence, to avoid the potential risk to participants' personal lives, every attempt will be made to recruit only a single member of a consanguineous couple for interviewing, but to ensure a balanced view, the gender ratio will not be disproportionate.

4.5 Ethics

Ethical considerations before conducting a study are critical to both the approach and the intended outcomes of a research, especially as it pertains to qualitative research with human participants (Denzin and Lincoln, 2005). It is argued that ethics in qualitative research is two-fold,

one which is procedural in nature and another which is in the research practice, whilst conducting the research (Guillemin and Gillam, 2004). This research addresses a topic which is a potentially sensitive issue for some, especially in a location with a history of political and ethnic strife as previously discussed, with a population that has been perceived by some health professionals, perhaps incorrectly, as either closed or unapproachable (Ahmad and Atkin, 1996, Darr, 2009). So, it was ensured that both procedural and practical ethics compliance was addressed to limit bias or complacency and also respect the sensitivity of the topic and the setting, hoping to limit future denigration and allowing the results of the research to be useful for the local community. However, there was a distinction made in the fact that while consanguinity as a topic was a sensitive issue in terms of the discussions and implications around it, which would be addressed in the ethical approvals, the ethical considerations involved with specific interventions like abortion and genetic testing for example and the specific emotional responses associated with those services, would be separate as they would fall into the responsibility area for the healthcare service provision. As such, both NHS Ethics' approval and University of Bedfordshire Institute for Health Research Ethics' approval was sought, but first some of the potential ethical considerations of a research into a potentially sensitive topic of consanguinity are discussed.

4.5.1 Sensitive Research and Ethics

Sensitive research issues are not limited to those with political implications, but also any discussion that may be private, stressful or considered sacred, or may generate an emotional response like when discussing death or sexual relationships, as well as the aforementioned cultural and ethnic feelings of stigmatisation (McCosker *et al.*, 2001). Research into consanguinity would relate to all of the above mentioned trigger points for a sensitive research. Hence it is crucial to address some of the ethical implications of a research that may be stressful for the participants, as well as the researcher, who can become vulnerable to some of the emotional distress of either the participants due to a blurring of boundaries between researcher and participants, or due to the

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emotional impact of the topic itself on the researcher (Dickson-Swift *et al.*, 2006, McCosker *et al.*, 2001). While empathy is one way to reduce the impact on the participant for such research, it can lead to distress for the researcher, as per above, and self-care strategies like support groups and professional help (Watts, 2008). The same type of support should also be made available for participants, giving them access to or information about where to seek help from support group or professional counselling and psychiatric services. For this reason, the researcher made himself available for any follow up questions the participants may have had regarding the research or health services, as well as made arrangements with one of the young participants from the lay community group who worked in social services and offered to assist any and all participants who may need professional assistance due to distress caused by the research questions. It was decided that if any participants were to use this service through her, she would have to be withdrawn from the research as a participant. Whilst this did not occur, arrangements were in place to address this issue if it was brought up. Similar arrangements for the service provider participants was not made, until after the recommendations of the NHS Research Ethics Committee, after which arrangements were made with the local hospital's occupational health and safety department, in case their assistance was required.

In an attempt to overcome fears of stigmatisation, all participants were ensured that the research is not meant to target or alienate anyone; rather it was an opportunity to learn more about consanguinity and how services could be better geared to improve overall care through better understanding. The fear of sensitive or emotional research should not deter a researcher from touching on challenging questions, rather, by addressing such issues, the research becomes more emotionally valid and with the potential to remedy the negative impacts that may be associated with such emotions (Malacrida, 2007). The failure to account for such ethical concerns in not only sensitive research but any research would result in a lack of faith in the research results and the researcher, leave participants in a state of distress, as well as deter them from taking part in future

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research (Weijer *et al.*, 1999, Ruger, 2008). All participants were to be given a two part informed consent form, considered an essential part of any research (Sade, 2003), and modelled after the WHO template for qualitative studies and NHS Research Ethics Committee's requirements. The first part is an information sheet, while the second is a consent certificate that was to be signed by all participants (see Appendices 5 and 6). If required, translation in Urdu (which is the native language for most British Pakistanis as well as the researcher) was also to be provided for participants so that they could better understand the research and their roles as participants. A third person witness outside the research team was to be nominated to explain the research in case any of the participants was unable to read or comprehend the information provided (none of this was eventually required, but it was important to plan for it). Furthermore, as the discussions were to be recorded for later transcription and analysis, verbal consent was to be sought at the beginning of each discussion. All results are reported anonymously, with aliases being used to mask real identities, and the results are to be made available to all participants, upon approach, once the study is completed. All personal data recorded was kept confidentially in a secured and alarmed building at the University of Bedfordshire's Putteridge Bury Campus, with access limited to only the research team. As suggested above, participants also had the opportunity to contact the research team or administrators if they required further information or if they had a complaint or comment about the study. Research progressed after receiving ethical approval from both the NHS Research Ethics Committee and the University of Bedfordshire Institute for Health Research Ethics Committee, as stated earlier. The approval from NHS Research Ethics Committee was being sought mainly because the research involved holding discussions with NHS Staff at NHS Facilities, but also because the rigorous process of NHS Ethics' approval would ensure rigour and quality in research.

4.5.1 Obtaining NHS Ethics Approval

Before the end of 2011, it was the requirement of the NHS to obtain ethical approval from July 2013

a relevant NHS Research Ethics Committee if a research were to involve any member of the NHS Staff. This policy has since been changed and this is no longer a requirement. However, it was still a requirement when fieldwork was to start for this study and an IRAS (Integrated Research Application System) application was filled for ethics approval accordingly. The IRAS application is a centralised web location for various different applications and guidelines which need to be filled and followed before ethics approval is considered by the NHS. As part of this process, the research protocol, along with the advertisement material, recruitment sites, topic guide and consent forms were to be submitted for consideration by the ethics committee. This of course meant that all of the theoretical and methodological build up that had been discussed so far was now required to be put in practice and on paper. A lot of effort was spent on extracting a research protocol from the methodology described in this chapter which ensured the constructionist approach of the overall research remained paramount. The topic guides were generated from the issues that were raised in the critical literature review and were designed to address a vast range of issues in a limited time and a culturally sensitive manner. Furthermore, insurance liability documents were required to be submitted for protection of both the researcher and the participants, and the University's legal office was approached to provide this letter, something which had initially been missed in the ethical considerations for this research, but were obtained as per required. Once all the documents were ready, they were inspected by the supervisory team, who had to co-sign all documents. The document preparation took almost two months, and three drafts were submitted to the supervisory team before a final version was selected for submission, ensuring all relevant ethical considerations and required documentation was addressed.

Then another aspect of the IRAS process, the Site-Specific Ethics approval form, caused a long delay in commencing the research, although it did not prevent the electronic submission of the first part to the NHS Research Ethics Service for the East of England - Norfolk. The IRAS requires not only the main ethics forms to be submitted but also approval is needed from the local Research

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& Development department of the research site, the above mentioned site-specific ethics approval, which happened to be the Luton & Dunstable Hospital for this study. Another requirement was for a local collaborator at the hospital to sign off on the research, and essentially take responsibility if something goes wrong. This proved to be difficult as most staff were hesitant to put their name on the research, fearing an added involvement on top of their already busy schedules. It was due to the persistent support of the R&D department staff, for which there is great gratitude owed, and constant visits and approaches to the hospital by the researcher that someone finally signed off on the study as a collaborator and the study could then progress. The NHS Research Ethics Committee signed off on the research through a sitting of its provisional committee (NHS REC Reference 11/EE/0359), because the study presented was deemed to be non-interventional and a benign qualitative study which did not involve recruitment of NHS patients (see Research Protocol, Consent Form, Topic Guide, Research Advertisement and NHS Approval letter in the Appendices). There was only a single issue that the committee required further explanation for, which were the steps that would be taken if a participant becomes emotionally overwhelmed with the sensitive nature of some of the questions in the topic guide, which included a narration of a fictional infant patient story. The committee was subsequently informed of the arrangements made with the Luton and Dunstable Hospital's occupational safety office to provide psychological support to participants if needed, which was deemed satisfactory by the committee and approval was granted. The entire process of approval took close to four months and fieldwork commenced in November of 2011.

4.5.2 University of Bedfordshire IHR Ethics Approval

While the service providers were covered under the NHS Ethics clearance, the work with the community members was approved through the Institute for Health Research Ethics Committee at the University of Bedfordshire. This involved submitting a similarly detailed package of documents for this second portion of the research, including a separate research protocol, topic guide, research advertisements (see Appendix 4), information sheets and consent forms (Appendix July 2013

6), were prepared and submitted for approval. The document preparation for the University Ethics' Approval was made easier due to the diligence in creating the protocol for the NHS Ethics Committee. Since the studies explore similar topics pertaining to this research, these set of documents were prepared with minor adjustments. However, considerable time was spent again on generating a topic guide that was now to be informed not only by the issues from the critical literature review but also the issues raised by the service providers, which could be explored further with the community members due to the order of the studies, with the service provider study preceding the community discussions. The University Research Ethics approval was expedient and was received without objections, allowing for the second part of the fieldwork to commence from March of 2012.

4.6 Data Collection and Analysis

Even though a research design and strategy has been presented, the flexibility allowed in qualitative research (Creswell, 2009), especially in case study research (Runeson and Höst, 2009), means that pragmatism can be applied in data collection, as long as the deviation from protocol is not too major, meaning it would not require to re-apply for an ethics approval, or would not contradict the conceptual foundations of the research, then it becomes practical to adapt strategies inductively. Practicality, feasibility and efficacy should be used to judge ideas and practices, as this determines their rightness or fit for purposiveness (Kumar, 2005, Rorty, 1982). This research strategy has already been shown to be pragmatic in design, with the application of a mixed-method approach in hybridising elements of phenomenology with ethnography into the case study protocol, as previously discussed. Within the case study approach, a key pragmatic feature of progressive focusing exists, allowing certain ideas from the ongoing research to be refined or explored further as per the interpretation of the researcher (Stake, 1995). This is of course, a key difference in designing research and conducting research, as fieldwork usually requires adaptability to the

changing scenarios and doing so transparently and within the overall research strategy framework adds reflexivity and quality to data. Owing to this transparency and the pragmatic changes made to the already discussed research design are discussed below in this data collection section, as issues encountered and changes made to the topic guides, recruitment and analysis are discussed in more detail next.

4.6.1 Refining the Topic Guides and Discussions

As previously discussed (section 4.4.3.1), both focus groups and in-depth interviews were to be used for data collection, based on the brief review of research methodologies used in literature (see Appendix 1). Topic guides were designed for both the service provider portion of the study and the community research, which mostly explored similar issues. Furthermore, as per ethical safeguards, all discussions were tape recorded only with the participants' consent, with all audio recordings kept on an encrypted drive as per the protocol submitted to the ethics committees. The service provider study was conducted before the community work and as such, it was the first time the topic guide was put in practice. Partly because of time constraints during the secondary care focus group and partly because the participants seemed to be quite familiar with dealing with patients with genetic disease and its consequences, the portion in the guide where a story was to be narrated to seek the response and judge participants' emotional intelligence, was not used and instead the related questions were asked in a more generic manner. During planning, this would have seemed to be taking away from the weight of the topic guide, but in practice it actually prevented the discussion from becoming stagnant whilst participants read a five minute passage, and silence in a group discussion can be problematic (Hennink, 2007). This segment was later removed from the guide for the community study before it was presented for ethics approval. Other differences in the two topic guides pertained to a question inquiring about the participant demographics from the community members, and where the patient story for emotional intelligence was removed for the service providers, an excerpt from a political debate was included to gauge

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participant reactions to sociocultural elements of ethnic views in terms of consanguinity.

It was also challenging to essentially pilot the topic guide in front of a very knowledgeable audience, but the rigor in design, based on the critical feedback from supervisors and colleagues helped as the focus rarely deviated from the topics of discussion. What did change was the use of the research tools, as participants' rigid schedules forced revision in the strategy. Not all GP's or Consultants could agree to meet on the day of their respective focus group discussion, and as such, in order to still gain their views and add depth to the data, individual interviews were conducted with them instead, using the same topic guides. So where, there were to be two focus group discussions with the service providers, there were now two group discussions and three individual in-depth interviews. In fact, the first interview was more impromptu as it was never decided that an interview would actually take place. The meeting was meant to discuss the research in general to gauge the interest of the participant in taking part, however, when in the meeting, the participant consented and asked to continue on and ask questions. Since there was no recording device available, most of the interview was recorded by hand and as such there are fewer direct quotes from that interview, but the essence of the responses has been recorded. After this episode, the recording device (and backup) was carried to every meeting and discussion. This of course was very useful, as an impromptu group discussion was arranged when an interview was scheduled with consanguineous males, who were 50+ years old. The recruited participants were hesitant to take part in individual interviews as they were mostly from an old age community group and asked to be "interviewed" together. So, it was decided to continue on with the group discussion, but for this reason the consanguineous female 50+ segment was also changed from individual interviews to a group discussion to try and keep balance in the protocol. Furthermore, while the requirement for individual interviews for these respective groups was for 3-5 participants each, when these were changed into group discussions, a minimum of 6 participants were used. This was deemed to not be a major deviation from protocol as the principles behind the methodological tools' choice was

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followed and the data collected still fell in the ethical framework.

4.6.2 Recruitment Issues

Another issue in data collection stemmed from the problems encountered in recruitment, which again required some pragmatic changes to the research strategy. Community research was always deemed to be more difficult to recruit, as had been reported by previous works, and as such, it was decided by the research team to use a £20 shopping voucher as an incentive for participants, something not all that new in literature (Ali *et al.*, 2008), nor opposed by the University Ethics Committee. However, at first, it was the service providers who proved to be difficult to recruit. Based on the statistics on multiple deprivations and the concentration of the British Pakistani population (Luton Borough Council, 2011, Taylor, 2011), the recruitment sites were in an around the Biscot and Dallow Wards, and included the Luton & Dunstable Hospital as well as GP surgeries in the vicinity. For the secondary care group discussion, every effort was made to include service providers from different departments and roles. While the consultants were busy, they made time in their schedule for the discussion, but it was the representatives from the maternity department that were most difficult to recruit, as it was almost impossible to get a hold of their head of department and simply placing the advertisements in the office area was yielding zero results. Persistent approaches through phone calls, emails and loitering in the waiting area also did not help. However, an email was sent to the Director that oversaw this department, as they were signatory in acknowledging the commencement of this research as per R&D protocol, they were able to persuade a nurse and a midwife to attend from the department, and their contributions to the discussion were very valuable. The final map of all the recruitment sites is presented in Figure 4.3, and includes all GP Surgeries centring mainly on the Bury Park area, as well as community centres, disability assistance and charity centres, the local hospital and University of Bedfordshire.

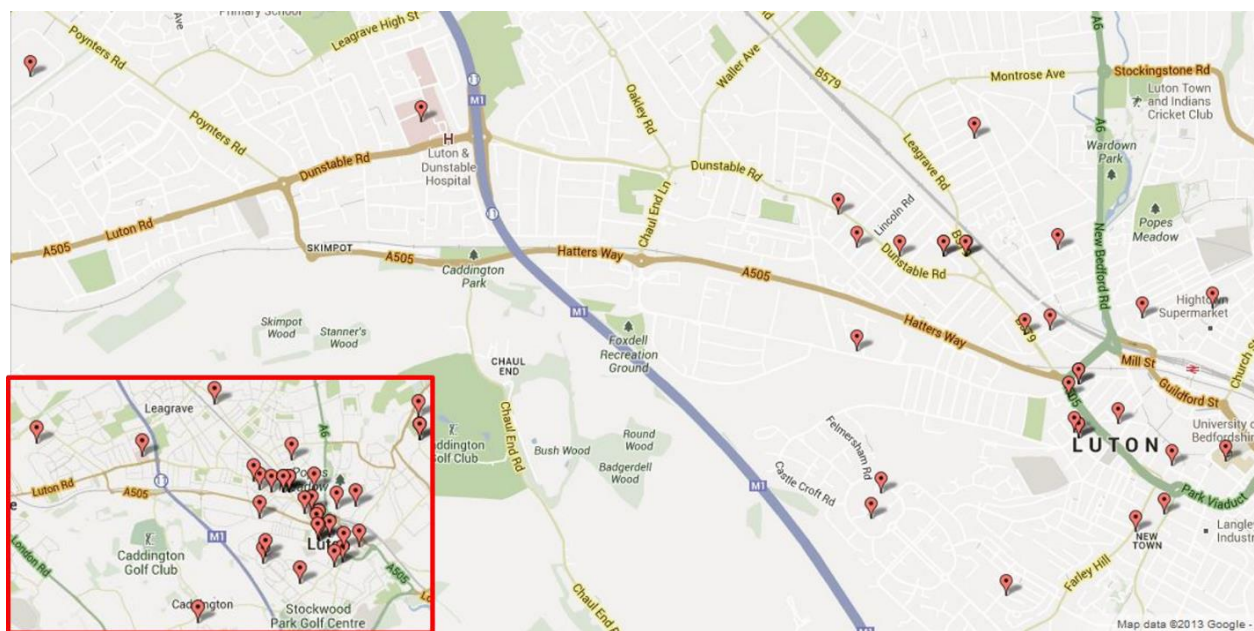


Figure 4.3 Recruitment Sites - Showing a map of all the sites that were visited to recruit participants for the study. The inset map is just a zoomed out version of the larger map to show the concentration of the recruitment sites around the Bury Park area of Luton, where a majority of the British Pakistani population resides.

4.6.2.1 Gatekeepers

Similar to gaining access to the nurses and midwives, access to the consultants was only granted once approaching the secretaries for the consultants. Receiving a staff identity card for the Luton & Dunstable Hospital was very useful as approaches could be made directly with the secretaries in their office space, which is usually off limits for visitors and patients. Face to face interaction resulted in many of the secretaries learning about the research in person rather than receiving a letter from their department heads or seeing the advertisement in the main lobby and bulletin boards. This personal relationship was then fostered with phone calls back and forth arranging for a suitable time for the consultants to attend the discussion, for which they were happy to do as it fit into their busy schedules. This cooperation and process was met with less success when recruiting the GP's at their surgeries. When the above process failed to result in any participants for the primary care focus groups, partly because of the reluctance of practice managers to make time in the GP's schedules and partly because it was difficult to be at all the different surgeries frequently enough so that familiarity could be developed, a concentrated effort was made

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to recruit very high profile GP's. This was a lengthier process but was beneficial when one such GP participant allowed a time slot in their monthly meetings for talking about this research. Once again, the talk then turned into a full group discussion with GP trainees and senior GPs in attendance, and with their permission, the discussion was recorded. While no incentives were used for recruitment of service providers, their only request was to be informed when the results would be disseminated, as most showed interest in the findings of this study. Persistence and self-belief were needed to get past the gatekeepers of the service providers, as at times one can feel like a salesman rather than a researcher, but if the effort is consistent and the study has substance, it does eventually pay off, as it did for the service providers' study.

Similar gatekeepers for the community research were also present. Different community centres and mosques were approached for recruiting community members and this was met with varying success. Rather than asking the mosque imams to appoint someone to take part in the research, announcements were made at mosques after Friday sermons and advertisements were placed in the bulletin boards. The community centres proved useful in recruiting the 30 years and above lay community members and to an extent the consanguineous members (especially the 50 years and above), however it was snowballing and word of mouth that mostly helped recruit the younger consanguineous community members. The younger (16-29) age groups of lay community members were recruited mainly at the university. When the advertisements around the university yielded poor returns, the employment office was very helpful in providing a database of a large number of students and their contact information. However, since this was not included in the research protocol, and seemed to be a major privacy issue, the University Ethics Committee was approached for approval of use of this database before proceeding to use it for recruitment. The database was further modified to show all students with British Pakistani descent who were from Luton and fell within the age group of 16-29 years of age. This group was then emailed (through blind carbon copy, so that others could not see the addresses of recipients) to take part in the study.

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This, in addition to the £20 gift voucher which was not made prominent in the advertisement, resulted in a large number of responses for the lay groups. It has however been difficult to recruit younger consanguineous community members, but through snowballing, the minimum required numbers of participants for this study, based on the idea of saturation (Miles and Huberman, 1994, Mason, 2010, Hennink, 2007) as determined earlier, have been achieved, and for the most part, the representation of the genders has been fairly even. The single sub-group where participation was limited to a single participant was the 16-29 male consanguineous community group, as a couple of participants confirmed than declined to participate, and there were not any alternate participants for this sub-group and it was decided to carry on with the data from the lone participant. This was mainly because it was believed that saturation had indeed been reached, as most responses from participants were repeating, as shown in the findings section.

4.6.2.2 Study Participants

The final participants that took part in the study are listed in the tables below (Tables 4.2, 4.3, 4.4), and preceded by the final sample frame in Figure 4.4, indicating the number of participants in each discussion. The identities of the participants have been protected and where names have been used, they are pseudonyms and not the real names of the participants. One concern in using pseudonyms is that with other defining characteristics of the participant, anonymity may get compromised (Corti *et al.*, 2000), this becomes an even bigger concern when using pseudonyms limited by the need to match the ethnic origin of a particular community or group, as in the case with the British Pakistanis. This is why there has been a concerted effort to use distinctively different names as pseudonyms for the participants, while the real names are kept confidential in the raw transcriptions of the discussions, viewable only to the research team, as per outlined in the ethics application. The tables below include the participants' pseudonyms and contextual information which will be used in the study findings presented in the following chapters. Although it is best practice to use self-described ethnicity information (Iqbal *et al.*, 2009), the ethnicity

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information from service providers was not collected, but was later deemed an important factor while analysing the results, as such the ethnicity information was assigned by the researcher but only major UK 2011 Census categories⁶ were used, which best described the participants based on researcher's knowledge of the participants and their backgrounds during recruitment.

⁶ Major or high level Ethnic Groups from ONS 2011 Census for England and Wales: White, Mixed/multiple ethnic groups, Asian/Asian British, Black/African/Caribbean/Black British, Other ethnic group. (These ethnic group categories are further classified to include specific ethnic groups like Pakistani and Bangladeshi under Asian/Asian British and Arab under Other ethnic group)

Available online from: <http://www.ons.gov.uk/ons/rel/census/2011-census/key-statistics-for-local-authorities-in-england-and-wales/rpt-ethnicity.html>

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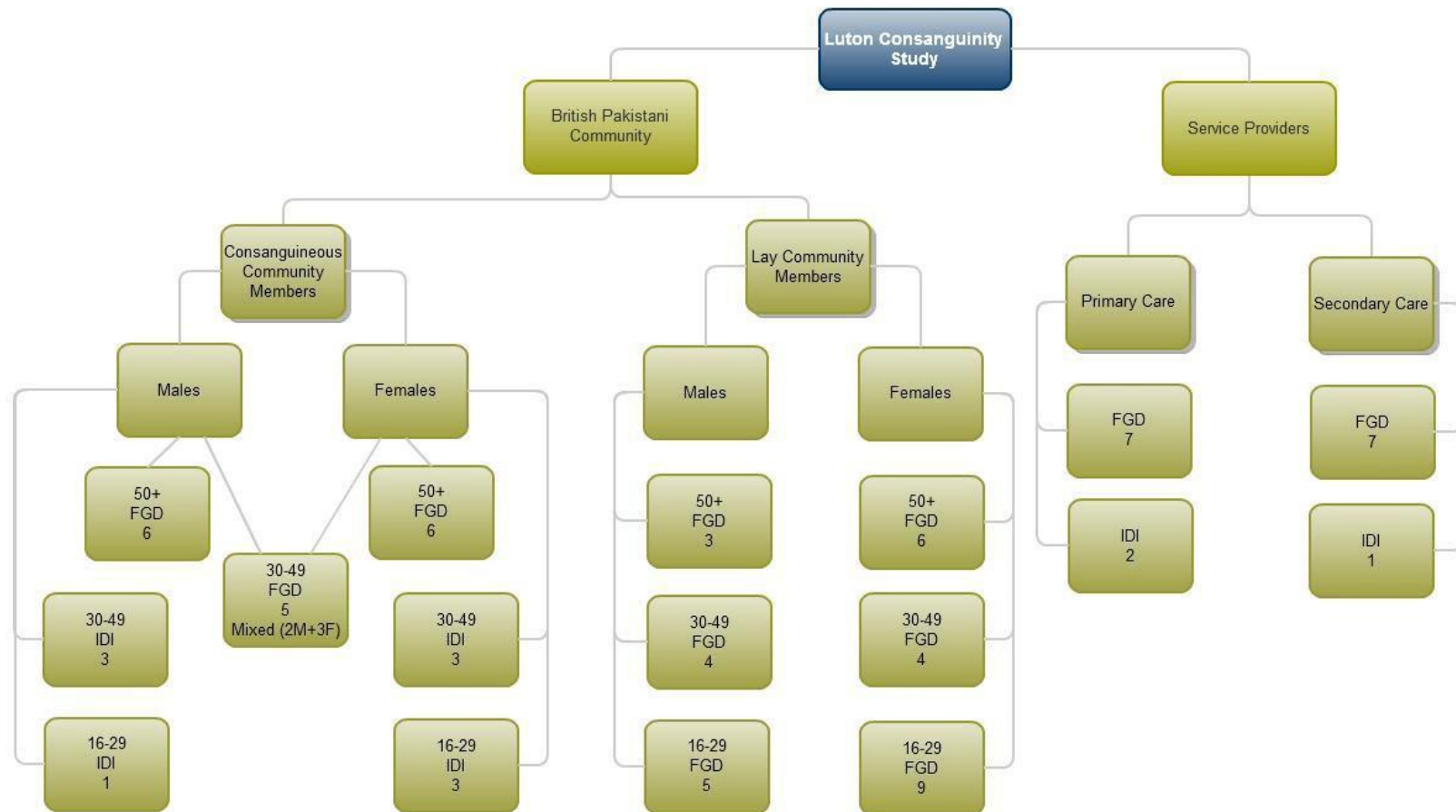


Figure 4.4 Sample Frame - The full study participants' breakdown is presented, with FGD referring to Focus Group Discussions and IDI to Individual In-Depth Discussions. The discussions are broken down into sub-groups depending on gender and age for the community and by Primary and Secondary care for the service providers. The number in the last lines indicates the number of participants in that FGD, while for the IDI, the number represents number of separate IDIs (each with a single participant).

Total Number	Discussion / Participant ID	Role	Gender	Ethnicity
<i>Secondary Care Focus Group</i>				
1	Participant 1	Social Worker	F	Black/Caribbean
2	Participant 2	Consultant	F	Other ethnic group
3	Participant 3	Nurse	F	Asian
4	Participant 4	Genetic Counsellor	F	Asian
5	Participant 5	Consultant	M	White
6	Participant 6	Midwife	F	White
7	Participant 7	Head Midwife	F	White
<i>Primary Care Focus Group</i>				
8	Participant 1	GP	M	Asian
9	Participant 2	GP	F	Asian
10	Participant 3	GP	F	Asian
11	Participant 4	GP	M	White
12	Participant 5	GP	M	Asian
13	Participant 6	GP	M	Asian
14	Participant 7	GP	M	Asian
<i>Secondary Care Interview</i>				
15	Individual Interview	Consultant	M	Asian
<i>Primary Care Interviews</i>				
16	Individual Interview 1	GP	M	Asian
17	Individual Interview 2	GP	M	Asian

Table 4.2 – Service Provider Study Participants – Shows the 17 service providers who participated in the study from primary and secondary care, with 14 taking part in two different FGDs and three taking part in IDIs, along with contextual information about gender and ethnicity (for later discussion).

Number	Participant Alias	Age Group	Gender	Education	Employment
<i>Individual Interviews</i>					
1	Sabeen	16-29	F	Post-Secondary	Employed
2	Samar	16-29	F	Primary	Unemployed
3	Reem	16-29	F	Primary	Unemployed
4	Laiba	16-29	F	Post-Secondary	Unemployed
5	Ahsan	16-29	M	Secondary	Employed
6	Nosheen	30-49	F	Secondary	Unemployed
7	Ruba	30-49	F	Secondary	Employed
8	Haris	30-49	M	Post-Secondary	Employed
9	Adeel	30-49	M	Secondary	Employed
10	Imtiaz	30-49	M	Secondary	Employed
<i>Mixed Focus Group Discussion</i>					
11	Hafsa	30-49	F	Secondary	Unemployed
12	Adeela	30-49	F	Primary	Unemployed
13	Riffat	30-49	F	Primary	Unemployed
14	Faizan	30-49	M	Secondary	Unemployed
15	Ismail	30-49	M	Secondary	Employed
<i>Focus Group Discussion – Females</i>					
16	Surayya	50+	F	Primary	Unemployed
17	Seema	50+	F	Primary	Unemployed
18	Razyza	50+	F	Primary	Unemployed
19	Nighat	50+	F	Primary	Unemployed
20	Kausar	50+	F	Primary	Unemployed
21	Zubaida	50+	F	Primary	Unemployed
<i>Focus Group Discussion – Males</i>					
22	Javed	50+	M	Primary	Unemployed
23	Munawwar	50+	M	Primary	Unemployed
24	Salman	50+	M	Primary	Unemployed
25	Yunus	50+	M	Primary	Unemployed
26	Gauhar	50+	M	Primary	Unemployed
27	Akram	50+	M	Primary	Unemployed

Table 4.3 – Consanguineous Community Study Participants – 27 Participants that were married to their cousins took part in 3 FGDs and 10 IDIs, with contextual information about education and employment status (for later discussion).

Number	Participant Alias	Age Group	Gender	Education	Employment
1	Fatima	16-29	F	Post-Secondary	Student
2	Sukhena	16-29	F	Post-Secondary	Student
3	Nazish	16-29	F	Post-Secondary	Student
4	Amina	16-29	F	Post-Secondary	Student
5	Saima	16-29	F	Post-Secondary	Student
6	Faiza	16-29	F	Post-Secondary	Student
7	Soha	16-29	F	Post-Secondary	Student
8	Bushra	16-29	F	Post-Secondary	Student
9	Chaman	16-29	F	Post-Secondary	Student
10	Abid	16-29	M	Post-Secondary	Student
11	Lawangeen	16-29	M	Post-Secondary	Student
12	Ikram	16-29	M	Post-Secondary	Student
13	Asif	16-29	M	Post-Secondary	Student
14	Usman	16-29	M	Post-Secondary	Student
15	Semra	30-49	F	Primary	Unemployed
16	Zeenat	30-49	F	Post-Secondary	Employed
17	Nargis	30-49	F	Secondary	Employed
18	Tania	30-49	F	Secondary	Unemployed
19	Inshaaq	30-49	M	Post-Secondary	Employed
20	Zain	30-49	M	Post-Secondary	Employed
21	Taimur	30-49	M	Secondary	Employed
22	Mujahid	30-49	M	Secondary	Employed
23	Saeeda	50+	F	Primary	Unemployed
24	Sakeena	50+	F	Primary	Unemployed
25	Zainab bibi	50+	F	Primary	Unemployed
26	Tahira	50+	F	Primary	Unemployed
27	Khalida	50+	F	Primary	Unemployed
28	Waheeda	50+	F	Primary	Employed
29	Muneeb	50+	M	Primary	Unemployed
30	Yaseen	50+	M	Primary	Unemployed
31	Daanish	50+	M	Primary	Unemployed

Table 4.4 – Lay Community Study Participants – Shows the 31 participants who took part in 6 different FGD divided by age, with contextual information about education and employment status included for later discussion.

4.6.3 Role of the Researcher

As discussed previously under possible limitations of this research (section 4.4.7.1), the last discussion in terms of data collection is focused on the role of the researcher as it applied to this research, in terms of subjectivity, insider researcher, the language barriers and the issue of interviewing female participants. In a constructivist-interpretive study, as mentioned earlier, the researcher becomes a tool of the research, a research bricoleur, in extracting experiences and understanding from the participants as well as placing this data in context with the overall setting (Leedy and Ormrod, 2005, McCaslin and Scott, 2003). In order to highlight the issue of subjectivity in research, a positivist research example will be taken, that of temporal displacement, a multi-disciplinary concept with different applications. Here it will be used to introduce subjectivity through a relativism and an experiential approach. Temporal displacement has evolved from defining an astronomical anomaly in determining transit times of celestial bodies to cognitive science in calculating the difference in response to stimuli based on distance and then to neuropsychology with the prediction of hypothetical situations and other forms of consciousness (Damasio, 2000). The one thing in common about all its applications is that subjectivity is highlighted and indeed proven in discussing temporal displacement. In other words, while studying the transit time of celestial bodies, different researchers recorded different times because of their different response to visual and spatial stimuli (Sinico, 1999). They differed in their ability to separate themselves completely from their present consciousness to project or accurately predict events, rather than reporting what actually happened, they reported what they perceived to have happened, and their perceptions varied. So, the issue of subjectivity is apparent even in positivist research, but in this qualitative constructionist research, it has been acknowledged and even built upon in the research design, giving an expanded role to the researcher to interpret different subject positions.

As such, an insider researcher has a further advantage and can recognise the empirical setting rather than getting the participant to set it for an outsider, and the insider researcher can build more trust with the participant (Zinn, 1979, Ochieng, 2010). While it is important to maintain ethical boundaries as an insider researcher (Darr, 1990), some caution and added responsibility must be taken as an insider researcher, as it is important when doing minority ethnic group research, not to become a “native informant” for the outsiders (Ali *et al.*, 2006), which can lead to continuation of stereotypes and devalue the conceptual framework of this research. With this in mind, it was useful for the researcher to be both Muslim and Pakistani, able to speak the common language and in addition for the service provider study, having a genetics background allowed knowledgeable discussions with medical professionals without feelings of intimidation and the ability to understand and evaluate any limitations in current genetic services.

While doing community research, apart from the younger age group (16-29 years), it became apparent that participants were more comfortable speaking in Urdu or Punjabi at times than they were with English. After sensing this, the choice was presented to conduct the discussions in Urdu. While most participants spoke either Punjabi or a dialect like Pahari, they were comfortable conversing in Urdu, the national language of Pakistan. This presented an added complexity in transcription of discussions, as words had to be translated on the go, which avoided pitfalls of representation of the participants by a translator (Temple and Young, 2004), but it opens up issues of translating findings, quotations and back translating to listen again to the audio transcriptions (Van Nes *et al.*, 2010). These issues are particular for researchers who conduct research in the native language of the participants, without using a translator, and the study recommends the use of a translator to avoid such setbacks (Van Nes *et al.*, 2010), however, others have argued the loss of meaning, especially in qualitative research, when the researcher allows representation of his or her participants by a third-party like a professional translator (Temple and Young, 2004). Esposito

(2001) suggests that the bridge between the source language and the target language is largely dependent on the translator's interpretation of not only the responses in the foreign language, but also on their interpretation of the questions being asked and the context behind those questions. This makes the researcher the better option to conduct such interviews, if they could speak the same language (Esposito, 2001), which is certainly the case in this research.

Speaking in the same language was a worthwhile exercise as it helped build rapport with the participants and more importantly, allowed them to easily take part in discussions. Still at times, perhaps due to the researcher's North American accent in English (with which introductions were initially made), participants at times showed hesitation in talking about "their" culture, making the insider researcher idea feel like a fallacy. Ochieng (2010) has spoken about her experience in researching participants of African descent as a researcher who also has African descent. The fact that her participants were mainly British born or lived mostly in the UK, whereas the researcher was from East Africa and was seen in her professional role capacity, set her apart from the participants (Ochieng, 2010). Similar dynamics were at play in this research where the participants had mainly been born or raised in the UK, while the researcher was seen as someone coming from North America and although there was common descent and spoken language, there were elements that made the researcher an outsider still. Such responses were followed up with empathy from the researcher to indicate that their meanings were understood and perhaps the experiences were also shared, this reflexive approach has been useful in allowing participants to open up and speak about experiences that they may have otherwise remained silent about with a non-reactive researcher (Bhopal, 2010). This helped in the participants returning to the point of discussion and carrying on in more detail, details that they may not have thought of themselves in the past, allowing a much richer and deeper look into their experiences to be co-constructed with the researcher (Etherington, 2007). This of course also works well with the overall constructionist approach and the co-

construction of meaning (Kincheloe, 2005). It also allowed the researcher to cope with some of the more difficult times during fieldwork, especially when some participants spoke about personal accounts of abuse in their relationships, or when parents with young children with disabilities spoke about their difficulties in dealing with their children's conditions, or how they coped with infant deaths, still-births and lost pregnancies. As discussed previously in section 4.5.1, sensitive qualitative research has an impact not only on the participants but also the researcher, exposing them to psychological stresses, feeling of anger, guilt and vulnerability (Dickson-Swift *et al.*, 2007). While arrangements were made to have participants speak with professionals about emotional distress if needed, self-care has been advised as the best strategy for researchers in dealing with such sensitive research (Renzetti and Lee, 1993, Rowling, 1999). As such, the researcher allowed for debriefing periods between sensitive interviews, as well as conducting analysis after a little period of time had passed from when the actual interviews took place.

The literature also informed of the difficulties accessing female participants for a male researcher, especially in the South Asian communities (Hussain-Gambles, 2004, Qureshi, 1997, Darr, 1990), the advertisement included a disclaimer that a female interviewer could be provided upon request. Furthermore, a female colleague was requested to attend, as a note-taker, in the first group discussion with female members of the community. While it was a useful exercise, it was deemed unnecessary as the participants were more than willing to converse openly with the researcher, one participant calling it, "like speaking to a doctor or a teacher" and that she could confide in such "respected" professions regardless of gender. However, it was made clear to these participants that while confidentiality was tantamount, they should be aware that the researcher was not in fact a doctor, to avoid misleading any participants. There was only one participant, in the young females' lay community group (16-29) who requested to be interviewed by a female representative. However, when she learned that other females of her own age group would be

attending discussion, and that it was a group discussion, she was eager to participate without asking for a female interviewer. This was a positive development, as it was thought that the researcher would have an advantage in obtaining male views only, but the willingness of the female participants to join discussions and speak up, made the discussions richer.

4.6.4 Data Analysis

As described in the research strategy, under section 4.4.6, framework analysis was used to analyse the data. The first step included transcribing all of the discussions, and as was described earlier, Express Scribe software by NCH was used to transcribe the discussions and then import them into QSR Nvivo v.10. All of the transcriptions were conducted by the researcher, including the ones in Urdu/Punjabi, which were first translated and then transcribed concurrently. As suggested before, Nvivo 10 was chosen to analyse the data because it allows better management of all data in one place including the framework matrices which are formed when charting, indexing and mapping as part of framework analysis (Ritchie and Spencer, 1994). A full list of all of the discussions, dates and locations of when and where they took place, as well as the length of discussion in minutes, is presented in Table 4.5.

All of the transcripts were loaded into Nvivo, as well as the corresponding audio recordings. Since the discussions were conducted by the researcher himself, as well as all of the transcriptions, the first step of familiarisation in framework analysis was already underway. When importing the data into Nvivo, the thematic framework started to become apparent. As a first step, all of the transcripts were coded (using nodes in Nvivo), and later arranged under themes and sub-themes. As part of triangulation, all of the audio recordings, transcripts and coded transcripts were made available to the supervisory team, Dr. Ali and Professor Randhawa, who selectively validated the transcriptions and coding. In consultation with the supervisory team, the themes and sub-themes were further focused and the framework matrices were formed. The data were divided into three sub-sets, one

for each major group, the service providers, the lay community and the consanguineous members of the community. Under each group, each major theme had a framework matrix of its own, which included all the different sub-themes and the corresponding quotes from each discussion (within the group). In order to maintain the context of the spoken quotes, the audio files (exact time stamp of the quote) were linked directly to each coded quote, allowing anyone that was rechecking or retracing the work to be easily able to follow along the discussion and the spoken context by the participants. As stated earlier, some of the discussions were held in Urdu and Punjabi as per the request of the participants. These discussions were translated by the researcher (who is fluent in Urdu, Punjabi and English) whilst transcribing in English. The framework matrices were then mapped together and the data was then interpreted as a whole before writing up the findings and discussion chapters.

4.7 Reflection on Methodology and Fieldwork

Before summarising the methodology chapter, I would like to give a personal account of the issues encountered during the recruitment and fieldwork stages. For this reason, this section, along with the reflection in the Thesis Conclusion will be written in first person, in contrast with the rest of the thesis. After confirming my methodology choice, I had to look into recruitment of participants. I wanted to include not just the local British Pakistani community members in this research, I wanted to also get the opinions of the local service providers, because no opinion about a subject matter that involves aspects of healthcare would be complete without including those that deliver this healthcare. However, the inclusion of service providers meant seeking approval from the NHS Research Ethics Committee. This process was long and required a set research protocol with complete topic guides and recruitment details. While it seemed to be difficult, it was exactly what was required for me to organise my data collection approach. The only negative aspect of this process was the requirement of the NHS to obtain a local collaborator from the local recruitment and research site which I had listed as the Luton and Dunstable Hospital. Even though the Research and Development department

Discussion ID	Date Held	Location	Total Participants	Audio (Time)
Service Provider Discussions				
Secondary Care IDI	28/11/2011	Luton & Dunstable Hospital	1	No audio*
Secondary Care FGD	21/11/2011	Luton & Dunstable Hospital	7	74m14s
Primary Care IDI 1	20/12/2011	Local GP Surgery 1**	1	61m45s
Primary Care IDI 2	19/1/2012	Local GP Surgery 2**	1	59m57s
Primary Care FGD	14/12/2011	Local GP Surgery 3**	7	60m43s
Lay Community Discussions				
Males 16-29 FGD	25/4/2012	University of Bedfordshire	5	80m44s
Females 16-29 FGD	20/4/2012	University of Bedfordshire	9	74m02s
Males 30-49 FGD	24/5/2012	Discover Islam Centre	4	63m51s
Females 30-49 FGD	10/7/2012	Khidmat Organisation	4	96m47s
Males 50+ FGD	8/3/2012	Khidmat Organisation	3	51m59s
Females 50+ FGD	7/3/2012	Khidmat Organisation	6	87m37s
Consanguineous Community Discussions				
Male 16-29 IDI 1	28/7/2012	Khidmat Organisation	1	54m01s
Female 16-29 IDI 1	16/3/2012	University of Bedfordshire	1	62m18s
Female 16-29 IDI 2	12/7/2012	Khidmat Organisation	1	61m43s
Female 16-29 IDI 3	12/7/2012	Khidmat Organisation	1	33m13s
Female 16-29 IDI 4	12/7/2012	Khidmat Organisation	1	36m47s
Male 30-49 IDI 1	19/4/2012	University of Bedfordshire	1	53m26s
Male 30-49 IDI 2	24/5/2012	Dallow Learning Community Centre	1	69m15s
Male 30-49 IDI 3	20/7/2012	Khidmat Organisation	1	60m48s
Female 30-49 IDI 1	7/3/2012	University of Bedfordshire	1	52m18s
Female 30-49 IDI 2	19/4/2012	University of Bedfordshire	1	78m57s
Mixed 30-49 FGD	9/6/2012	Discover Islam Centre	5	68m37s
Male 50+ FGD	8/3/2012	Khidmat Organisation	6	59m03s
Female 50+ FGD	7/3/2012	Khidmat Organisation	6	86m18s

Table 4.5 - Details of Interviews and Focus Groups – This table provides a full list of all of the discussions, dates and locations of when and where they took place, as well as the length of discussion in minutes. *The first interview with a consultant from secondary care was not recorded due to the impromptu nature of the interview, however the interview was recorded on paper by the researcher, as explained in section 4.6.1. **The local GP Surgeries are not named here to protect the identity of the participants.

(FGD = Focus Group Discussion; IDI = In Depth Interview)

at the hospital was very helpful in getting all the paperwork ready, it was near impossible to get a local collaborator to sign on for the study, and all that was to be required of them was a mere signature with no actual research involvement. It took many trips and few persuasive emails to finally have one of the department heads sign on for the study and I was able to submit my full application to the NHS. It was also good to get external feedback on my research from NHS REC members, and it was even better to know that they approved the research and my protocol without objections. The research similarly passed through the University of Bedfordshire's research ethics committee.

Recruitment started off in a flurry and I had my first focus group discussion and individual interview with the secondary care service providers within six weeks. The only difficult part was to fit in all of the busy schedules of the service providers for a group discussion. I am very grateful to them for taking time out to discuss this important issue. Contrary to previous warnings, there was no hesitation on the part of the service providers to discuss this issue, there only concern was with the time constraints. As such, a little pragmatism was required in adjusting the research protocol to include both group discussions and interviews with the service providers, to ensure participation of all those that wanted to participate but were not available at the designated time for group discussions. In the focus group discussion with the service providers, the overall feeling was the participants were genuinely concerned for their patients' health and clearly felt that consanguinity was a subject that had a great deal of impact on their particular patients. An interesting observation from the focus group with the secondary care service providers was that when the discussion moved towards discussing the relation of consanguinity with negative health outcomes and with Pakistanis, there appeared to be a divisive line between the participants as one side of the room vociferously adhered to this link while the other half remained either sceptical or silent. It was also noteworthy that the former half were all White while the latter were all of other ethnic groups. The discussion started to get dominated by the former half, as they continued to agree with each other's comments, and I had

to mediate to encourage responses from some of the other participants. In terms of their responses, I felt that while the consultants and the genetic counsellor were very knowledgeable in terms of genetics, the nurses, midwives and the social worker were quite clearly not. While this would not be unexpected, it was still interesting to note how persistent the midwife and the maternity nurse were in their view that consanguinity had a clear link to infant deaths, but could not articulate the genetics behind the link. I had hoped to gain more participation from the social workers, but only had one give time and this social worker was most interested in talking about the impact of forced marriages in this debate. So each participant had their frame of reference with which they viewed consanguinity, and it was good to have professionals from different areas of health and social care to give voice to their opinion on the matter.

Getting time for a discussion from the primary care doctors proved to be even more difficult, even after recruiting from more than fifteen different surgeries in the local vicinities. Again, the hesitation in participation came not because of the subject matter, but due to time constraints. Often, the doctors were keen to participate but the practice managers were more difficult to get past to get the message to the doctors about the study. However, I was able to get enough participants for another focus group discussion and two more interviews. The responses from the primary care GPs showed for the most part that they too were convinced of a link between consanguinity and negative health outcome, but they were less knowledgeable or perhaps less confident in articulating their knowledge about the specific genetics behind the link. When one GP mentioned the unusually high numbers of infants with heart defects or with disabilities in their surgery, they failed to acknowledge the overall high number of patients in the surgery or the social deprivation in the ward the surgery served. The primary care GPs were however more knowledgeable about the cultural aspects of consanguinity based primarily on the fact that most were South Asians and were more often than not familiar with Pakistani and Muslim culture. Some of the respondents in the community discussions stated how

they felt that South Asian doctors were harsher in their attitudes in doctor-patient communication. This was evident from some of the primary care participants' responses, as they were critical of their patients whom they felt deliberately continued to marry within cousins even when in their view there was overwhelming evidence linking this to disabilities and negative health outcomes. From their responses it seemed that they believed because they were the same ethnicity, they could be blunt with their words and not be called out for racism, which they said their White colleagues were wary of in these discussions with minority patients. Although, the community members' responses showed that this attitude from South Asian doctors is not well received and can act as a barrier in their access to care, as discussed in the previous chapter.

The recruitment for the lay community discussions was steady and there were group discussions held with good frequency. The recruitment for the younger participants was made easier with the assistance of the career recruitment office which provided email addresses for all university students of Pakistani ethnicity. There was special permission sought from the University Ethics Committee before using this dataset, and recruitment progressed only after approval was given. The other participants were recruited mainly through two local community centres, who also generously allowed the use of their premises to hold the discussions. The community centres, a local disability charity service and snowballing were crucial in recruitment of the consanguineous community members. However, recruitment for male members of the 16- 29 age group in the consanguineous member discussions proved difficult and there was only a single participant from this gender and age group where at least three were expected. Since there was a large amount of data collected from all the community discussions, it was felt that saturation could be achieved without getting ample representation from this sub-group. There was little difference in the responses of the two different community members' groups. As mentioned earlier in the findings, their knowledge of genetic risk was minimal and was exclusively through the consanguinity context. The topic guide was designed

to gradually build up the discussion towards consanguinity, but respondents in these discussions seemed edgy and wanted to quickly start talking about consanguinity. It almost felt like that they were expecting me to want them to talk about consanguinity as much as possible, because that is what they have come to expect of research studies into consanguinity, which threatened to have their responses be based on social desirability rather than actual experiences (Krefting, 1991). So, even when they were asked to introduce themselves and talk about where they were from in Pakistan, they would almost always mention if they were or were not married to their cousin and some would even add “and I think what you say is right, that cousin marriage is bad”. There of course was no such inclination given to them from me, but they presumed my position would be the same as what they had heard in the media. For this reason, some reframing of questions was required to ensure a response based on experiences. It turned out that most respondents felt that the “bad” in cousin marriages was mostly related to sociocultural issues, while they remained sceptical of health issues being linked to consanguinity. Perhaps the most telling example of this overall view was from the discussion I held with the parents of children with disabilities. Even though these parents were advised by the doctors that their children’s disabilities were linked to consanguinity, and even though one of the respondents had gone through eight pregnancies with multiple infant mortalities and only one “normal” child, they still did not know much about genetic risk, and did not believe in links to consanguinity. Their main concerns were with the cultural aspects of their arranged marriages and the day to day struggles in dealing with a child with disabilities.

Once all the data was collected, it had to be transcribed. As mentioned earlier in section 4.6.3, one of the complexities of data collection was that some of the discussions had to be done in Urdu or Punjabi, which added a layer of difficulty when transcribing the discussions verbatim. Some of the Punjabi idioms used had no literal translation in English, but I tried my best to draw out the essence of participants’ comments. This did add time to an already time consuming exercise, and

overall, data collection, transcription, analysis and writing up the results took nearly an entire year.

4.8 Summary

This chapter presented a detailed description of the methodology used to conduct this research. In keeping with the constructionist conceptual framework of this research, the choice of research methodology was contextualised and justified in relation to other possible approaches. A hybridised instrumental case study design was chosen with elements of both phenomenology and ethnography. This approach added rigor through triangulation in data collection. The chapter then presented the proposed research strategy taken in relation to the sample selection and recruitment, research tools used and the analysis of collected data. The data analysis was conducted using the framework method. The critical literature review of the current understandings of consanguinity helped inform the issues explored as well as best practice in terms of the tools used for exploration, helping place theory into practice. The research strategy was followed by the ethical considerations for this research, including discussing the sensitive nature of this research. Ethical approvals were obtained from both the NHS Research Ethics Committee as well as the University of Bedfordshire's Institute for Health Research Ethics Committee. While the research strategy outlined the proposed approach, the data collection section detailed the changes that had to be implemented to the proposed approach based on issues encountered in the field. This included refinement of the topic guides through progressive focusing, a feature of case study research. Other issues included recruitment hurdles in terms of access to potential participants beyond gatekeepers and adjusting data collection tools and schedules to better suit participants. Lastly, this chapter also discussed the role of the researcher in conducting the research and data collection, where the researcher became part of the research in a way which is indicative of qualitative research and the constructivist-interpretive paradigm. The next three chapters will present the findings of the fieldwork, followed by a discussion of the presented results in light of literature and theory.

CHAPTER 5 - SERVICE PROVIDERS FINDINGS

5.1 Introduction

This chapter turns its attention to the findings from the discussions held with the service providers from Luton. As previously discussed, the aim of this research is to construct an understanding of consanguinity through examining its sociocultural impacts and the implications for healthcare. Given that, one of the main objectives of the study was to ascertain the knowledge and views of Luton's service providers about consanguinity and all the elements of this discourse, considering the important role service providers play in healthcare delivery, the uptake of healthcare messages and services as well as ensuring positive health outcomes. This important role of the service providers has been expanded further with the recent changes in the NHS giving doctors control over their local health areas through Clinical Commissioning Groups (CCG). The objectives of these changes is to improve health equity, by removal of avoidable inequalities, and a focus on local rather than national priorities (Gridley *et al.*, 2012). This is where the local service providers are crucial to understanding consanguinity, as highlighted by the local health report in chapter 1, local service providers have highlighted consanguinity as a modifiable factor in infant deaths (Taylor and Whiterod, 2011), essentially declaring it as an avoidable inequality. Moreover, the service providers' interactions with the local community influence their understandings of consanguinity as well, and thus to attain a better understanding of consanguinity, service providers from both primary and secondary care were invited to participate in this research, as discussed in the previous chapter. There were two focus group discussions, one with primary care and another with secondary care service providers, as well as three individual interviews, two with primary care and one with secondary care service providers, for a total of seventeen participants in this part of the study, as shown earlier in Table 4.2 and in Figure 5.1 below, which shows the focus of this chapter being on the service providers in relation to the entire study.

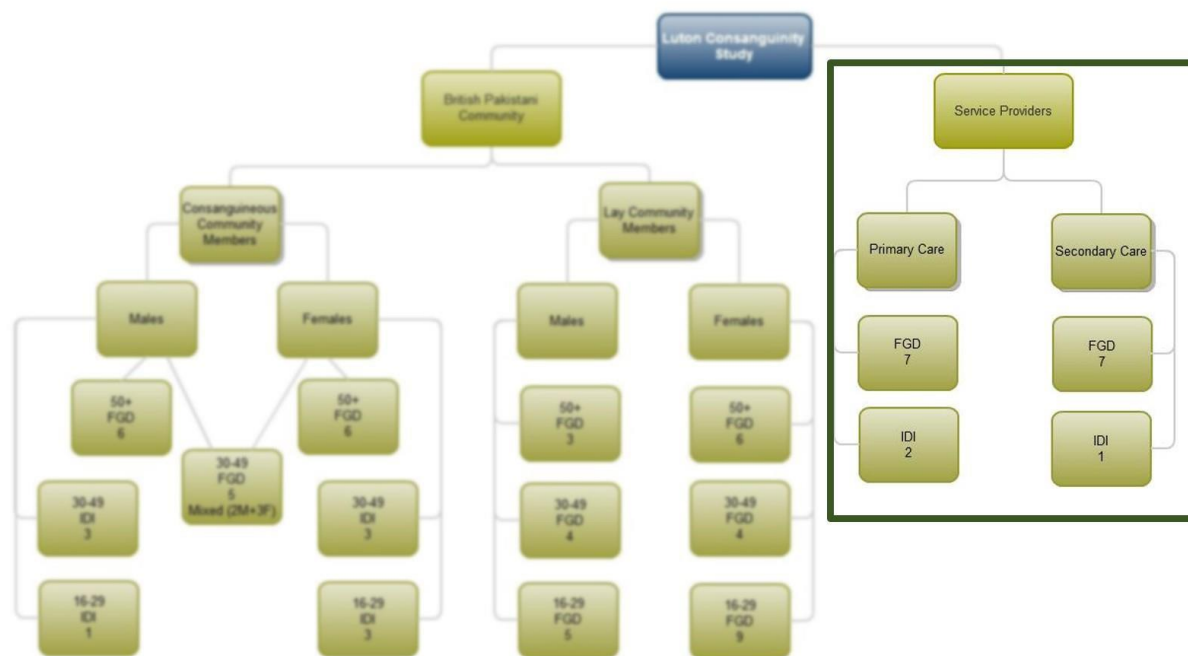


Figure 5.1 Service Provider Study - This figure shows that the focus of this chapter is on the findings from the service provider portion of the larger study. (other parts of figure intentionally blurred)

The findings from the focus group discussions and the interviews with service providers are presented below thematically. Where relevant, comparisons are made between the views of primary care and secondary care service providers, but there were not many contradictions in their views. The discussions focused on the service providers' perceptions of consanguinity, the role of religion and ethnicity in consanguinity, cultural aspects of consanguinity, the hereditary risk associated with consanguinity, delivery of healthcare services with regards to consanguinity and strategic actions that the service providers felt were necessary to address in terms of consanguinity in Luton. The extracts from the narrative are provided verbatim to highlight the way in which service providers view consanguinity and the importance they ascribe to its impact on healthcare.

5.2 Perceptions of Consanguinity

Overall all the service providers had a good general awareness of consanguinity and many quoted the definition of consanguinity that had been provided in the study information sheet. Only one participant said that she had not heard cousin marriage being referred to as consanguinity

before. During discussions none of the respondents made the distinction between consanguinity, defined as encompassing any marriage union between second cousins or closer (Hoodfar and Teebi, 1996) or the more popular and broader term of cousin marriage which could be a marriage union between cousins. In other words the two slightly separate definitions were used interchangeably throughout conversations. What was particularly interesting then was the way in which some respondents expressed negative views about the practice of consanguinity and in some cases ascribed stigmatised language that circulates in the Western world, linking cousin marriage, rather than consanguinity to inbreeding and incest.

“I was talking to a patient in hematology and she it was her second child. (The consultant said to me to do the family tree, and I started doing the family tree, and it was horrendous and (sic) five sisters married to the five brothers!” - Participant 3, Female, Primary Care FG

“Even when they know (about risks associated with consanguinity) they go ahead with it. I wouldn't say that the population that they don't know things. They are quite clever people.” - Participant 6, Male, Primary Care FG

Respondents associated consanguinity with inbreeding as the narrative from one of the individual interview below highlights;

“Kerala's mental illness was high due to 'inbreeding', so they took action to decrease rate of consanguinity.” - Male, Secondary Care, Individual Interview

In the primary care focus group another respondent referred to and went on to explain cousin marriage as inbreeding as the extract from his narrative below highlights.

“I'm from the Southern and Eastern part of India, also where L (another participant) comes from is a neighbouring state. There was a time, I don't know what it is now, it's almost like, like (an) uncle has got (a) right to marry to the niece.” - Participant 1, Male, Primary Care Focus Group

Clearly for this respondent consanguinity is seen as incest and no distinction was made that cousin marriage was something different. At a later stage in the discussion this participant went onto discuss how negative comments about consanguinity were unhelpful in addressing any potential issues surrounding the practice. In many ways this discussion illustrates how (often unwittingly) language is used to stigmatise practice that has come to be seen to be deviant from

normal social behaviour.

5.3 Culture and Consanguinity

5.3.1 Religion and Ethnicity

Focus group discussions and one to one interviews highlighted that the majority of respondents were aware of the global nature of consanguinity. Religion and ethnicity are important elements of a culture; however, as per the understandings applied in this research, they are distinct entities within sociocultural realm and a society or a culture can have multiple ethnicities practicing different religions and vice versa, as previously discussed. The service providers were asked to identify any links of consanguinity to a particular religion. Only two respondents associated it with non-Muslims. One respondent gave the example of the Irish Travellers, who he explained regularly married within family.

“In Caucasian ethnicity there have been unexplained deaths, like Irish travellers, (and) they also have a higher risk of consanguinity and smaller gene pool and we equally see early deaths in Irish traveller community. It’s not just Pakistani community it’s other communities we’re aware of (sic).” - Participant 5, Male, Secondary Care Focus Group

Another participant referring specifically to consanguinity in South India stated that cousin marriage was a characteristic of the Hindus in his native State as he explains below;

“I’m from South India. It (consanguinity) happens in Orthodox Hindus only (sic).”
- Male, Secondary Care, Individual Interview

For the majority of participants consanguinity was associated with Muslims although respondents did make the distinction between the practice being more common among some Muslim ethnicities than others as the extract from the narrative below indicates;

“I’ve found a big different (sic) in the Pakistani community and the Bengali community, both are Muslims, (but) it’s frowned upon in the Bengali community and the Pakistani community it is almost expected.” - Participant 6, Female, Secondary Care Focus Group

“Same in my experience, every time I ask this in the Bengali community, not only do they deny it, they are really taken aback by the question, as something very odd.”
- Participant 5, Male, Secondary Care Focus Group

In fact, for the majority of participants, consanguinity was a practice synonymous with the Pakistani ethnic group (the majority of whom are Muslims) and some of the extracts from narratives below illustrate;

“I think it is, the highest is the Pakistani community.” - Male, Primary Care, Individual Interview 2

“We're talking about a Muslim population clearly.” - Male, Primary Care, Individual Interview 1

“We have a large almost 25% of the total population in Luton are of Asian, mainly Pakistani decent. Those are the figures I've been given. A significant proportion are consanguineous families. I don't know the exact figures, I'm sure you're know.”
- Participant 5, Male, Secondary Care Focus Group

Whilst respondents emphasised consanguinity occurring predominantly in the Pakistani community there was a great deal of discussion around the importance of distinguishing communities within communities (Ali, 1999) and ensuring that the Pakistani community is not seen as being homogenous. Conversations around the heterogeneity of the Pakistani community centred on the clarification that the majority of Pakistanis defined as such through the passports they possess, were actually from Azad Kashmir (Ali, 1999; Ballard 1990; Shaw, 2009). Participants articulated that consanguinity was practiced more fervently within this group. There is now an established body of literature that recognises the separate identity of the Azad Kashmiri community in the UK (Abbas, 2007, Ellis and Khan, 1998, Ibid, , 2003, Ali, 1999, Ballard, 1994, Shaw, 2009). Certainly Ballard (1994) argues that up to two thirds of Pakistanis in the UK are actually Azad Kashmiri. However, this distinction was not recognised by a majority of the group and was discussed at length with a few participants who had a South Asian background. Some of these discussions around the differences between the Pakistani and Kashmiri communities in this study centred principally on the class difference between these two groups.

“(Mainly) people from Kashmir region, Azad Kashmir (are consanguineous). I guess Pakistan should be included as well probably, (but) it's just that the numbers are (lower) and they tend to be more scattered (as opposed to Kashmiris, who have a concentrated population in Luton).” - Male, Primary Care, Individual Interview 1

Despite the overall association of consanguinity with predominantly Pakistani Muslims in this study, generally the respondents were knowledgeable, regardless of ethnicity, on the religious sanctions pertaining to cousin marriage within Islam. In other words, they were aware that Islam does not sanction or condone cousin marriage.

“(I) don't see the (sic) consanguinity unique to a Muslim population. I think it's quite relevant in South India (referring to the Hindu population).” - Participant 1, Male, Primary Care Focus Group

“Religions have made statements or religious leaders have made statements regarding cousin marriage (that it is allowed), (like) the Catholic Church and (also) in Islam as well, (and) as far as I'm aware in Hindus (as well, they) discourage consanguinity or say it completely is not allowed, as a position, but no complete denial as far as I know (in Islam).” - Participant 5, Male, Secondary Care Focus Group

“It is allowed but not preferred (in Islam), my understanding is that in terms of religion (Islam), the only criteria is that both persons should be Muslim. Otherwise there isn't any other preference, there's nothing else like that (that you must marry a cousin).” - Male, Primary Care, Individual Interview 1

This knowledge was not necessarily from an intimate understanding of Islamic teachings but anecdotal evidence from the experience of working with a large Pakistani/Muslim population some of whom do not practice consanguinity.

“Even the Pakistani population here, I think it's not just the religion, because the same people, their relatives in Pakistan won't that much (be) married (sic) to first cousins.” - Participant 3, Female, Primary Care Focus Group

Extracts from the discussions highlight that the majority of respondents articulated consanguinity as a cultural practice and deeply embedded within certain ethnic groups and as mentioned above in the case of Luton consanguinity was associated predominantly with the Pakistani Muslim settler population. One respondent described culture as;

“Something that has been happening for generations after generations for whatever reason.” - Male, Primary Care, Individual Interview 2

“I think the culture/religion discussion is interesting, because it's almost a derivative, because it's a community habit (in local British Pakistanis), because it's their parents have instilled this in their generation that this is the way we do things.” - Participant 2, Female, Secondary Care Focus Group

There were interesting discussions during conversations where respondents discussed the often ambiguous distinction between cultural and religious practice.

“Culture plays a huge part in (it) you can’t get away from it. If you don’t have an understanding of it, they get deeper and deeper into it, into their faith.” - Participant 1, Female, Secondary Care Focus Group

“I think there is (sic) cultural reasons being mixed with religious reasons, or being claimed that it is religious groups (or) that it is a religious (sic) sanctioned issue. I think this is (sic) various interactions between religion and culture.” - Participant 5, Male, Secondary Care Focus Group

5.3.2 Culture and Marriage

There was a great deal of discussion on the way in which marriages are arranged within the Pakistani community and the impact that this has on the preservation of consanguinity. According to the respondents, the powerful roles played by the elders of a household have an impact on marital choices and decisions of younger family members including those of marriageable age. Like many South Asian families Pakistanis subscribe to the arranged marriage system, not to be confused with forced marriages, although the two marriage systems are often described as being interchangeable. At times respondents described consanguineous marriages as arranged marriages and arranged marriages as forced marriages highlighting the ease with which these controversial associations are made leading to negative stereotypes (Ahmad, 2006).

“I think it is an issue with tradition of arranged marriages. I’m not sure that there is a cultural link between consanguinity and arranged marriages, (or) if there is an infringement in liberties. This cultural tradition (of) arranged marriages, (of) any pressure, which is against free will of person (is an issue). We all know (and) are aware that this can happen and has happened and has been reported.” - Participant 6, Female, Secondary Care Focus Group

“You find that cultural marriage now is done with consent. There is a difference between arranged marriage and forced marriage. Arranged marriage now occurs between consenting adults.” - Participant 7, Female, Secondary Care Focus Group

“I think that people that (are) living here, the (different/multiple) generations, it's not just the first generation here, we can say that the 1st or the 2nd generation did not have the knowledge of the stuff (sic) but the newer generation might be (knowing) more. They know about stuff, that what's going on what's the problem (in terms of consanguinity), it's more or less the family pressure they might give in.” - Participant 6, Male, Primary Care Focus Group

For many respondents the arranged marriage system (and therefore consanguinity) was linked to the desire to maintain links ‘back home’ and preserve and extend family wealth. Service providers explained that as immigration routes for relatives of Pakistani settlers have dried up, transnational marriages have become a means of sustaining familial link.

“These people (local British Pakistanis) have come from a different environment. They are coming from a different country, where the culture, language, diet, the dress is different, and these people have come and hung on to their values of what they knew about. And so the cultural aspect (of cousin marriages) is sort of trying to keep that going, trying to keep it community together (by marrying relatives from Pakistan).” - Participant 4, Female, Secondary Care Focus Group

“We still see now that a lot of girls that are married (to) their first cousins, have come from back home, Pakistan and Bangladesh.” - Male, Primary Care, Individual Interview 2

As mentioned above arranged marriages to cousins were seen to preserve and extend family wealth.

“I think one of the issues sometimes is keeping property within the family members, and not inviting external members into the family as a threat.” - Participant 2, Female, Secondary Care Focus Group

“I think there is financial reason, they want their relatives to come over here. Maybe one brother who's got a family member (over there) and family pressure from a financial support to the families back home.” - Participant 3, Female, Primary Care Focus Group

Service providers also pointed out that where cousins were not available, often marriages are arranged for the reasons outlined above with members of the *biraderi* (kinship group) which allows for continued social and economic relations with the extended community.

“Caste (or biraderi as she clarified later) is the issue, it's not the religious issue. Caste comes from the Hinduism and South Eastern Pakistanis were Hindus 400 years ago, the caste system is continuing, despite changing the religion.” - Participant 3, Female, Primary Care Focus Group

Some participants also noted the changing nature of arranged marriages to cousins over time to reflect the marriage requirements of Pakistanis born and educated in the UK.

“It's a fairly localised area (Luton). If you look at the Kashmir region where they came here perhaps in the 60's or so, the original generation have all been here and

then the following generations have tended to marry from amongst themselves, or (have) gone back to those two cities Kotli and Mirpur, (so) tend to be so concentrated, it's like a tale of two cities. So looking ahead at the next generation, again whoever is living in Luton, or planning to live in Luton, they will probably marry someone from Luton, or someone from those two cities.” - Male, Primary Care, Individual Interview 1

“Because a lot of them are being educated now. But I think people who are working, who have done GCSE, and higher studies, all will know, a little bit (about genetics and health risks). I don't know. That's the way it (is). Education, certainly (is the way forward).” - Male, Primary Care, Individual Interview 2

5.3.3 Culture and Health Behaviour

As well as providing the conventions for the social fabric of society (Ahmad *et al.*, 1989, Neal *et al.*, 2006), culture is well documented as playing an important role in health behaviour (Helman, 1990, Kreuter and McClure, 2004). Respondents were quick to point out that this relationship is particularly significant in the case of consanguinity and greatly impacts on what the service providers deemed to be barriers to care, such as the level of knowledge of hereditary risk associated with marrying first or second cousins, of appropriate and available services e.g. genetic screening, pre- and post-natal services, confidentiality, perceptions of the effectiveness of any interventions, fatalism and the role of an influential decision maker in the household. Most of the participants felt that the Pakistani community does not utilise some of the services provided due to their health beliefs impacting on health behaviour and acting as a barrier to taking up appropriate services.

In terms of the knowledge of hereditary risk, respondents pointed out that their patients had limited understanding of hereditary risk.

“(You) tell them what is the risk and complications of what's happening, (but) because of the beliefs or something, it would be very rare that too many people will come up in the open (and discuss or disclose issues). It is very hard to change their beliefs, because of lack of education. (They) just don't believe that because of consanguinity this thing has happened.” - Participant 7, Male, Primary Care Focus Group

For many participants there were a number of issues related to culture that impacted on clients accessing and utilising services related to consanguinity.

“It was found (talking about previous work they had taken part in) a lot that the South Asian population did not seek help as early as we would expect them to. They would come to hospital typically when baby hasn’t moved for two to three days.” - Participant 7, Female, Secondary Care Focus Group

“At some point there was a concern whether he (a child with disabilities) was receiving proper care at home, because again, the other thing is that these families will use lesser carers, they themselves are the carers.” - Male, Primary Care, Individual Interview 1

This respondent continued to point out that the community’s refusal to utilise some of these social services could also be for the fear of the unknown, as in letting an outsider come in to their household and take care of their child, an outsider who may not understand their culture, their ways and may judge them on their beliefs and behaviours, as the narrative below by the same participant continues. Whether it is a lack of knowledge or understanding of the available services, or trust issues with the carers, this appears to be a barrier that service providers believe will need to be overcome.

“Probably one of them is that this feeling that you should do everything for your family member, that’s very strong, because of that people might not access care, because all the family members are carers, possibly. I mean I remember seeing a mum who was really tired, worn out, clearly had been up all night, she could have asked for carers (for her disabled child). Just normal (someone) where near the family were. There, and she would have had a break, but she wouldn’t. Reasons being, probably guilt, not knowing that someone else (who will) come or thinking that there could be some other carer (besides herself), some other (ethnicity/religion), some Polish, or White person, (and) how would they communicate, how would they fit in their house?” - Male, Primary Care, Individual Interview 1

“Generally the uptake (of some available services) is not good. Just to give you an example, in the [name removed to preserve anonymity] local Mosque, there’s a consultant of palliative medicine who set up a service, a special service, because the Muslim cancer patients were being missed (for early diagnosis of disease). They were not taking these steps, and again they were being cared by their family (rather than a health professional) and so on. And he does this clinic, (an) open clinic on Wednesday(s), and nobody attends it, which is a shame. I don’t know exactly what’s the barrier? (sic)” - Male, Primary Care, Individual Interview 1

Confidentiality and the need to keep medical issues private within the household was also mentioned as an important cultural factor impacting on service utilisation. This is especially obstructive, as mentioned by one participant (Participant 4, Female, Secondary Care Focus Group) in a post-discussion comment, when in order to create a full genetic profile or to trace the inheritance pattern of a genetic disease, tests need to be carried out on other members of the family who may only be carriers and not be effected by the disease, but those tests will not be done because the patient refuses to contact them or even let the hospital contact them with their reference. This, according to this respondent, maybe because it is felt that this will somehow lower their position in the community or diminish their authority in the family if the children find out about genetic risks when it is their wish that they marry their cousin. Confidentiality also becomes an issue when children or other members of the family are used for consultations with the doctor because the patient does not either understand the language or comprehend the information being provided by the doctor. Participants explained that there was a genuine fear among consanguineous couples of medical confidentiality.

“Here we see the elders coming in for a consultation, and the child who has come in from school, 5-6 year (old) grade 5 or 6, they're translating and sometimes it's very awkward because they're sometimes translating for some quite sensitive things.” - Male, Primary Care, Individual Interview 1

Many of the respondents also discussed the role of fatalism as a barrier to accessing and utilising appropriate services and the impact that this has on the service providers. Chattoo *et. al.* (2002) have previously shown that the service providers in their study believed the terminal nature of diseases like cancer can create a deeply fatalistic mind-set in their South Asian patients. However, Randhawa and Owens (2004) posited that it was perhaps these patients' late stages of presentation that lead to the fatalistic mind-set, as most cancers have poor prognoses the later the stage of presentation. This may hold true in cases of certain congenital disorders or lethal developmental issues as well, but what is clear is that the service providers in this study felt that fatalism was prevalent in the local community.

“Patients will say I'm not taking such (medication), inshallah (if God wills it) I'll be alright. They'd say I'm going to live so many years.” - Male, Primary Care, Individual Interview 1

“There are some religious beliefs, because it's god written, whatever syndrome you say, it's god written.” - Participant 3, Female, Primary Care Focus Group

There are other decision makers, besides God, who also play an important role in the decision-making process of these individuals, according to the service providers. This may be a household elder, like the mother-in-law, the husband/father, or perhaps a community elder or religious leader who is trusted with helping make a decision about not only marriage, but about a health service and interventions.

“We sort of found in our research is that mother-in-law is quite powerful [laughter]. We thought it would be good to work with mother-in-laws, because they that's where they go for advice and support.” - Participant 7, Female, Secondary Care Focus Group

“It depends on how much they trust (service providers). They might trust a member of family that's more vocal and more influential and if you can involve that influential person, they will listen to you. Like many women are not allowed by their husbands to go out on their own, but certain “baji” (big sister) will come and she can take them anywhere, because they trust that person.” - Participant 3, Female, Primary Care Focus Group

5.3.4 Social determinants of health

As has been mentioned before, consanguinity was deemed to be a contributing factor to poor health outcomes in a recent local health report (Taylor and Whiterod, 2011), however, another related report also found that Luton ranked amongst the most deprived towns in all of England (Taylor, 2011). According to some of the respondents, this social deprivation may be the real cause of poor health outcomes seen in Luton.

“So they come from ethnic minorities, but the way of living and everything, according to national standards, they will fall into deprived category as well. And all the papers they suggest that deprived patients will have more health related problems. Mortality, morbidity, Luton is very (low in these and).stands out quite a bit actually. The death rate, the age which people live in Luton to is ten years more (lower) than the national average. The average life span in Luton is ten years lower than the national average. And it's nearly 37% of the population is ethnic minority now.” - Male, Primary Care, Individual Interview 2

“Majority of deaths in infants in our population is not related to consanguinity at

all. (It's) social factors and smoking and social deprivation, (it's) related to these factors." - Participant 5, Male, Secondary Care Focus Group

This participant felt that while consanguinity was not the only cause of infant deaths in the local population, it was associated with certain cultures, and knowing this aided him in his diagnosis for patients.

"With a similar social deprivation in South American countries you find much less consanguinity (but similar numbers of infant deaths). So it's cultural reasons, so it's not socio-economic factor and not ethnic factors, it's more cultural group, independent of ethnic (sic) it's consanguinity in certain countries (and cultures)."
- Participant 5, Male, Secondary Care Focus Group

The participants suggested that the underlying social determinants of health were a factor in the poor health numbers seen in Luton, but they also suggested that cultural factors, such as consanguinity in the British Pakistanis, was more relevant for them in determining health risk.

5.4 Hereditary risk and consanguinity

The extracts from service provider narratives above show the complex relationship between culture and consanguinity and the impact that this has on the provision of appropriate services. For the service providers who took part in this study there was a clear link between consanguinity and hereditary risk of abnormalities and/or disabilities.

"There is a very high percentage of my patients who marry within the families or other things....and that is why we have a lot of children with failures, problems related to that. And the majority of the families that have children with major problems, they are in consanguineous marriages, and they are several, and they come and say they've married into the family." - Male, Primary Care, Individual Interview 2

"I have paediatric experience, and the speculation you are talking about is true. I do believe that they're true. The thing which touched me was here in the practice I saw a lady and she came with her one child and as the consultation went on she said 'oh I've got another child who goes to a different hospital' and I think the marriage was consanguineous and their three children all had problems, all. And the problem which (sic) needed them to be in the hospitals. So one parent was here with one child and another one was with the other one, so that was the (issue) which one thinks that linkage with (health issues) with so much (sic) problems going on."
- Participant 3, Female, Primary Care Focus Group

The above response by the respondent came during introductions, and no such speculation

about health issues related to consanguinity or indication had been given, showing the prevailing inclination that some service providers had in associating consanguinity to adverse health.

“Thalassaemia trait is so common that even in probably even in our subcontinent, even if they don't marry their cousins, there is a high chance, they might marry someone who still has the thalassaemia trait. I think the number of children in Luton with major Thalassaemia, is much much (sic) higher than anywhere else. We have three or four children with major thalassaemia (in the surgery). In 8,000 population (of surgery patients), we have 3 to 4 children who have major thalassaemia, so the whole of Luton, will be much more.” - Male, Primary Care, Individual Interview 2

“Within that community, possibly again I couldn't say (for sure) whoever they marry, if you think of it that one city, those two cities (Mirpur and Kotli) and this city of Luton, you can think of it as a very limited gene pool, isn't it? We already know that there are lots of (genetic) conditions going around, thalassaemia traits and maybe not the main medical disease itself (but the traits). And these other special diseases I've spoken of, some of them you've never heard of, so they're bound to crop (up). They're bound to come in some family member and it's going to happen again and again, and it's going to follow the rest for generations.” - Male, Primary Care, Individual Interview 1

“Latin American collaborative study on congenital malformations, based on 34,000, actually 341,902 of new-borns found a significant association of consanguinity with bilateral oral and facial clefts. So there's (a) scientific study.” - Participant 5, Male, Secondary Care Focus Group

“The majority of the families that have children with major problems, they are in consanguineous marriages, and they are several, and they come and say they've married into the family.” - Male, Primary Care, Individual Interview 2

“The closer the relationship, the higher the chance (of genetic disease). And if there's (sic) any medical problems in that family, there's a higher chance obviously of it passing on” - Male, Primary Care, Individual Interview 1

While there has been doubt raised to the validity of the evidence and the extent of the impact of consanguinity on risk of genetic abnormalities and/or disabilities in the literature (Darr, 1997, Bittles, 2012), the service providers in this study were certain of the links between consanguinity and hereditary disease, as highlighted by the narratives below. Discussion of the type of risk and abnormalities and/or disabilities was centred on autosomal recessive disorders, congenital disorders and other rare disorders.

“Autosomal recessive disorders, which are linked not only to consanguineous relationships but also in the Pakistani community to sub-culture

phenomenon...biraderi. Sort of clan or group, within a certain country which is a (sort of) genetic pooling that increases the recessive disorders.” - Participant 5, Male, Secondary Care Focus Group

“I mean I see parents of children from consanguineous families, every week in every clinic. Because it’s a question I ask as a matter of routine when I take a history, because it helps me develop a sensitivity (sic) for particular conditions. I need to think automatically of the rarer conditions as well. It influences the way I investigate patients presenting. It’s quite (an) important consideration (consanguinity).” - Participant 5, Male, Secondary Care Focus Group

Interestingly, although service providers were sure of the links between consanguinity and hereditary risk through description of experiences, some participants, mainly in the primary care discussions were unable to articulate the specific genetic science behind this risk.

“There isn’t anything scientific thing, we presume or the (doctors) in the hospital, the secondary care as well would presume that this is why it has happened. It might be worth tracing the history, if you go back in to the history, then okay (they’ll say) ‘my father had six brothers and three of them died in the first three months,’ but nobody has looked into it or why it has happened. So they presume that probably they were born with certain disorder, which was singular. So (sic) trace it actually and link it, has been difficult (and) it hasn’t happened that much. Some of the things we know, like children who are born with major thalassaemia and all.” - Male, Primary Care, Individual Interview 2

“Yeah, if you’re a first cousin, they’re more chances of accelerate (acceleration of risk) for two generations. And not just you are first cousins, if your parents, or siblings, or your parents’ parents (grandparents) were cousins and then 3rd generation will have the disease the 2nd generation will miss out.” - Participant 3, Female, Primary Care Focus Group

Participants also mentioned the high prevalence of rare diseases in Luton and insinuated that this was due to higher levels of consanguinity in the population.

“In my experience, I mean, a certain disease that I’ve never seen before, because it’s so rare, I’ve encountered in Luton” - Participant 5, Male, Secondary Care Focus Group

“There is (sic) quite a few diagnoses like that, which you’ve only read about but never saw it before, and then it comes up.” - Male, Primary Care, Individual Interview 2

“We did a lot of work on still births. And we found that that our Asian population had a high incidence and it was suggested that consanguinity was linked. Because the number of still births at L&D was sticking out, and an enormous pressure was put on to reduce the link. And it (consanguinity) was identified as factor.” - Participant 7, Female, Secondary Care Focus Group

“I’ve seen several children die due to incurable autosomal recessive disorders in the time I’ve been working here.” - Participant 5, Male, Secondary Care Focus Group

Previously, whilst discussing social determinants of health, a participant narrative suggested that high rates of infant mortality among the local community may be linked to the high rates of social deprivation experienced by the community. Other participants in this study did not however subscribe to this view.

“I think some can be. But the amount of birth defects, and the things we see, probably might be very difficult to justify that. Birth defects, not only anatomical defects, but problems with metabolism and other things that we see... learning disabilities, high incidence of cystic fibrosis.” - Male, Primary Care, Individual Interview 2

5.5 Delivering Healthcare Services

The provision of adequate services in relation to consanguinity deemed by some participants as the sole reason why they wanted to partake in this research and this was seen to be particularly important for service providers in light of the current changes to the NHS and the allocation of funds. The section above has discussed service provider’s views of barriers to accessing services related to consanguinity. In relation to delivering healthcare services some respondents also discussed the overuse of services and its implications. When explaining overuse of services, there were two different views presented, one attributed it to the health beliefs of the community while another blamed the adverse health effects of consanguinity that resulted in overuse of NHS resources.

“But all the research and all the work suggests that the ethnic minority patients, they consult much bit more (sic) than as a Caucasian patient. And a lot (of it has) to do with the culture and the setup. So whenever we see a child, it's usually the mothers that bring the child, for the immunization, for their checks, when they fall, they are the ones who bring. So, probably a bit of that support being lacking (sic) that increases the consultation rate as well. Because the mother will come, will not have much of an idea, and will become panicky as well if a child has two vomiting (sic) in the morning, 8 o'clock in the morning, (and at) 11 o'clock (they are) at the surgery. But I think we can't say it's because of consanguinity and all that, the important (thing) will be to show them (NHS) that okay the amount of diseases that we have (in this group) and the amount of patients we consult, people from ethnic minorities, especially people from Pakistan and Bangladesh, they consult more

than twice the national average.” - Male, Primary Care, Individual Interview 2

“Every weekend she would call you (a mother in a cousin marriage who has children with disabilities), and she would almost every weekend or other weekend she would want a home visit. The son is typical, young teenager, I think 12 year or 13 year old or something like that, disabled, with recurrent chest infections. (And) because his elder sister died from the same condition, and he had it (now). She also died in the late, mid-teens I believe (as) they don't have a long life expectancy. So he probably won't make it to 20 or something like that. So obviously you can imagine that she's (the mother) very anxious isn't it (and that's why she calls so often).” - Male, Primary Care, Individual Interview 1

Some service providers discussed the cost to GP surgeries that are located in areas of high Pakistani settlement and have high numbers of registered consanguineous patients and/or their children. Consanguineous couples and/or their children were regarded by service providers as being a drain on current NHS resources because they require ‘expensive medications for their conditions’ and thus these surgeries would be financially worse off than GP surgeries based in areas of lower Pakistani settlement. One participant (Male, Secondary Care, Individual Interview) noted that in order to preserve the impact on NHS resources, services should be more targeted, “Since they’re short of staff, incidence rate should determine if counselling is to be provided or linked with every department.”

Besides the overuse of services and its financial implications, service providers also highlighted other challenges related to delivering health care services for people in cousin marriage unions. These were related to language and communication, discomfort with discussing issues related to consanguinity, limited existing services and sometimes poorly understood referral patterns. Service providers explained the difficulties of delivering information around the risk of consanguinity. Firstly service providers explained that English language proficiency of many of their patients/users was poor and therefore translation was necessary. Even where translators were available they indicated that delivering information on genetic risk and consequences of cousin marriage unions was problematic because of the difficulties of translating genetic information. Commenting on her observations, one respondent pointed out that this was an added risk for this

ethnic group.

“And they (service providers) would see that if they were non-English speaking, it was an additional risk. Because they were less likely to seek help (for problems with their baby).” - Participant 7, Female, Secondary Care, Focus Group

Some service providers also said that they felt uncomfortable in discussing issues around consanguinity especially if they were from a different ethnic group. Other participants felt under experienced in providing information related to consanguinity.

“The patients might not take on board what they're (doctor) saying or might not be prepared to take it. They might get offended like what you're saying? (sic) Another interesting thing, that the doctor or the Caucasian person would have a barrier in saying those things as well. You know how we often say (Inshallah as Muslims)? Patients will say I'm not taking such (medication), Inshallah I'll be alright. They'd say I'm going to live so many years. In the meeting (doctors' meeting) one of the Muslim doctors said, I said to that (response from the patient), close your eyes and cross the road and say Inshallah, I'll be alright! So, straight away a Caucasian GP said that I can't say that, (only) you can say that!” - Male, Primary Care, Individual Interview 1

“Yeah, ethnicity has a big role actually. First of all, we are five partners, (in) which one is from [country name hidden to preserve anonymity of surgery], he doesn't (speak the South Asian languages), but rest of us all speak all the ethnic languages, Hindi, Urdu, Punjabi, and I can understand 100% of Bengali, but can't speak it very well, but can communicate with them. Four of the doctors will not need any help at all and all the patients can communicate absolutely freely. There is (sic) no problems in communication and we have two female doctors as well. So this practice is in very high demand. There will be barriers (if patients go elsewhere). There have been quite a few surgeries that have opened new. And if they don't see people, doctors working there who can speak their language and can correlate to that (then there will be barriers).” - Male, Primary Care, Individual Interview 2

Service providers (with the exception of specialist consultants and the genetic counsellor) expressed the need for further training to assist them in delivery better care, especially in terms of genetic medicine and to a lesser extent, cultural competency. They expressed that the depth of training would depend on the role and departmental affiliation of the service provider.

“I think us as GPs as well we need probably need a bit of more training in terms of Genetic problems and conditions.” - Male, Primary Care, Individual Interview 1

“I think there is a big need. We don't understand (genetic disorders) that well, because they are rare. And they will not be a bulk of my work, or I will not have detailed knowledge of it and nor would I know. And this is a highly selected population that you are interested (in Luton). So there is a quite a lot of need among the health professionals to learn about it and then understand about (it enough) to be able to signpost it (the local population) in the right direction, I think there is a critical need.” - Participant 1, Male, Primary Care Focus Group

“I think if you involve the medical plus cultural plus religious thing into it, I would say that okay I'm from the same ethnicity, I know the culture, may be a little bit of medicine right now, and the religion, and even I'm a Muslim as well, but I wouldn't say I have any authority. I'm not a scholar, so I might need to know more before I can answer questions.” - Participant 6, Male, Primary Care Focus Group

“It depends on the department they work on, I mean in maternity I'm sure they know (enough already).” - Participant 6, Female, Secondary Care Focus Group

“It is something that would be interesting, it's something we're all very interested in, I'm sure. But if you were focusing on an area I think pre-conceptual would be really important.” - Participant 7, Female, Secondary Care Focus Group

On a visit to the tertiary centre, The North-West Thames Regional Genetics Services at the Kennedy Galton Centre, to understand the current service provision and to contextualise the available genetic services for the local community, the diagnostic research staff indicated that they only have capability to do specific types of screenings and the equipment needed to do genome wide analysis to identify novel mutations and develop screens specifically for these mutations was beyond their scope. Hence, the screenings that exist are for the most common mutations, according to the staff, which is an issue with regards to the British Pakistani community, as most service providers had indicated the presence of rare mutations and genetic disorders showing up in these families. This suggests that the available genetic tests would have limited use for these patients.

“A lot of the time they come (for assistance), most of the time they're already married (so we cannot really counsel), because we never counsel them that you shouldn't marry (your cousin), because it's (a) slightly difficult subject as well to counsel somebody on that. You have to have the balance, because you don't want it to come into the community that you are against all this.” - Male, Primary Care, Individual Interview 2

“Because of the beliefs or something, it would be very rare that too many people will come up in the open (to discuss or seek help), that's my view on this.” - Participant 3, Female, Primary Care Focus Group

“If you've got a lady who's (already) pregnant or married, (and) then potentially she's got a baby that may have died, to say to them that you may have had this because you are married to your cousin (is not ideal). They are already upset, (and) they don't want to go down divorce route, (so) it's very difficult. They've already gone down the path.” - Participant 6, Female, Secondary Care Focus Group

5.5.1 Referral Patterns

Although the topic guide did not specifically ask about service providers understanding of referral patterns for people in consanguineous unions, discussions highlighted that there was considerable confusion among participants. Discussions highlighted that there appeared to be no consensus on the mode of referral for patients with genetic disorders. The GPs stated that diagnosis was the role of the secondary care professionals. They mentioned that they referred only to consultants and were unaware that they could request genetic tests or refer directly to a genetic counsellor as the genetic counsellor indicated. This hesitation on taking a bigger role in genetic diagnosis and a lack of clarity in referrals has been noted elsewhere (Emery and Hayflick, 2001, Elwyn *et al.*, 2002), and was also evident from the responses of GPs in this study.

“We don't explore that far (in diagnosis and counseling). In fact, we never give counseling for marriages and things as well. So that history is only taken if they are, if one of them gets pregnant, or they come to discuss about (that) they're having a baby and all that. That is the only thing we discuss and we try to put it in somewhere in that context, are they (or) have they married within the family. We don't explore much more into detail, if they say yes, we take it as yes, if they say no, then we say ok no.” - Male, Primary Care, Individual Interview 2

“You already have the expertise, and I think it's accessing that area of expertise. You mentioned earlier about education and an individual's ability in communicating information, now in genetics, a lot of it has to do with disabilities and so on (and) we are there as a resource. And I often get phone calls from various people, GPs, midwives and (they say) I've got a patient sitting in my surgery, this is what they're saying, what do I do? We in Genetics, do (our part) and Dr. [name removed to preserve anonymity] does talks, and paediatricians (do as well) and so on and so forth. And I have links with health visitors, and very good links with the maternity unit here with the consultants and the specialists and midwives. So it's looking at the resources (already available) rather than setting up a new service.” - Participant 4, Female, Secondary Care Focus Group

“Actually, the neo-natal medicine are the first point of contact, because when they're born, they're diagnosed there. Especially the children (with) syndromes and metabolic disorders. We don't get that much involved. I think geneticists and paediatricians get more involved.” - Participant 3, Female, Primary Care Focus Group

“I mean I see parents of children from consanguineous families every week in every clinic. Because it's a question I ask as a matter of routine when I take a history. Because it helps me develop a sensitivity for particular conditions. I need to think automatically of the rarer conditions as well. It influences the way I investigate patients presenting. It's quite (an) important consideration. It changes the way I see and investigate the patients (because) I don't want to miss these conditions.” - Participant 5, Male, Secondary Care Focus Group

In response to a question on expansion of a GP's role, in terms of providing first point of contact counselling or referrals, the role of the GP was deemed by some to be more involved, especially in terms of being able to reach the patients more based on the long standing relationship they usually have as their family physician.

“As General Practitioners we are at the front line, you might say as well. The contact with the general population we do get more sort of chances.” - Participant 1, Male, Primary Care Focus Group

“General practices I think you really get to know patients, in hospitals you just see them for a few minutes, you're doing lots of things, (and) they're probably too sick. But in general practice you build up a relationship as well.” - Male, Primary Care, Individual Interview 1

There were also suggestions from the service providers that the community and patients themselves are in fact in control of their treatment and its direction. The service providers felt that as professionals, they could only present the facts to their patients, and it was then up to them to either take up or decline the services, whether it was to take up certain medications or proceed with a pregnancy, as they could not ensue with any treatment without informed consent or patient choice. This is also where they felt the influence of other more powerful members of the family or the community may influence the decision making process of the patients. Moreover, issues surrounding level of education and comprehension of both language and medical condition was of concern to service providers.

“I think recently somewhere, somebody was talking about it. They were expecting a baby and the scan showed problems with the baby and something was offered and they wanted to go ahead with the pregnancy knowingly. They (had) measured their pros and cons and then they still wanted the baby.” - Participant 6, Male, Primary Care Focus Group

“This lady, I had a good relationship with the mum and I mentioned (to her) what my fear was (that) look you already got (one child who died of this condition, another who is suffering from it). And she already was thinking of it as well. And she point blank said that I am worried (about having another child like this). But I am prepared to have another child just like this, in order to have another child, and in the hope actually of having a normal child.” - Male, Primary Care, Individual Interview 1

In discussing actions that would be useful for the community, some service providers did indicate that the intention was to somehow limit consanguinity, or at least the impact of consanguinity, in terms of reducing the numbers of infant deaths and preventing families from going through the ordeals of taking care of a child with disabilities when they've already had one such child. However, no one spoke of banning consanguinity and one suggested that such an action would be harsh on the communities that practice consanguinity. Most also agreed that further research was needed to improve diagnoses and predictive services, and also suggested that an increase in full-time genetic counselling services was justified, although they realised that this was going to be difficult during the current cutbacks in NHS budgets.

5.6 Strategic Actions

Most if not all of the service providers voiced their support for increasing community involvement in addressing any issues that may be related to consanguinity. This ranged from advocating support for health education and promotion programmes that would let the community make informed choices with regards to consanguinity to getting the local leaders involved in starting up such promotion campaigns in unison with service providers. Community engagement followed by effective collaboration with service providers was regarded as the key to the success of the uptake of any awareness campaign.

“This certainly sounds difficult (pre-marital screening like the Cypriots). I think it's possible, but it would be very difficult with this current set of generation of the elders, who are really involved in arranging marriages and all. Mainly because of lack of education. (Maybe) with the local (leader involvement) you know someone from the local community who has some influence, (if) they get involved. They do this programme during Ramadan, a radio program where they have doctors coming in (and) there's a local GP who gets involved in that who might be useful. (Perhaps) They could use these other forms of getting information to them, again these people might not read the paper, might not watch those TV channels that we watch. They only rely on whatever bit (of) information they get (from word of mouth), a leaflet probably wouldn't be enough.” - Male, Primary Care, Individual Interview

“Or reach out to mosques (for involvement). You talk about education (through them). That will be very great (sic) because they can be VERY influential. They change whole families. I've seen very modern mediocre Muslims (not very religious) completely change to very fanatic religious (Muslims) through this. I don't know how they do it, but they are very powerful.” - Participant 3, Female, Primary Care Focus Group

“I'm going to bring the religion/culture issue back in. Let's take a community like (the) Cypriot community, it's very secular. Culture is more about socialising and social interaction rather than adhering to a faith or as a certain member of a conducive you should behave in a certain way. It's interesting that there should be a few changes happening in these (secular) communities. Could that be linked to different interpretations of religion and separating religion from local culture for the benefit of the population?” - Participant 2, Female, Secondary Care Focus Group

Service providers felt that a partnership approach could therefore lead to ensuring that key education messages are delivered in a culturally sensitive way. A more educated younger generation was seen to be more receptive to health messages related to consanguinity.

5.7 Summary

In this chapter, the findings of the discussions with the local service providers about consanguinity have been presented. The discussions focused on the understandings of consanguinity, the importance of culture, including religion and ethnicity, both in understanding consanguinity as well as in healthcare service delivery. The discussions on healthcare delivery also included the importance, understanding and use of genetic services, as well as on strategies needed to improve both health and healthcare in the local community.

While most of the service providers understood the meaning of consanguinity, there were a few responses that ascribed negative language in describing consanguinity, equating it to incest and inbreeding. The respondents felt that although religion was an important aspect in impacting the beliefs of their patients, they did not feel that consanguinity was limited to only Islam and Muslims. They did however feel that given the local context, consanguinity was seen mostly in the Pakistani community. The South Asian service providers were the only ones aware of the heterogeneity in the “Pakistani” population of Luton, which consisted mainly of settlers from Azad Kashmir region, who ascribe to a an independent identity variable to that of other Pakistanis (Ali, 1999, Shaw, 2009, Ballard and Banks, 1994). The majority of the service providers did not know any consanguineous couples outside of their place of work, maintaining only a doctor patient relationship. Consanguinity was seen overall by the service providers as being negative with a clear genetic link to poor health outcomes, however, effects of social deprivation on these health outcomes was mentioned only briefly with a major focus on the biomedical model of health.

Whilst discussing genetics and service delivery, the respondents felt that there existed a lack of understanding of genetic risk amongst their patients and that the health beliefs and behaviour of the patients served as barriers in service delivery. In addition, respondents felt the both ethnic and language barriers impacted service delivery. Some of the White service providers felt that their ethnicity may have acted as a barrier in the dealing with patients who invoked cultural and religious beliefs in health matters. Lack of confidence in genetic knowledge has previously been cited as a reason for GPs hesitation in delivering genetic information to their patients (Fry *et al.*, 1999), and the responses from this study seem to concur, even though respondents felt that GPs were in fact best placed to deliver this information because they were the patients’ first points of contact and had built a relationship with the patients over the years, reducing any trust deficit. Perhaps realising this dearth in genetic knowledge, some respondents called for additional training for health professionals in genetics while others still felt that it was needed only for those involved in pre-

natal care and not at every level of service provision.

The respondents called for implementation of health promotion programmes that would be community led to bypass the trust deficit they feel exists between them and the local community. The service providers felt that these programmes were necessary to disseminate information about genetic risks associated with consanguinity and the healthcare services that were available for the local community.

The responses from the service providers presented in this chapter show that they focused on ethnic, religious and cultural issues of consanguinity as they pertained to genetic risk and healthcare delivery. The next two chapters, 6 and 7, will turn attention towards the responses of the local community and their understandings of consanguinity and its impact on healthcare, where some of the assertions of the service providers will be further probed.

CHAPTER 6 – LAY COMMUNITY FINDINGS

6.1 Introduction

In chapter 5, the findings from the focus group discussions and one to one interviews with the service providers in Luton were presented, this chapter turns its attention to the findings from the lay members of Luton's British Pakistani community, who were not married to their cousins. A total of six focus group discussions were conducted with the lay community members, and as discussed in detail in Chapter 4 (section 4.4.3), these were organised accounting for the participants' age and gender. There were three focus groups with males and three with females, including one each for the three different age groups, 16-29, 30-49, and those who were 50 years old or above, with a total of thirty-one participants, as shown in Figure 6.1, highlighting the portion of the overall study this particular chapter will be focusing on, that is the lay community findings.

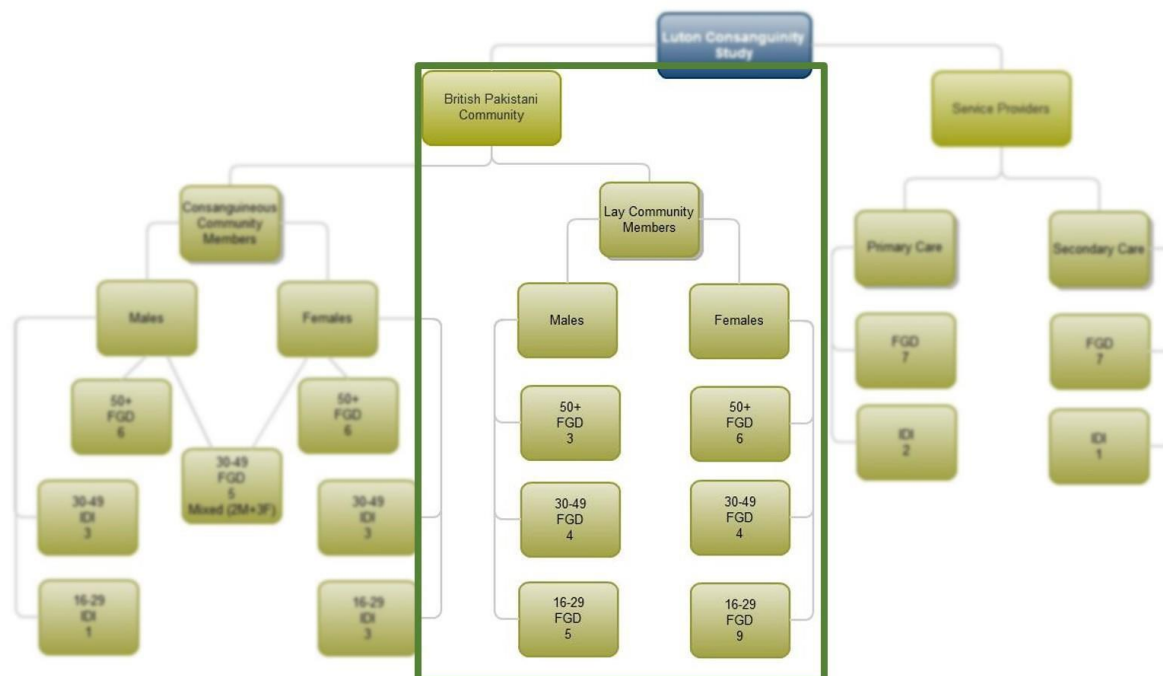


Figure 6.1 Lay Community Members Study - This figure shows that the focus of this chapter is on the findings from the lay community member portion of the larger study.

The topic guide used for these discussions was close in content (differences discussed in chapter 4, see sections 4.4.5, 4.6.1 and Appendix 2) and structure to the one used for the service providers for comparative purposes and to construct an understanding of consanguinity with contributions from possibly differing perspectives. In particular, the topic guide was designed to explore the third objective, to examine the views and experiences of consanguinity in Luton's British Pakistani community. The current understandings of consanguinity have thus far been informed by developments in anthro- psychological theories, knowledge of genetics and healthcare, and the sociocultural elements, as discussed in Chapter 3. An addition into the topic guide used for the community members, the section dealing with sociocultural elements of consanguinity was supplemented with some contextual information by collecting demographical data about the participants. The rest of the questions in the topic guide continued to explore the current understandings and theoretical explanations of consanguinity further but also addressed the issues and barriers around access to services that the service providers raised and the steps that can be taken to improve these services and their utilisation especially as they pertain to consanguinity. As such, the major themes in the findings remain the same, focusing mainly on roles of sociocultural elements, including ethnicity and religion, as well as genetics, and healthcare delivery on consanguinity, with discussions around strategic actions needed to bring about a change in the current healthcare of the community, as suggested by the respondents. There were some new sub-themes that emerged from the findings, while other sub-themes from the service provider findings did not resonate with the lay community members. The findings are presented here along these themes and sub-themes, directed by the responses of the lay community members whose names have been replaced with pseudonyms.

6.2 Culture and Consanguinity

Cultural issues around cousin marriages were a dominant topic of discussion with the lay

community members. Certainly, the sociocultural implications of consanguinity have been shown to weigh heavily in the lives of not only British Pakistanis, but also other communities which prefer consanguineous relationships (Darr, 1997, Modell, 1991, Shaw, 2000, Bittles, 2012). The findings from the respondents in this study show that a majority of the responses focused on the ethnicity and religious aspects, the culture of marriage within the community, the factors that limit cousin marriages and the importance of beliefs on health behaviour. However, first, the background information providing some contextualising attributes of the participants is presented.

6.2.1 Sample Attributes

As stated above, the lay community members were recruited into different group discussions based on their age and gender. Background information was collected during these discussions to contextualise the participants and the setting, which has been a feature of this constructionist research, and also aids in interpreting the responses (George *et al.*, 2010, Bittles, 2010b, Cobern, 1993). The sample attributes show that there were similarities and differences between the age and gender cohorts, for example, differences in levels of education and similarities in their roots in Pakistan, as explained below.

The majority of male participants under 50 years old were either university graduates or were currently studying at university level. This also held true for the female participants under 30 years old, but the level of education dropped to secondary or even primary levels in the older generations of both males and females (see Table 4.3). This is perhaps indicative of the initial recruitment of semi-skilled workers from Pakistan to the UK in the 1960s, which was mainly to provide labour in the steel and textile industries (Ahmad and Bradby, 2007), as well as the automotive industry in Luton.

6.2.2 Ethnicity, Kinship and Religion

The majority of participants were either from Northern Punjab (Rawalpindi, Jehlum or surrounding villages) or from the Azad Kashmir region of Pakistan, and identified mainly as

belonging to the Malik, Chaudhry, Jutt or Raja *biraderi* (clan/caste/kinship group). *Biraderi* has been used interchangeably with *qaum* or *zaat*, however, there may exist a hierarchy in the use of the words, like *qaum* denotes a higher level of grouping, as in Muslims or Hindus or Pathan or Punjabi, whereas *zaat* or *biraderi* refer to smaller kinship, clans or community groups (Sikand, 2004). Whilst the *biraderi* system was important to the older participants, forming an important institution which guides many cultural practices including marriages (Darr and Modell, 1998, Shaw, 2001), younger members of the lay community stated that the system was largely dated and had little relevance to them.

“Even though it (marriage) was not family, it was at least still Malik biraderi.” - Yaseen, Men 50+

“That's sometimes, that's more. I think some parents are like, there's more shame in her talking to a Chaudhri, she's Raja, than talking to a White person.” – Abid, Men 16-29

As discussed previously, under section 3.5, kinship networks like *biraderi* traditionally serve important roles in Pakistani communities, influencing a range of life events including marriage, political votes, gifts exchanges and business deals (Shaw, 2000, Wakil, 1970), and the importance of these networks was only amplified when the first generation of Pakistanis came to the UK, finding security and comfort within people that were known to them (Ali, 1999), and what Ballard (1994) calls networks of reciprocity. A common feature in the marriages that take place in these networks, is that they tend to be endogamous (within the *biraderi* or kinship group) and mostly consanguineous (Wakil, 1970). The responses from the younger participants suggest that this traditional importance of the *biraderi* is subsiding, and it is increasingly being seen in a negative light, something that belonged to the old guard. Perhaps it has more to do with the wider debates on diaspora and the younger generation seeking an identity of their own (Ali, 1999, Hussain and Bagguley, 2005, Werbner, 2004, Werbner, 2002b), as they do not see themselves as migrants, yet reside in the diaspora and are not always seen as just British (Cressey, 2006), and hence seek to

identify themselves sometimes with religion and the larger Muslim *Ummah* (Mythen, 2012, Jacobson, 1998), as one participant says below.

“I don't understand why that is (biraderi). It's not from Islam. It's from Sikhism, Muslims nowadays, have taken it from them. I've got Sikh friends and they're always like, I'm a Jutt and I'm this... I'm like hold on a minute, what? And Muslims are supposed to be all equal and everything. But people are like, I'm a Jutt, Raja I'm better than you. And I'm like, I'm just Muslim.” – Fatima, Women 16-29

Although Fatima states that the concept of *biraderi* has been imported by Muslims from Sikhism, it is important to note that Sikhism does not promote any caste system intrinsically (Puri, 2003) nor do the religious teachings of Hinduism (Fuller, 1979, Nadkarni, 2003), rather it is the development of cultural norms that have propagated a social caste/class system, or as some would suggest, as a colonial construction for creating civil order (Puri, 2003). *Biraderi* could possibly be seen as a Punjabi cultural phenomenon, as Babra (2008) suggests in his Urdu/Punjabi publication, *Vichoray da Daag* (translated by the publisher as the burning wound of separation), that before the partition of British India, religion was superseded by *qaum* (caste or *biraderi*) for identification of families in the Punjab, and the names originated from their occupations or land ownership (Puri, 2003). Moreover, as these families migrated out of Punjab, or their native areas in Punjab to other areas in Punjab, they would look to start a new life by adopting the name of a higher *qaum/biraderi/zaat* because no one would know their original caste, gaining them an instant elevation in social class (Babra, 2008). Certainly, this is an idea which resonated with some of the participants, as suggested by the narratives below:

“It's the status for each of them. Some (biraderi) are considered as higher. They'll say we'll just stay married to Maliks or Rajas.” – Sukhena, Women 16-29

“Most of them just use the names like that, calling themselves Malik or Chaudhri just so that they can feel better about themselves (because those castes are considered to belong to a higher social class).” – Suha, Women 16-29

6.2.2.1 Kashmiri vs. Pakistani

Another facet of ethnic identification came about due to the composition of the participants

from a similar geographical background, which in turn is a representation of a large portion of British Pakistanis. Since the participants were mainly from the Kashmir region or very close to it, there was a distinction made between Pakistani and Kashmiri practices. A majority of the participants felt that although it was unfair to categorise cousin marriages as being limited to only Muslims or only Pakistanis, they did feel there was a link to ethnicity in that it mostly occurred in Pakistanis, and even more so in Kashmiris.

“Not sure about the rest, but in Azad Kashmir it is a lot. Don't think it is in Pakistan” – Muneeb, Men 50+

“I think it was a year ago, I was reading on BBC news, basically they done like this, they said like, you know places like Bradford, because they have quite a lot of big Kashmiri population. There it's quite common, (they) marry their cousins.” – Ikram, Men 16-29

Some participants likened Luton to Bradford, in that it was different than some other major cities of the UK, because towns like Luton had a lot more Kashmiri population, indicating a difference in cultural beliefs that may seem alien to other Pakistanis.

“I think you find that, you know where they have a lot of Kashmiri population, they have a lot more culture there. As in like, my friend is from a different town where they have a large Pakistani population but they're all mixed, or they're all from Punjab and stuff, they won't have as much, they're a bit more open, they've still got that culture, but not as close like the Kashmiri population is.” – Ikram, Men 16-29

“My wife is Pakistani, and we're Kashmiri. She couldn't even understand my mum and speaking when she first came here. She couldn't understand my mum. Now, it's been ten years on, she does. She got a massive culture shock. She was from London. If she was from Luton, they would still know, because everybody in Luton knows how everybody is.” – Taimur, Men 30-49

The lay community members' views of a difference between the Kashmiris in Luton with the Pakistanis in the rest of the UK stemmed perhaps from their overall view of people from urban areas of Pakistan as being more open minded when it came to their beliefs about marriage (as in lesser cousin marriages) and this was deemed to be because of more education and interactions with people of different backgrounds.

“It also depends on the place as well. One of my sister-in-law, she's from a village

area, and she's not that literate and that. Whereas my other sister-in-law, she's from Lahore, she's been college, she's been Uni (sic), obviously she knows how everything is like. It's kind of, it's not the same as here, but it's kind of similar.” – Sukhaina, Women 16-29

“I think the education comes in here a lot as well. I mean, our forefathers weren't that much educated. They were mostly into the family roots. Education gives you a broad mind. You know what's wrong or right. And you can choose yourself, and you can convince your parents as well.” – Ishaq, Men 30-49

The participants thus categorised cousin marriages as mostly occurring in Kashmiris as opposed to mostly Pakistanis, and they also felt that Luton, because of its higher Kashmiri population, was different to other localities, in terms of its culture (inclusive of the practice of cousin marriages), due to its Kashmiri population. Furthermore, there was an inclination in the responses that considered people from other parts of Pakistan, especially urban centres, were more educated and were broad-minded in terms of not restricting themselves to marrying only within cousins.

6.2.2.2 Perceptions of Consanguinity

The majority of the participants, regardless of age, understood consanguinity as marriage between cousins, simplifying an otherwise debatable notion of defining consanguinity, as discussed in Chapter 3 (section 3.3). In the information sheet that was handed out for this study, consanguinity was referred to in the more commonly referred term of cousin marriage, this was deemed necessary in order to recruit people from the community for participation (see Chapter 4, section 4.4.4). It was proven to be a logical approach as the participants failed to even recognise the word consanguinity when asked, but linked cousin marriage to either first or close cousin marriage, or simply marriage within the family. The participants also highlighted the important role of religion in understanding cousin marriages. Most people felt that religion was often used as a scapegoat in justifying cousin marriages and also used as a means to categorise consanguinity as belonging exclusively to a group of people (Muslims). The participants felt clearly that while Islam allowed for cousin marriages, it did not deem it compulsory.

“That's where people get confused with culture and religion. I was explaining that
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to one of the girls when I came here, and she said I thought it was in your Quran, so many young girls come and say that married because it's in the Quran, their parents told them that. And I was like no, let me give you a couple of English Quran, it might make sense to you. I was really getting frustrated explaining to her that it's not religion it's culture.” – Fatima, Women 16-29

“It's permissible in Islam, but it's not like its encouraged or anything, it's permissible. But parents they like to do for their own personal reasons, that's more a cultural thing.” – Lawangeen, Men 16-29

“The media. It's all from the media. When I'm sitting in the office and someone would come up to me and say oh you're Pakistani, Pakistani people all get married to their cousins. And I'm like, hold on a minute, the Queen, they had arranged marriages. All these other people who are Non-Muslim and that have had arranged marriages but yet, people seem to focus on Pakistani people having arranged marriages.” – Fatima, Women 16-29

These initial stages of the discussions set the stage for more in depth discussions about cousin marriages and the issues surrounding it. Half of these discussions were held in Urdu, a middle ground language that the participants who could not speak English comfortably, had in common with the researcher. Regardless of language, discussing the participants' backgrounds allowed the discussion to naturally flow into relevant topics, sometimes crossing themes, like the discussion on urbanisation and education lead to that of cultural issues surrounding cousin marriages that the participants felt for strongly, and as the narrative above from Fatima shows her using cousin marriages and arranged marriages interchangeably, showing her not only classifying cousin marriages as arranged marriages, but also pointing to the cultural issues surrounding marriage and consanguinity.

6.2.3 Marriage

It has been suggested in literature that communities that have a higher rate of cousin marriages usually weigh their options in terms of social and cultural advantages versus perceived risks (Bittles, 2012, Shaw, 2009). Clearly, cultural issues hold a very important place in the dialogues on consanguinity and a majority of the group discussions with the lay community revolved around addressing these issues that started with the institution of marriage. The responses

from the lay community show that some participants associated cousin marriages with arranged marriages and also forced marriages, which they saw in a negative light.

“It still exists. I have some friends who've had their parents take them back home and get married, and they had no objection to it.” – Asif, Men 16-29

“Even today in our country, parents preference is that forget what the boy or girl wants, parents want to marry them within family.” – Daanish, Men 50+

“My daughter in law, it (was going to be) a forced marriage. They (her parents) took her from here to Pakistan and then dumped all three sisters (there) and then (said) wedding would happen with Phuppo's (aunt's) son.” - Waheeda, Women 50+

“Yes, but getting an agreement (for marriage) is necessary. Not sure if they have that much with agreement, as they say, but forced is there. This is a problem in all families, forced marriage.” – Muneeb, Men 50+

However, the participants did not consider arranged marriages to be negative; they even considered that some love marriages, usually deemed as the polar opposite of arranged marriages (Ballard, 1978, Batabyal and Beladi, 2002), could possibly be arranged.

“I think there can be an arranged love marriage, like they say, if someone likes you and you like them, then obviously what happens is that they'd tell their parents and then they'll see the family side and then in a sense that would be arranged like that.” – Amina, Women 16-29

While showing acceptance for arranged and love marriages, some participants felt that cousin marriages in fact equated to forced marriages. Fatima, participant in the below 30 years old women's discussion, was passionate about the need to stop forced marriages, partly due to her experience in helping those who have suffered through the pitfalls of forced marriages.

“Because there are arranged marriages in Britain and they're not to your cousins. I don't know, when you say cousin marriage, I think it's more a forced thing.” – Fatima, Women 16-29

The fact that Fatima equated cousin marriages to forced marriages, could also be based on the populist castigation of arranged marriages as being forced, an ‘ancient’ practice not in line with the ‘modern’ methods of Western civilisation, used as a hegemonic means to define the South Asian

Others (Ahmad, 2006). This is also part of an overall pathologising of South Asian and in particular British Pakistani culture that has resulted in not only labelling arranged and forced marriages as backward, but also the culture and some have gone on to link forced marriages to honour killings and even terrorism (Wilson, 2007). There is now a law against forced marriages in the UK, the Forced Marriage (Civil Protection) Act of 2007⁷, which is meant to offer greater protection to those vulnerable to forced marriages, however, it has been argued that the law provides little added benefit to the victims, as laws against kidnap already exist and most children forced into marriages would not want to take their parents to court. Instead, this new legislation is just seen as another means of policing the South Asian Others and their ‘backward’ customs (Wilson, 2007, Chantler *et al.*, 2009). Fatima, who is training to be a social worker, equates cousin marriages to forced marriages in the same way that others equate forced marriages to terrorism, as it is the ubiquitous influence, the discursive formation of this time. However, not everyone in the community believes in this equation, as others show the many facets of arranged marriages.

“I think it all depends on how the household works. Because my sister-in-law, she's my cousin sister. She says like, obviously at that time it was an arranged marriage, but it wasn't forced, she agreed to it and now she says it's more easier for me (in the household). She thinks that if I was married into another family, I wouldn't be that comfortable with how the household works.” – Nazish, Women 16-29

“I think there's a difference between arranged and forced. Because you're saying you're totally against arranged and forced marriages. Whereas I think like that there are so many love marriages that don't work out. Yeah, you should be against forced marriages, but I don't think that arranged marriage is that bad.” – Nazish, Women 16-29

Indeed there are different types of arranged marriages, as Ahmad (2009) cites Stopes-Roe and Cochrane (1990), with varying degrees of involvement and influence of parents and children, and as suggested by Amina above. This variance in arranged marriages has led to newer

⁷ Forced Marriage (Civil Protection) Act – “An Act to make provision for protecting individuals against being forced to enter into marriage without their free and full consent and for protecting individuals who have been forced to enter into marriage without such consent; and for connected purposes.” [Online] Available at: <http://www.legislation.gov.uk/ukpga/2007/20/contents>. Accessed: December 2, 2013

terminology, perhaps in part to dissociate them from forced marriages, recently marriages that are both arranged and have consent of all parties involved have been termed assisted marriages (Ahmad, 2006, Ali *et al.*, 2008).

Other participants may not have agreed with Fatima's point of view on forced marriages being the same as cousin marriages, but they did speak of other ways in which children can be forced or coerced in to marrying someone of their parents' choice, usually a cousin and usually from Pakistan. These types of forced marriages often resulted from social or family pressures and "emotional blackmail", and have been explained as the non-physical but mental coercion approach to forced marriages (Gangoli *et al.*, 2006, Hossain and Turner, 2001).

"I think the parents these days are much more smarter (sic). They don't force you like back in the day. They use more psychological, emotional blackmail." – Asif, Men 16-29

"That's what they do, marry for the sake of their parents." – Saima, Women 16-29

"If I go back to Pakistan yeah, no one can force me, it's my life, at the end of the day. I'll let my parents have a say to it, yeah. They know there's a certain amount I could take but after that isn't it. Obviously my parents, they're aware of that. If they push me to a side I don't really want, then I won't have a choice. I'm not going to be like, like a little boy and say alright mummy daddy, I'm going to do my own thing. So, if I go back, I know what it's going to be like, all the aunties are going to be like this and that yeah. Everyone knows what it's like yeah." – Abid, Men 16-29

The participants suggested that sometimes these pressures are exerted on the children who are to be married into a cousin marriage, and sometimes the pressure is exerted on the parents from the wider family or *biraderi* to fulfil promises that were made when the children were born.

"And it could be one of those things that it is pre-determined. At a young age, for instance, if your family makes arrangements with cousins or other sort of uncles and aunties. It turns out that's actually pre-determined and pre-conceived." – Faiza, Women 16-29

Respondents spoke about the sense of obligation they felt towards relatives 'back home' and how arranging marriages between the children of siblings and relatives was often one way of amortisation. As discussed earlier in Chapter 1 (section 1.2), migration is not usually an

individualistic enterprise, it involves the wider family in most cases, with siblings and parents who invest either financially or emotionally to facilitate the migration of the individual, and that individual then bears the burden of repaying this favour, again by either financial means or by offering them a chance to avail opportunities in the UK, through marriage and immigration (Ballard, 1994, Shaw, 2001). Sometimes this obligation is then passed on to the newer migrants, as in some cases, families will call over loved ones from Pakistan and then have them be obligated under them, expecting them to repay the favour by always being grateful to them, as one participant suggests.

“It's like girls who come over from Pakistan they have to like, think, they have to be grateful that they brought them over.” – Usman, Men 16-29

“Yeah, when my dad sat me down, sat me down two years ago and talked to me about marriage. About like if you bring a girl from back home, she'd look after you, she'd look after us, this and that. If you get married from over here, she'd kick you.”
– Asif, Men 16-29

“You get tension (when you're here in UK and family is not), you cannot have independent advantage. One thing could be, that one son or daughter goes to one family and then another to other side of family (so they could come over as well).”
– Yaseen, Men 50+

The matter of migration or immigration into the UK, through transnational marriages to family members in Pakistan, was raised as a major issue by the participants related to consanguinity. Many participants, mainly the younger generation, under 30 years of age, spoke about how hesitant they were to take “holidays”, as Asif emphasises below, to Pakistan for fear that they may be pressured into marrying a cousin from there.

“I hear people saying, oh I got an arranged marriage from Pakistan. And then they'd say, I went to Pakistan on a holiday and then I got married and I got back.”
– Fatima, Women 16-29

“My mum yeah, she's very traditional. She's like Pakistan aghay hafta jaa sa (let's go to Pakistan next week) and this and that, as in we going next week to Pakistan and get you married and all that.” – Abid, Men 16-29

“Not that I want to (go to Pakistan), but yeah I do (go). Not that often. Last time I went was 8 years ago. I think my dad's planning on taking me again. On ‘holiday’.”
– Asif, Men 16-29

One reason for their opposition to such marriages was the differences that they felt they may have with cousins from Pakistan in terms of having the same interests in sports and pop culture to problems with communication as their cousins may not even speak English very well.

“Yeah (I would oppose marrying a cousin from Pakistan), because I wanna (sic) be able to get along with the person. I'm not trying to be wrong, the thing is like, most of my mates, nearly most of my mates, are like modern people, they'll speak full English yeah, nearly half of my mates are white or black, they can't even speak like Pakistani. If I bring her, I'm not the type of person who would sit at home all day, I have to be out and about, even if it's just walking shop. Take my dog out, get out, go to the gym, do something. She's got to be willing to do the same thing, and if she can't speak English like, that's it for me like, it's better for me to just stop there. And every two seconds she'd be like what do I do?” – Abid, Men 16-29

Yet another reason for their opposition revolved around the issue of immigration itself. A large majority of the participants felt that these transnational marriages occurred only to allow their cousins from Pakistan a way to obtain a British Passport. In fact, some reported that there appeared to be an understanding between the marrying parties that once the relative came over from Pakistan and received his or her legal status here in the UK, then they could go their separate ways, free to marry someone of their choice. Marriages of convenience occur in most Western countries (De Hart, 2006, Tucker, 1989) but here the participants have drawn a link to cousin marriages.

“You lose them half the time! Because my friend's sister, (her husband), once he got the passport, he was gone! And they were cousins and she'd just done it for the sake of the family.” – Soha, Women 16-29

“Yes, even here, but it is mostly from Pakistan. Like, when they know you're from England, they always wanna come here. They think it's a big thing to come here.” – Bushra, Women 16-29

“Immigration is massive. How many times have we heard families say, we have to get him married to my brother's kid, because they can come.” – Mujahid, Men 30-49

“It is about (the) visa. And when they get the visa, they're like, you're there I'm there, it's an understanding.” – Ishaq, Men 30-49

“They're like, okay, you're here now. You've got your visa. Then they go back and marry and bring another person over.” – Taimur, Men 30-49

In linking cousin marriages to immigration issues, the participants are not defining immigration fraud as a consequence of cousin marriage, that link would be as flawed as the previously mentioned link between cousin marriage, forced marriage and terrorism. However, the participants do feel that cousin marriages in part can be a consequence of immigration fraud. This does not feed into the discursivities that chastise cousin marriages as the cause of rising numbers of illegal immigrants, it in fact proposes that restrictive immigration policies can lead to a perversion of culturally important practice of cousin marriages, which have successfully aided in the establishment of a prosperous community of British Pakistanis in the last half century.

Another reason that the participants felt cousin marriages occurred often was for a sense of security. Parents who are afraid to have their children's marriages fail or they fear that they may not be able to find suitable matches for their children's marriage, often resort to marriages that are called *Dawati* or *Atta Satta*, where a daughter from one family marries into another family (mostly related), and one of that family's daughters marries into their family. This way, the marriages will sustain for fear of having both marriages fail and a daughter being sent back home (Shaw, 2009).

"Yeah, our parents are inter-married. Like my mom is her dad's sister and my dad is her mom's brother. It's what you call atta satta" – Chaman and Sukhena, Women 16-29

Cousin marriages are also used to secure land or inheritance within family. In fact, a few participants felt that this was at the crux of the entire practice of cousin marriage within the community, and that religion was used only as an excuse to hide the true intentions.

"They bring Islam (into it) and raise swords in the name of Islam but actually, in fact mostly that's the reason they want their property to stay in the family." Sakeena, Women 50+

"I think it has something to do with wealth and properties as well. [All others agree] If it's like say you're cousins with somebody, your grandfather has like say three sons and he's left him like one property, they're gonna think the easy option is that if we get our sons and daughters married, then we won't have the issue of someone else getting a part in it." – Sukhena, Women 16-29

"Inheritance and dowry..the thing is that the daughter gets it from her dad's

inheritance, that is in our custom. Dowry is always there, the same.” – Muneeb, Men 50+

However, the idea that marrying within cousins eases the pressures of dowry on a family was negated by some as saying that sometimes it is the opposite and that there is more expectation of a better dowry as there is more love between family members.

“They say you should give even more. [laughs] They say, this is your own house, right, so you should give even more.” Yaseen, Men 50+

Marriages within the *biraderi* also could be seen as providing this sense of security. As mentioned earlier, the younger participants did not feel that *biraderi* was personally an important concept for them, yet they knew of its importance to their parents and grandparents and the sense of security it provided them that if one was not to get married to a cousin, then there was an expectation that at least the marriage will occur within the *biraderi*, which literally means brotherhood (Tovey *et al.*, 2005), who will be at least be more caring than an outsider.

6.2.4 Factors Limiting Cousin Marriage

Although these group discussions occurred with the lay community, those that were not married to their cousins, this was not always due to a conscious effort to avoid marrying a cousin. The participants that were above 30 years of age were not necessarily opposed to the idea of cousin marriages, they just happened not to be married to their cousins because of their circumstances. On the other hand, the younger boys and girls were mostly opposed to the concept of cousin marriages, as reflected by their discussions on forced marriages and their perceived incompatibility with Pakistani cousins. This has led some to believe that cousin marriages, or at least transnational cousin marriages, are on the decline in the British Pakistani community (Shaw, 2000), a view that was countered by Ahmad (2006), and later retracted by Shaw based on statistics of rising numbers of these marriages according to the Office of National Statistics (Shaw, 2009). This view, nonetheless, was also propagated by a majority of the lay community participants, who felt that cousin marriages were becoming less and less common as the generations progressed, and will not be happening at

all in the near future. This was seen mostly as a result of education and the younger generation speaking their mind.

“It used to be very different back then, in the olden days. The newer generation, they're tending to go different way.” – Usman, Men 16-29

“Boys now say that first cousins are our sisters and we won't marry them. In next few years you won't need it (research like this). Like 20 years ago it was strange to have love marriages, then 10 years ago cousin marriage was strange. Kids do this that whichever girl or a boy they like, they say here we want to marry. That's all.” – Semra, Women 30-49

“Although it is a little different now. There are so many more people from District Kotli, who have gone outside country. Especially in (to the) UK. So, it's quite different. But not 100%, only 50 or 75% problem (of cousin marriage has dissipated). Only 25% or 20% left. It will take another 2-4 years for it to completely change.” – Muneeb, Men 50+

Education was seen as a limiting factor for consanguinity, which was largely called a cultural practice by the lay community members. Participants felt that people in the community have confused a cultural practice as a religious one, which was mostly due to a lack of education, or as previously stated by some participants, done wittingly and people just use religion as a scapegoat.

“I think from our parents' generation, there were other cases, where people got married to their first cousins, from Pakistan, where things have gone pear-shaped. And it's about being open-minded, these kids, they've been brought up here rather than in Pakistan. They're educated. Education all comes in line. It gives you a more broader (sic) sense of what's going on around you.” – Zain, Men 30-49

“The thing is it (cousin marriage) is part of our culture, or society as they say, everyday life.” – Yaseen, Men 50+

Participants also talked about other possible disadvantages of cousin marriages that may be seen as limiting factors. Their answers revolved mostly around the issue of closeness, which incidentally was also mentioned as the single most advantageous aspect of cousin marriages. First, from an advantageous point, most participants agreed that the reason why their parents or elders preferred cousin marriages was because family members will have more care or “*dard*” (literal

meaning of pain) for each other. The parents would expect natural altruistic feelings from a daughter-in-law who was also their niece, and who will take better care of them once they are old. Furthermore, if something were to go wrong in the marriage, then this closeness would allow the families to work things out better as opposed to an outsider who would not be as amenable to a resolution.

“If you marry within family, then they get closer. They have more feeling for you. This is my relative and I have married them, I should be nice to them.” – Yaseen, Men 50+

“See, when one person calls the family over, does not do it because they are my cousin. I think that is not a plus side, there is some other advantage, that's not a help, it's a good deed. If I help someone, like you or this brother here, that's just it, nothing else, don't need anything from them.” – Muneeb, Men 50+

“I think it all depends on how the household works. Because my sister-in-law, she's my cousin sister. She says like, obviously at that time it was an arranged marriage, but it wasn't forced, she agreed to it and now she says it's more easier for me (in the household). She thinks that if I was married into another family, I wouldn't be that comfortable with how the household works.” – Naazish, Women, 16-29

“Family bond more strong (sic). And if you have any difference in your status, in your marriage, the elders will sit with them and try to solve it, rather than breaking it so quick. Like in the English (people). So, it is like, no one has a check on you. In ours, everyone has a check. Everyone will know.” – Ishaq, Men 30-49

However, this closeness, when not seen in terms of altruism, was seen as a limiting factor to marrying one's cousin. The lay community mentioned the negative effects of closeness as one of the biggest disadvantage to cousin marriages. While on the one hand closeness can lead to families assisting in a couple's misunderstandings, on the other hand, if those misunderstandings still lead to a breakup of the marriage, the marriage is not the only casualty. It was felt that when such close unions lead to separation or divorce, entire families are torn apart. This of course makes life very difficult in a close knit community where extended families are involved in all joyous and solemn occasions.

“I spoke earlier on about family bonding, that's one way of looking at it, but another way of looking at it when things go wrong, the whole family splits up. I've seen it in my own family, when my cousins have married their first cousins, everyone is happy

when they get married, and then when things go pear shaped, the whole family just splits up.” – Zain, Men 30-49

“(People say that) Family’s hurt we can bear but I don’t think so. I think if they are outsiders then people say that we didn’t know anything about them. We didn’t know them, so we will never see them or (have to) listen to them (again), but if you marry in the family, since biraderi is (the) same, then if problems happen, then everyone knows (the) problems of each other and then you see them at weddings and funerals, you see them (everywhere), people talk and it’s very stressful and gives tension (sic).” – Nargis, Women 30-49

Another limiting factor mentioned by the lay community to cousin marriages is closely related to the incest taboo and natural aversion theories in literature (see section 3.3). While the word incest was mostly used to describe how the “white” people felt about cousin marriages, most participants were opposed to cousin marriages, especially if they grew up with that cousin, because they would see them as a brother or a sister. This was a feeling that would be difficult to overcome as they would have been raised to respect them as a brother or a sister and could not see themselves then as their spouse.

“When it comes to my cousin, first of all, close cousins, or anything like is related to me, first cousin so on, is like, it doesn't matter for me, I just consider them my sisters, brothers or sisters.” – Usman, Men 16-29

“It happened to my sister that she married my dad's cousin and they were married for two months and (then) they got divorced and he (dad’s cousin) says (sic) I could never think of you like that (as my wife), as I thought of you as my sister. Even though we were (a) group from (the) new age and we were very close and there were plenty of children but from the times when we are early teenagers we would think like this and they would say you are like a sister because we played together. We grew up together, we played together.” – Zeenat, Women 30-49

“And bhai (literally brother, but referring to cousin here) came too (for rishta, asking for hand in marriage) but first I was calling him brother and now he was there for nikkah! (marriage) And I raised hue and cry about it (laughs), how can I marry my brother. Kill me or whatever but I can't, so this thing was over.” – Waheeda, Women 50+

6.2.5 Religious Beliefs and Health Behaviour

Another aspect of cultural issues around cousin marriages is the religious belief of the participants, which contributes heavily to the overall cultural make-up of the British Pakistani

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community, or indeed any community (Stander *et al.*, 1994). Although participants had mentioned how culture was wrongly mixed with religion when it came to cousin marriages, the impact of religion on the health beliefs and behaviour of the local community seems relevant from the responses of the lay community members on abortion and fatalism below. Religious restrictions on abortion were cited, without specific reference to verses in the Qur'an or to *Hadith* (sayings of the Prophet), as the reason to refuse termination in cases of terminal or near terminal pregnancies, an issue that comes up often with consanguineous couples in Luton according to a recent public health report (Taylor, 2011). Previous research has indicated that South Asians generally respond to genetic disease with a fatalistic retort (Croot *et al.*, 2008, Dyson, 1999, Hussain, 2002). Additionally, responses from the service providers in this research (see Chapter 5) highlighted the frustrations they felt with patients who were either in denial or deemed repeated pregnancy risks after the birth of a child with disabilities inconsequential in their pursuit for a healthy child.

“Abortion isn't allowed.

Yeah, it's not allowed in Islam.

The only time, somebody's said maybe abortion is not allowed, you see the soul has not gone into the body. So there's a certain amount of time, before that time, you can, but even that you shouldn't really be doing it unless life or death.” – Lawangeen, Asif and Ikram, discussing abortion, Men 16-29

“I don't know. You mean in terms of an abortion? I don't know. I've never spoken about that with them (parents of a child with disabilities). I can't see any of those two parents, getting rid of the child. Even if having the option of abortion, none of them would take it. You still have to take that. It's not an option. Only Allah knows when someone's going to die. Doctors can only predict but that kid could live all his life. We don't know at that point. Allah (SWA) knows, He gives life and takes away. We don't know. The doctor, they cannot give you 100% guarantee. The only thing in life that's guaranteed is death. At the end of the day, you could say advantages or disadvantages in the child. But the child is produced by Allah (SWA), whoever is produced, however he is produced.” – Zain, Men 30-49

“No, they're just in denial. They just don't want to know the truth. Because I've studied, there was a study in Bradford as well. And every single person was in denial about it. They just didn't wanna accept it, it's common ancestors, you have a limited gene pool, all these statistics are out there, but they don't want to accept it. Because it damages their culture.” – Soha, Women 16-29

“I have seen it (in) hospitals as well, where doctors say to moms (sic), every child you've had so far has some kind of disability. I don't want to make this sound horrible but the mom... I've seen doctors say to moms, that your child is like that because your husband and you are (cousins), they've explained it to them, the blood cells and all this. And the mom just sat there and says, but I want more children. They don't understand. They've had three children with special needs. And then you're gonna have another one as well ?! The impact that has on the whole family, I don't think it (resonates).” – Fatima, Women 16-29

Although, as discussed in the previous chapter, placing blame on patients' health beliefs alone while failing to address the shortfalls in care and policy aids to the pathologising of the British Pakistanis. So, while the lay community members felt strongly about the influence of religious beliefs in making health decisions on matters that come up often, although not exclusively for consanguineous couples, they do not suggest that these decisions alone are what lead to poor health outcomes. Furthermore, it has been suggested that religious beliefs offer a strong coping mechanism when dealing with difficult health decisions and outcomes, and what many understand as a resignation of responsibility through fatalism, is in fact a coping device for some patients (Atkin and Ahmad, 2008).

While discussing cultural issues surrounding consanguinity, and the impacts of religion within that context, the community members were asked to comment on a news story about a speech given by Baroness Deech at Grisham College in 2010 where she stated that cousin marriages result in more disabled babies and that this practice was mostly in immigrants from Pakistan and also that it was not spoken about for fear of offending Muslims. In response, some participants objected to her point about offending Muslims, but less so about this happening mostly in Pakistanis. Some participants also asked about the proof that she may possess for her claims.

“It's biased when people say that Muslims do it (marry cousins).” – Usman, Men 16-29

However, very few felt that this was racist or a biased opinion towards British Pakistanis. Most lay community members did object to Ann Cryer, a conservative politician, calling for a ban on cousin marriage, calling it a “human rights violation”, but even here there were a couple of

exceptions in the over 50 years male discussion, where two participants welcomed such a move, calling it the only way to control cousin marriages, which they felt were the cause of poor health in some children, an assertion they derived from media, as discussed later in the chapter.

“No, if there is a law (to ban cousin marriage), that is not a disadvantage. Law is fine. Because then it will be on board, that doctors and government have researched that the kids that are born are getting handicapped, so this is better that they marry outside.” – Daanish, Men 50+

“Yes, it would be good. If it's the law (to ban cousin marriage). Everyone will respect the law, it won't be a choice. Then it will be better for the kids.” – Yaseen, Men 50+

Overall, there were some comments made about possible bias against British Pakistanis and Muslims about cousin marriages, but it was not an overwhelming response, something contrary to literature where feelings of stigmatisation by the British Pakistanis have been reported (Ali *et al.*, 2008, Smith, 2007).

Cultural issues around cousin marriages dominated most of the lay community discussions, with emphasis on marriage, in terms of arranged, forced and transnational marriages, issues on immigration and property inheritance, the perceived advantages and disadvantages (which were mainly social disadvantages) of cousin marriages, as well as the importance of religious beliefs on health behaviour. It was perhaps no surprise then that when asked in summation if participants felt consanguinity was something of an issue in the local community, most identified it as a cultural issue, clearly relegating health concerns as a secondary concern.

6.3 Genetics, Healthcare Services and Consanguinity

Although the findings so far have focused on the participants' responses on cultural issues and cousin marriage, genetics and health related issues in the consanguinity context were also discussed at length with the lay community members. The questions posed to the participants sought not only to gauge their knowledge level about genetics, but to also elaborate on their perception of health risks posed by consanguinity, as per the health belief model (see Chapter 1, section 1.4.2), and to explore their usage and views on health services in order to test assertions made in literature

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and by the service providers about the health impact of consanguinity. In particular, the discussions focused on the knowledge of genetics and hereditary disease, the participants' views on the evidence presented in literature linking cousin marriages to genetic disorders, healthcare services delivery and use, as well as the role of primary care and the GP in particular in providing healthcare and genetic information to the community.

6.3.1 Knowledge of Genetics

Most respondents had heard, primarily through the media, of some type of link drawn between cousin marriages and negative health outcomes in children of such marriages. Others have also reported a similar mode of knowledge transfer through the media, and in some cases, these health promotion campaigns had an unexpected outcome as the marriage choices did not change as intended and instead received a negative backlash from the community (Darr *et al.*, 2013). Those participants who had gone through at least a secondary education were aware of genetics, at least in a general sense that it had something to do with their parents and heredity.

“Like, (it's) inside me. What I am, what makes me.” – Abid, Men 16-29

“(Genetics is like) your genes, your parents' genes.” – Saima, Women 16-29

As the responses below from Muneeb and Zainab Bibi highlight, the level of understanding of even the word genetics was minimal at best amongst the older participants, and was usually linked to something to do with blood and pointed to heredity in a very generic way, these responses are not uncommon (Richards and Ponder, 1996, Shaw and Hurst, 2008).

“Yes blood relations. Genetic means your germs (sic). It has come out of germs. like if you are marrying your paternal uncle's (son) then you would have same germs as your uncle. This is genetics.” – Zainab Bibi, Women 50+

Most of the discussions around genetics were non-specific in nature, owing to the poor understanding of the term, and most participants related the presence of disabilities in children of consanguineous couples as a possible risk associated with cousin marriages, which again was something that they had absorbed through the media.

“That there are some faults in it. Some people have done research in it, I watched it on television. They said that some disease forms in genetics. If you marry within close relatives, there is a change in their blood. It can happen in girl or boy. There can be many such diseases.” – Muneeb, Men 50+

“There was a thing in the media. If you continuously marry cousins, somewhere down the line there may be an effect. But I don't know.” – Zain, Men 30-49

“There (in Bradford) it's quite common, (they) marry their cousins, they said like, they did a study, within they found out like, especially because it wasn't just first cousin marriages, it was second generation, third generations, they all marry their cousins, because of that, their kids were born with like, some of them were born with defects or learning disabilities, you know. And that could be one of the problems as well.” – Abid, Men 16-29

The only specifics came from Soha in the 16-29 female discussion group, who was a science student undertaking a genetics course at the time. Soha mentioned the limitation of the gene pool as a result of continuous cousin marriages through successive generations. In fact, other participants also associated negative aspects of consanguinity with cousin marriages that take place over multiple generations, like something Zain from the men's 30-49 discussion group mentioned above in a very general sense, displaying a lay understanding of illness causation that may in fact be linked to genetic science, as in the rise in the number of homozygous regions in successive generations of consanguines (Bittles and Black, 2010a, Cherkaoui *et al.*, 2005, Woods *et al.*, 2006), as discussed in Chapter 3 (section 3.4.2.2).

“They just didn't wanna accept it, it's common ancestors, you have a limited gene pool, all these statistics are out there, but they don't want to accept it. Because it damages their culture. The queen carried, they all carried haemophilia and they all married cousins. Albert Einstein married his first cousin. I think Charles Darwin married his first cousin. So, it's not just practiced in our culture. It's just that they think their families will be closer and they won't have this whole burden of it's another family we won't feel as comfortable. They just wanna (sic) stick to their own people.” – Soha, Women 16-29

Soha was also the only person to mention specifically the possible risks of not just cousin marriages but also marriages within the *biraderi*, pointing towards endogamy, which has a possible negative effect on genetic risk, especially in smaller populations that inter marry over multiple generations (Hamamy *et al.*, 2011, Bittles, 2012).

“A lot of Kotli people are intermarried. Not first cousins but still inter married. So, I would still check genetic risk.” – Soha, Women 16-29

Other respondents made reference to this potential risk unknowingly, and once as an argument against the risk posed by cousin marriages, as disabilities existed in the family of a couple who were not cousins, but when further probed belonged to the same *biraderi*. In fact, most lay community members did not feel there was any health risk associated with marrying within the *biraderi* as opposed to cousin marriages, where only a few respondents felt the potential of risk.

“My other mamu (maternal uncle) who is married outside the family and he has a physically disabled son. And my father's brother married outside the family has a physically disabled daughter.

Is it the same biraderi? (question from researcher)

Still Rajput but not very close.” – Semra, Women 30-49

“But I never thought that that would have an impact on things like genetics. Like the whole Malik Chaudhri thing. What my parents told me is, it's like (the biraderi names, titles) to do with the jobs you do in Pakistan, from ages ago. It was classed that Maliks do this and others do that.” – Nazish, Women 16-29

Whether it was the lack of understanding of the term genetics, or the risk associated with cousin marriages or within the *biraderi*, it was clear that the lay community, barring a few exceptions, had an overall poor understanding of genetics and genetic disease. Furthermore, they only seemed to have heard of the phrase genetics in reference to cousin marriages, meaning that they saw genetics through the cousin marriage perspective, something that can act as a barrier in the understanding of genetic risk due to the overemphasis on consanguinity (Ali *et al.*, 2012, Ahmad and Bradby, 2007).

6.3.2 Disputing the evidence

The doubts that existed in the community members about the possible risks of genetic disorders or disabilities due to cousin marriages centred mainly around a single argument, that children of “White” people, as referred to by participants, also had disabilities, if not more than South Asian children, and since they did not marry within their cousins, they could not attribute disabilities in children from cousin marriages to the nature of the parents’ relatedness.

“White people do not marry in cousins and Muslims do. So first thing (they say) is that these disabilities are more in Muslims maybe it’s because of first cousin marriages, so why are the kids of white people disabled? They aren’t marrying in cousins.” – Tahira, Women 50+

“You don’t have to be related to someone to have a child with special needs. Because I’ve got friends who aren’t related and married, and they’ve got kids with special needs and I’ve got friends who are white and have kids with their boyfriends and they have special needs. So, I don’t believe you have to be related to have a child with special needs.” – Fatima, Women 16-29

“It (disabilities) isn’t because of cousin marriages; it can be like that anyway. Because there is so many, more of the English people, they have disabled kids and they don’t marry cousins.” – Ikram, Men 16-29

This lay perspective on illness causation is not unique (Richards and Ponder, 1996, Shaw and Hurst, 2008, Darr *et al.*, 2013), but it has been countered by the service providers (see Chapter 5) as the community simply not understanding the nature of the disabilities and the true cause behind different medical conditions. While the service providers may have a point about not understanding the underlying causes of different disorders, and certainly the community members may also be justified in doubting some of the proof provided in studies about the genetic risks of consanguinity (Bittles, 2010b), but denying it all together, as some participants did, would be contradictory to existing literature on potential risks posed by genetics of consanguinity (Shaw, 2009, Hamamy *et al.*, 2011).

“It’s nothing wrong in it (cousin marriages). You are married with a cousin or not, it doesn’t matter, but things that people say, that diseases are spread and all, in my opinion it doesn’t happen.” – Nargis, Women 30-49

“You can’t prove it, that’s the thing.” – Abid, Men 16-29

“I think two years ago, there was an article in a local paper or something and it said in a year there’s like a 100 something marriages in Luton that are forced, but they made that figure up. So obviously as a reader, I believed it. Because we see it, we hear about it. I went to a conference where they had councillor, Kurban Hussain, he pointed out to them, prove it, where do you get the figure and they couldn’t. And they made them apologise.” – Asif, Men 16-29

“I don’t think there is anything conclusive that proves that marrying your first cousins is going to result in your kids being disabled. I mean my parents are first cousins, alhamdulillah (thank God) none of us are disabled. Yet, there’s another

member of our family who's married outside the family and she's got disabled kids. And none of my other cousins who are married to their first cousins, any of them have disabled kids. So, I don't think there is any conclusive truth.” – Zain, Men 30-49

The responses from the lay community show that the reasons why some participants dispute the existing literature on possible links of consanguinity to genetic disorders lies in their lack of understanding of genetics, their own observations of family histories, as well as a distrust of official reports presented on the matter based on prior experiences with media reports that may have been misleading. This does not however equate to denial of facts, as was suggested by Soha and also by some participants in the Service Provider study (see Chapter 5), as these participants have explained their own reasons for doubting the evidence rather than a simple denial.

6.3.3 Service Utilisation

Even though the lay participants disputed some of the evidence of a link between genetics and consanguinity, many participants were open to the idea of a genetic screening service being offered to consanguineous couples. When an example was presented to the participants of the Greek Cypriot and Ashkenazi Jews, who are highly consanguineous, and where successful pre-marital genetic screening programmes have reduced or eliminated the cases of thalassaemia and Tay-Sachs disease respectively over the years, the respondents suggested that such services should be offered before they were married, as it may become ineffective after marriage, as most couples would avoid any drastic steps owing to health beliefs dominated by their religious restrictions.

“I think whoever you get married to, if they have any kind of relationship to you, far or close, you should have a blood test done, or something beforehand so that you know they're not thalassaemic carrier and you're not either.” – Fatima, Women 16-29

“Yes, (they should get tested) before they get married. Someone gave advice, somebody once told me, one guy who got married to his cousin from Pakistan yeah, get married from back home. He was like too careful isn't it (sic), he was like before you get married, do this genes thing, that you just mentioned.

Yeah (test should be before marriage), because you don't want to take the risk and that.” – Abid and Usman, Men 16-29

“(Genetic screenings) Should happen. Who (whomever) wants to marry in cousins, should smart(en) up and get himself screened without feeling bad.” – Waheeda, Women 50+

When participants were asked questions about health services not being fully utilised currently, be it genetics or otherwise, an assertion made by service providers (chapter 5) and has also been shown in literature (Randhawa and Owens, 2004), they were asked of the possible barriers that existed in patients’ access to services. One such barrier was the lack of information about the full breadth of services that are currently available, as most participants, regardless of age or gender, were unaware of the available genetic counselling services, as all the participants in the male 30-49 focus group discussion stated that they had never heard of a genetic counsellor. While some were aware, they were unsure of it being offered in the local area.

“I’ve heard of it. It’s offered to people that are first cousins. But whether they take it up or not I don’t know.

Do you think there’s a genetic counseling service here in Luton? (researcher)

I don’t think so” – Soha and Sukhena, Women 16-29

Perhaps the biggest hurdle in going to see the GP, as relayed by the participants, was getting appointments that suited the patients’ time and needs. Most believed that the appointments were difficult to obtain for the same day and when they did receive them, they did not get them at a suitable time for them to be able to attend the appointment, in which case, most people either waited out their ailments until they felt better or went to walk-in centres instead, which were not the best option and were often compared to services that one would expect in a “third-world country”.

“I have to wake up 8 o’clock in the morning, ring for half an hour and they pick up when they want to.” – Asif, Men 16-29

“I just feel with GP’s I don’t waste my time making an appointment with them. Because that’s ridiculous. I’d just go to walk-in. Because first of all you have to make an appointment on the day, you have to ring up in the morning. For me to ring up in the morning is difficult yeah. So, you ring up in the morning to make an appointment, if you can’t, then you have to try the next day. If you want to make an appointment in advance, you have to make it two-three weeks in advance. By that time the problem is already gone.” – Taimur, Men 30-49

“If you call on Wednesday you get an appointment for Friday. And if you have a problem on Wednesday and you recover on Friday then what’s the use? So when you call, they should be able to see you the same day.” – Zeenat, Women 30-49

“And if you go the walk-in clinics, you have to sit in and wait, it's like a third-world country you're just sitting in the surgery for two-three hours before you get seen by a doctor, it's crazy.” – Taimur, Men 30-49

Language barriers also existed when going to a GP or a specialist and the older participants factored this in when choosing a GP. This was less of an issue for the younger participants in the discussions who had been born and raised here in the UK and had no issues with language and communication.

“He (doctor at hospital) said a very good thing that why do we choose doctor of our own language? I can converse in English but I say I want a doctor who can speak my language so he (my doctor) called me from health centre that why do you need a doctor who speaks your language? I said because you can explain in your mother tongue in a good way.” – Zaineb Bibi, Women 50+

There were other barriers that some participants stated as holding them back from using services as often, including transportation, lack of a personal bond and shyness in seeing a male doctor for female related issues.

“I don't mind, whichever doctor. If it's like something where I have to show my body or something, then I would like a female doctor.” – Bushra, Women 16-29

“My grandad knew someone and we just kept going there, I don't know why. But then that doctor moved to another area his practice (sic) with some other doctors, we just, obviously because he jumped there, we just been there since then. And then about three years ago, a doctor surgery opened on the top of my road, and then (we thought) might (as well) be changing (to this closer surgery).” - Abid, Men 16-29

“It's not like that though. It's not just like 1 or 2 GPs that you go and see. My surgery has got like 10 different doctors in there. So, it's like a medical centre than your traditional doctor surgery, so you don't have that personal touch with your doctor anyway these days. You don't even see the same doctor. And if you request for the same doctor, then you're done, your waiting time will go sky rocketing.” – Taimur, Men 30-49

Another deterrent in the use of services seemed to be the racial barriers that existed at doctor surgeries. While some participants noted that they would be treated differently by the surgery staff because they were Asian, others mentioned how doctors would give less credence to their concerns

because Asians are known to ‘exaggerate’. However, some participants noted that they would rather see a White doctor because it was the Asian doctors who gave less importance to their issues. In fact, some felt that surgeries run by White staff were more understanding and helpful. Only one participant from the over 50 female discussion group, Saeeda mentioned any racial bias or stigmatisation in terms of cousin marriage in particular.

“Kids weren’t born to her (an acquaintance) means they never survived after 3-4 months (of pregnancy). And (when) doctors were unable to understand and (then) they started saying maybe because she is married to a cousin but we found out (that) there was no relationship at all (between the married couple).” – Saeeda, Women 50+

“If you were in a group of Islamic friends and that then you wouldn't find it that awkward really. You know them saying that oh you got married to your cousin and whatever. But if you go out with like white or black or whatever, then it would be a bit more (sic) harder to explain it to them. Some of them might find it, they'd be appalled and that, like what's he doing.” – Ikram, Men 16-29

“My brother and sister are GPs as well. They tell me. They do locuming (sic), so they work at quite a few different places. And what they tell me, they don't actually like working within certain Asian communities. All sorts of people come in and they start asking questions like, even if they might have a little pain in the arm or something.” – Ikram, Men 16-29

“Sometimes our own doctors stereotype us more. Doctor of my sister-in-law is an Indian doctor and speaks Urdu with her. My sister-in-law is from Pakistan (and) so she talks to her disrespectfully. Because she used to think that she won't be able to go to any other doctor so we would believe it (whatever she said). Until my sister went with her (one day) and saw how rudely she was talking then my sister told her that you won't be her doctor anymore and we need another English doctor no matter if there is any translator required (or not). Sometimes our own people stereotype us more.” – Nargis, Women 30-49

There was however, an instance where greater cultural sensitivity may have been useful, as explained by Tania, who was repeatedly pushed towards family planning by her doctor, something she was very uncomfortable with at that time and that she later said was not permitted in her family.

“It’s a confidential interview so I will share that when I got married 6-7 years ago, I was working so hard and now my daughter is born only a year ago. So when I didn’t have a girl they tried do the same thing that (they do with others), I was pushed quite a lot to not to have any more kids. And by the doctor! Not that I will listen to him because I have already started a family now and I have worked so hard for years and I am 32 years of age and this is my time to start a family and but I don’t know was it because of my background or do they do it to others too but

he really was talking to me about birth control and you must do this and think about not getting pregnant again.” – Tania, Women 30-49

The above responses by the participants show that the lay community is open to using health services but they face barriers in their use of these services which range from lack of information about the available services, unavailability of suitable appointment times, language gaps and cultural insensitivity from doctors. This highlights the importance of primary care services for the community as most of the comments and experiences were related to GP surgeries.

6.3.4 Role of the GP

Participants mostly had negative reviews about their GP's, in that some believed that the GP's had limited knowledge about genetic issues or any health concerns for that matter. This lack of trust in GP's was prevalent amongst most participants, and while there is evidence that GP knowledge levels in genetics may be lacking (Baars *et al.*, 2005, Miller *et al.*, 2010, Emery *et al.*, 1999), the participants seem to be pointing towards an overall lack of trust in the GP's ability to care for them. This barrier to healthcare services is more personal towards the GP rather than the primary care service, which were discussed in the previous section.

“I hardly ever go to the doctor. I only go if I have a problem and want to discuss something but only after doing my own research and then from people I know and trust. Doctors I do not trust, because they're not as well educated as they should be. For example, doctors get three salaries, they get their normal salary, they get from the goods that they give out, they might have investments in those, that's why some doctors give out prescription when they don't even need it, all that extra bit of money goes in their pocket. So, everything is turning into a money making business, so I can't really trust any of them doctors.” – Lawangeen, Men 16-29

“Yeah, GP's don't know much. I don't think so. My GP, I can't stand him. Because he doesn't have a clue what he's talking about.” – Soha, Women 16-29

The lay community participants did feel that the GP's could in fact play an important role in disseminating important medical advice like genetic disorders and risks associated with some cousin marriages, more so than imams or religious leaders. However, some participants felt that perhaps the community's antagonism may put them off from getting too involved.

“I think parents, they listen to the doctors more than imams (to deliver genetic information). Because when it comes to religion, they mix the culture up don't they, tradition.” – Asif, Men 16-29

“Doctors do say things. But they do not say too much. Because it is a family thing. If some outsider says it, then people do not see the good side, they feel slighted. They will be like, who are you to say something to us. This is why doctors or others with knowledge, they stay away from saying.” – Muneeb, Men 50+

When discussing the health related issues and genetics, most participants talked about the risks they had heard in the media, their distrust in the genetic link to cousin marriages and in doctors, as well as access issues faced when going to a doctor. None of the participants sought advice on the genetic evidence or inquired about any genetic tests that could be or should be available locally. However, they did speak about steps they would like to take in order to improve health, healthcare and genetic services in Luton, especially related to cousin marriages.

6.4 Strategic Actions

6.4.1 Health Education and Promotion

In chapter 5, the responses of the service providers under the theme of strategic actions focused mainly on health education and promotion amongst the community members. They suggested that that these programmes needed to be led and owned by the community in most cases. There seemed to be some agreement in this regard with the lay community whose responses show that they strongly feel there should be more information available to the community about the potential risks of genetic disorders possibly related to cousin marriages and also about the healthcare services that are available currently to the community. The lay community members also agreed that there should be such educational programmes or information.

“I think they need to be informed of the risk more. [Others agree] Definitely families of Southern Asian communities need to be informed of the risk that this carries, which I think they're not really subject to (currently). But they should be.”
– Faiza, Women 16-29

The participants also mentioned how these programmes should be delivered in a culturally sensitive manner, with an understanding of the importance of cousin marriages. The importance of

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delivering culturally competent service in this regard is amplified by earlier responses of the lay community members where they showed doubts about studies and services, seeing them as an attempt to curb cousin marriages and the growth of the Muslim community. Similar backlash has also been reported for such health promotion programmes elsewhere (Darr *et al.*, 2013), but developing culturally competent health promotion programmes and healthcare have had proven success (Papadopoulos, 2006, Laird *et al.*, 2007, Bradby *et al.*, 2007).

“If it's delivered in the right context. If it's done in a negative way, like don't get married to cousins, then people won't take that.” – Zain, Men 30-49

Some participants also mentioned how this information should be given by the GPs, as discussed earlier, but a majority had a similar opinion to that of the service providers, in that the information should be delivered with the assistance of community leaders, mainly the local imams, whom the community trusts.

“Yes, but there has to be consultation. Like in mosques, people who are in charge, there should be a consultation through them. Like if the government wants to take an initiative then they need to involve these people. Like you have explained it and if they are explained in a good way (too) then they can help as they have influence in the community.” – Nargis, Women 30-49

“In order to implement that, I think they should go through the Islamic society you know the Imams. Let the imams broadcast the issue.” – Usman, Men 16-29

6.4.2 New Services and Improved Care

The lay community members called for more services, specifically in terms of genetic services and social services. Fatima, from the under 30 girls' discussion, lamented the lack of social services available for victims of forced marriages, a fact also noted by the social worker who participated in the secondary care service providers' focus group discussion, or services for immigrant mothers. One participant also called for wider availability of “free” services that would encourage people to take up these services, although an opportunity was perhaps missed here as this participant was not asked to elaborate on any NHS services that were currently not free.

“No, I mean what services? I don't think there are many in Luton. There aren't
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enough services in Luton to get help. There's women's hostels, the women can stay there for three months then they have to be out there. What services are there for young people trying to get out of forced marriages? What services are there for mums, the women who are from Pakistan, married to guys from here and their children have disabilities? What service is out there to explain to them that your child is like that because of genetics?" – Fatima, Women 16-29

"Things like free services. Like they get a free blood test or something. People will get off their couch (then) if they absolutely must get something done." – Taimur, Men 30-49

Finally, the participants also felt there was a need not only for the community to receive more education on health issues but to have more training provided to service providers, especially GPs, whom they felt could be better informed about genetic conditions. The lay community members suggested similar strategies in improving health and services locally as to the service providers, and called for the availability of more services, contending that there were not enough services presently in Luton. Although the participants were short on specifics of what these services would entail, from their responses, it could be said that they were not necessarily looking for new services, rather newer options and more availability for existing services. For example, in North America, in order to tackle health disparities in areas with low uptake of health services, the local authorities have introduced new means of taking these services to the most deprived areas through community outreach programmes and mobile clinics. This approach has resulted in avoiding the barriers posed by transportation, lack of appointments, childcare and even language (by including local health workers) (Jesus Diaz-Perez *et al.*, 2004, Bramley *et al.*, 2005, Guruge *et al.*, 2010), which include a majority of the barriers that the lay community members have mentioned in their responses earlier. So, while the participants spoke about new services to be made available in Luton, perhaps there is a need for a newer approach to existing services, which some suggest are being under-utilised.

6.5 Summary

In this chapter, the views of the lay community members on consanguinity have been

presented, who showed more concerns about social and cultural issues related to cousin marriages than any possible negative health or genetic issues. These responses centred around the same themes as the responses of the service providers, that is culture, genetics and healthcare services, as well as strategic actions for health and healthcare improvement. There were however, new sub-themes, including expanded discussions on the sociocultural aspects of ethnicity, arranged marriages, *biraderi*, and religious beliefs, as well as the patient perspectives on healthcare delivery.

In terms of ethnic categorisation of consanguinity, the lay community participants felt that cousin marriages occurred mostly in Pakistanis, who were a heterogeneous community with distinctions between Kashmiri and other Pakistani identities. However, they also felt that this trend was on the decline and that there existed a generational gap in the approach towards cousin marriage. This was seen mainly due to an increased level of education, as the younger generations were moving away from this cultural practice of cousin marriage, which they felt was often mistakenly mixed in with religious beliefs. Issues surrounding marriage were of major concern for the lay community members as they felt cousin marriages were related to arranged marriages that were sometimes pressurised and forced. They felt that property inheritance and immigration were the main drivers of cousin marriages. While closeness, family bond and altruism were seen as positive effects of consanguinity, most of the younger generation could not consider marrying their cousins that they grew up because they thought of them as a brother or a sister and could not marry those from Pakistan because they felt they would have little in common in terms of language and lifestyle.

The lay community members discussed the major barriers that existed in their access to available services and singled out appointments and language barriers as their biggest obstacles while racism and transportation also acted as barriers in their access to care. The knowledge level on genetics and available genetic services was very low and progressively declined as the age group of the participants went up, perhaps directly related to the level of education, which also showed a

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similar trajectory. According to the participants, any strategies for improvement of health and healthcare services must involve the local community members along with the service providers, as there was distrust shown both in the evidence of genetic risk and consanguinity and in the knowledge levels of the doctors presenting this information. In Chapter 7, the results of the discussions with the consanguineous members of the local community will be presented, who were asked to take part in almost identical discussions but in individual interviews (where possible).

CHAPTER 7 – CONSANGUINEOUS COMMUNITY FINDINGS

7.1 Introduction

In chapters 5 and 6, the findings for the service provider and lay community studies have been presented, and in this chapter, the findings from the study conducted with the members of the local British Pakistani community who are or have been in a consanguineous relationship are presented. This third part of the study was similar to the second part with the lay community members, in that it used essentially the same topic guide to explore and expand on the study objective looking at the views and experiences of consanguinity in Luton's British Pakistani community (see Appendix 2 for topic guides, differences highlighted in light blue). As discussed in the methodology (Chapter 4, section 4.6), this part of the study was to include individual in-depth interviews with each participant, but due to the availability of some of the participants, a few participated in focus group discussions instead (the participants of the group discussions will be identified as such, whereas all other responses are from participants in individual interviews). This study thus included three focus group discussions and ten individual interviews, with a total of 27 participants from different age groups (16-29, 30-49, 50+) and gender, all having been in a consanguineous relationship, as shown in Figure 7.1, highlighting the portion of the study that this chapter will be focusing on, which is the consanguineous community members. These results are presented here in narrative form divided into the main themes and using the direct quotes from the participants, as with previous findings. These themes are similar to the ones in the service provider and lay community study, focusing again on roles of ethnicity, religion, culture, genetics, and healthcare delivery on consanguinity, and the strategic actions the respondents suggested are needed to bring about a change in the current healthcare of the community. The dissemination of the findings begins first with the biographical data about the participants which adds context to their responses that follow. The names again have been substituted with pseudonyms to protect the

identity of the participants.

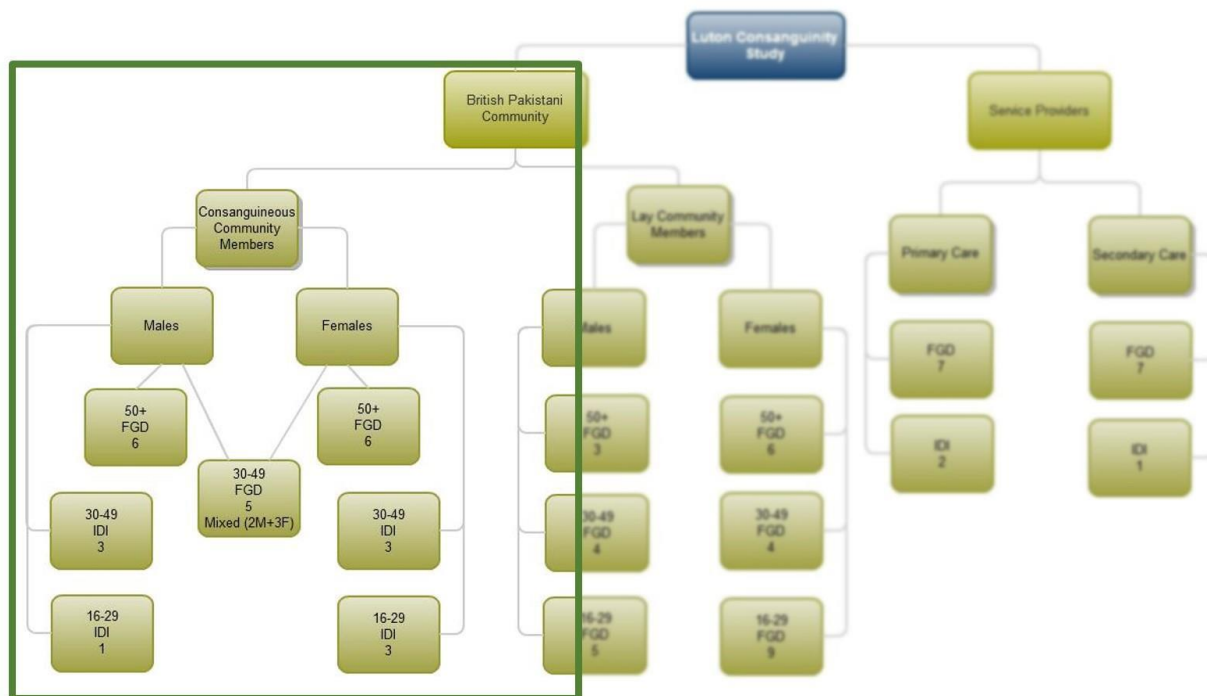


Figure 7.1 - Consanguineous Community Members Study - This figure shows that the focus of this chapter is on the findings from the consanguineous community members' portion of the larger study.

7.2 Culture and Consanguinity

Cultural issues have been highlighted as being an important factor in discussions about cousin marriages by the lay community (chapter 6), the service providers (chapter 5) and also in literature (Bittles, 2012, Shaw, 2009). While the majority of the responses from the consanguineous community resonated well within the themes from the lay community responses, there were a few new sub-themes that emerged. Those married with cousins added an emotional undertone to their responses, with their very personal experiences of struggles with broken, abusive, and forced marriages, as well as dealing with children with complex needs and disabilities. However, not everyone spoke of negative experiences, as some of the participants of the older generation did not have objections to their marriages, or how they came about, nor did they report any health concerns due to their relationships. The participants also discussed the

impact of education and the consequences of their beliefs on their health behaviours. The first theme presented here includes the participants' discussion on their cousin marriages which were almost always arranged.

7.2.1 Sample Attributes

In a constructionist research, it is important to contextualise where any data comes from, and this was the main reason to collect background information from the participants, to locate their responses in the context of their culture and everyday lives, as was done with the lay community members (Bittles, 2010b, Cobern, 1993, George *et al.*, 2010). The participants belonging to the older age group of 50 years old and above took part in two focus groups, one for the men and one for the women. The third group discussion was with parents whose children attended a local disability assistance organisation and this group belonged to the 30-49 age group and was a mixed discussion with three women and two men, all unrelated to each other but married to a cousin (details of group composition and sample selection are discussed in sections 4.4.1, 4.4.2 and 4.4.3).

There were differences between the lay community participants and the consanguineous members of the community in terms of the representation of the different age groups, the levels of education and employment status. There were no students in this group and the participants in this group had higher unemployment and on average, a lower level of education than the lay community group, which had a larger number of post-secondary students. Perhaps as a result of this, the representation from the youngest age group was also lesser in the consanguineous community than the lay community. These numbers can also be related to the circumstances of the participants, in that a majority of the participants were married at a younger age, perhaps making education a lower priority in their married life, something which has been noted previously in a study of young, mostly consanguineous couples (Ertem and Kocturk, 2008).

7.2.2 Ethnicity, Kinship and Religion

A majority of the participants belonged to the Azad Kashmir region of Pakistan or its
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vicinities, much like the lay community members. Also, a majority of them belonged to the same Jutt, Malik, Chaudhry and Raja *biraderi* groups as the lay community. However, there was less vociferous opposition to the importance of *biraderi* in the community, and marriage within it, as there was in the younger lay community discussions (chapter 6).

“Yeah, it's like a tribe, the Raja tribe. Gutka Raja they say, but I don't pay much attention to it. It doesn't really mean anything to me. We had loads of people coming (for marriage), we had educated guys, but my mom wasn't interested. Not outside of Kayanis. And I was like, I'm getting older, I might as well just agree to it.” – Ruba, Female, 30-49

“Well, I understand the concept of biraderi meaning. It's what your ancestors used to do, they used to trade in (a particular field or profession), or something similar to that. And that's why you follow sort of that name. And that name sticks with you as a family name. And then people just think that they've got the same name as me, okay they belong to that same ancient history line as me, then okay I should get married to him.” – Ahsan, Male, 16-29

7.2.2.1 Perceptions of Consanguinity

This section also contains the user's responses to their understanding and perception of consanguinity or cousin marriage, as it was mostly referred to by them, and its relation to ethnicity or religion, if at all. There have been discussions about the debates surrounding the definition of consanguinity (See section 3.2), and for the local community, it was decided to refer to consanguinity as simply cousin marriage, as it was a more familiar and commonly used phrase. However, users were still asked if they recognised the term consanguinity and all of the participants answered that they had never heard of it. When it was asked if they knew what cousin marriage meant, they were more familiar with this phrase and it was found that a majority related it to marrying within cousin, but mostly to first cousins. It was also interesting to note that all participants were or had been married to their first cousins, a trend that has remained constant over the years (Darr and Modell, 1988, Shaw, 2001, Dale and Ahmed, 2011, Hampshire *et al.*, 2012).

“Any cousin. As long as they're within the family structure, they're ok.” – Sabeen, Female, 16-29

“Cousin means parental uncle or aunt, maternal uncle or aunt's daughter. When

our marriages are arranged then they are (to) our cousins.” – Javed, Male, 50+ Discussion

“All of them, but mainly I think of first cousins.” – Laiba, Female, 16-29

In the service provider study findings (chapter 5), there were references to consanguinity as either inbreeding or incest, but this was not the case with the consanguineous community members. The only time they mentioned the words were when stating how the “White” people thought of cousin marriage as inbreeding or incest. The mere mention of relationships that are considered incestuous by the masses, like an uncle marrying a niece, something common in certain parts of the world (Bittles, 2001, Rao and Inbaraj, 1979), drew faces of disgust and disapproval from the participants.

“As we are here and as we have grown up (here) and (had) science classes, you know your biology teacher, I remember them talking as if marrying a cousin was incestuous and it was you know biologically it wasn’t right. The white friends felt it was incestuous. How can you marry your cousin? That’s quite disgusting.” – Nosheen, Female, 30-49

“Have you ever heard of an uncle and niece marrying?”

Astaghfurullah (May Allah Forgive)

It’s not allowed in Islam.” – Adeela and Hafsa, Females, 30-49 Mixed Discussion

Furthermore, religion was repeatedly mentioned as the reason why such relationships would not be found in the local community. The only uncle niece relationships that they had seen in their community usually occurred between a girl and her parent’s cousin, meaning they were actually first cousins once removed, but colloquially called uncle due to their relationship to their parent. This perhaps can account for some reports of such marriages amongst a Muslim population (Rao *et al.*, 1972, Jain *et al.*, 1993), contrary to both religious beliefs and findings of a majority of studies which state that Muslim populations avoid such unions (Bittles and Hussain, 2000, Shaw, 2009, Khoury and Massad, 2005).

7.2.2.2 Categorising Consanguinity

Religion however, was not seen as a motive for cousin marriages. Most users were clear in
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their conviction that while cousin marriages were allowed in Islam, they were not compulsory. In fact, Azaan, participant in the male over 50 years' focus group, stated that Islam promoted the opposite. Azaan felt that in Islam the more marriages that occur outside of family or tribe, the better it is, as he remembered from a *Hadith* (Prophet's sayings), and a sentiment also shared by Nosheen.

“No, because Islamicly (sic) speaking, you are supposed to be marrying outside the family and you get more reward for marrying outside the family. Other tribes and because you are spreading that relationship between one Muslim to another as opposed to if you are marrying just cousin to cousin. (Then) you are not actually getting to know the people. Because everyone is Muslim (and you must treat them the same).” – Nosheen, Female, 30-49

The majority of the participants also felt that cousin marriages were not linked only to Muslims and that it occurred in other religions as well, although their information on other religions was limited and a few equated the presence of cousin marriages in India to it being present in other religions, when in fact, India has a large population of Muslims, who also have customary cousin marriages (Rao and Inbaraj, 2007).

“I understand why she's saying (Pakistanis marry cousins), because they tend to be Pakistanis and they tend to be Muslims, that's what they see. But a lot of people, who are Pakistani and Muslim, don't marry in cousins.” – Sabeen, Female, 16-29

“No. I think it depends on personal likes and dislikes, it does happen in family, it's not like it doesn't. But even Indians, they have cousin marriages.” – Samar, Female, 16-29

Just like the lay community, the consanguineous community did not object to cousin marriages being linked to Pakistanis in general and specifically to the Kashmiri population, as indicated by this statement by Haris, one of the male 30-49 participants, who said that *“(If) you pinpoint a particular community then I would say that Pakistani Kashmiri community stands out more for cousin marriage.”* However, unlike the lay community, there was no emphasis on the differences that may exist between Pakistanis and Kashmiris. While there were differences in this response between the lay community and the consanguineous members of the community, there were agreements where differences could have been expected.

In the Chapter 6, the lay community members' study findings revealed that the community considered cousin marriages to be a subject with implications on sociocultural issues rather than healthcare issues. When a majority of the consanguineous members of the community stated the same, it was a peculiar response as many members had first-hand experience of dealing with health complications which their doctors advised them was possibly due to their marriage within family. However, this was indeed the case, as only a couple of respondents felt that cousin marriages were a health concern for them, and the responses below clearly indicate the participants' inclination towards cultural and social issues.

“It's a concern when it comes to extremity (sic), it shouldn't be so. It is becoming a concern, when it comes to forced, out of choice.” – Sabeen, Female, 16-29

“Maybe a social issue but not a health issue.” – Nosheen, Female, 30-49

“But I'd say people seriously need to think about it. Parents need to think about it that ok if the purpose is to just bring the person here (from Pakistan), that's ok, fair enough. But if you want your children to live happily then that means that they need to understand each other and they need to have some sort of form of tolerance.” – Adeel, Male, 30-49

The background information of the consanguineous British Pakistani community members showed that they were slightly different than the lay community, in that there were more participants from the older age groups, with their unemployment higher and education level lower than the lay community members. This group, which was mostly married to their first cousins, felt that cousin marriages were marriages within close cousins that were mostly present in Pakistani Kashmiris but were not exclusive to any ethnicity or religion. They also felt that cousin marriages have a bigger impact on cultural issues than on healthcare ones, and their discussions of these issues are presented next.

7.2.3 Marriage

The lay community members in the previous chapter often equated cousin marriages to arranged marriages. In the findings of the consanguineous community members study, it was seen

that every participant's marriage was arranged, and not always in the facilitated or assisted sense (Ali *et al.*, 2008, Ahmad, 2006), but mostly where the participants either did not have a choice of whom they married at all or had a choice but the choice was restricted to marriage with a cousin.

“In us, marriages only happen in blood relations. Yes, we only do marriages in the family. All of our weddings are in the family. Maternal aunt's daughter, paternal aunt's daughter. My daughter's and my son's wedding is in the family.” – Zubaida, Female, 50+ Discussion

Participants spoke of the difficulties of breaking away from their family norm of marrying a cousin and explained that marriages could be arranged from a young age (Ertem and Kocturk, 2008, Hewitt, 1996, Khanam, 2005).

“It was arranged. For a long time it was arranged that we are going to get married anyway. You see, the kind of culture we have, parents used to find somebody within the family. Whether it is the girls' side (maternal family) or the guys' side (paternal family).” – Adeel, Male, 30-49

“So, I told my parents, that I'm thinking, I think I'm ready for married life. I think it was my dad who said, okay, we've got some relatives in Kashmir, I've got some of my brothers who've got daughters that are roughly your age. And said okay, it's up to you, have a think about it.” – Ahsan, Male, 16-29

“Around my age. Sometimes, possibly younger. They'd be like, oh no, but I grew up with him, that is disgusting. Especially the people from our, from England, majority of British Pakistanis. Whereas in Pakistan, I don't know if all of them would say that, but quite a few would who live in that framework (where marriages only happen in cousins), and they'd be like, no it's so bad if you marry outside the family, or Syed if you're in that framework. If you're born and bred in that culture, then that's what you say.” – Sabeen, Female, 16-29

Such was the strength of this family tradition, the arranged marriage system, that it even crossed divisive sectarian lines of Sunni and Shi'a Muslims.

“They were all originally Sunni, do you understand. Two of the families became Shi'a, and then the factor, you can't marry outside your family, on that basis, they would require you to marry family, whether they'd be Sunni or Shia. Yes, it creates problems in terms of religion, but in terms of family marriage, they're not seeing that as a problem.” – Sabeen, Female, 16-29

So that the marriage would stay in family or at least within the Syed *qaum/biraderi* in the case with Sabeen, the youngest participant who was now 22 years old but was married at the age of

16. *Biraderi* again played an important role in these arranged marriages, as there seemed to exist a hierarchy of preference, where if one could not marry a cousin, then at least they would marry within the *biraderi*, before eventually looking outside if at all necessary.

“I mean, it's like a common knowledge. And we say this amongst each other that this has become like a little Mirpur. Because a lot of people are from Mirpur in Pakistan, they have all their cousins. This is the common thing within my neighbours, someone came to ask for her daughter's hand, they were their second cousins, and the father said, well, I'm going to see amongst my first, the girls' first cousins first, if I can't find someone there, then fair enough, I'll talk to you. This was someone from their second cousins. So, there are some families who wouldn't even go out of first cousins.” – Ruba, Female, 30-49

“We are Rajput. (Your husband?) They are also Rajput. Biraderi is different (than cousins). Yes, definitely (if first preference is cousins, then second is biraderi). If you can't marry in family then if you must go outside, it must be a nice family, above your own, not below (in terms of stature and caste).” – Laiba, Female, 16-29

Another feature of these arranged marriages was that even when a person's marriage to a cousin failed, their second marriage also was arranged with another cousin. Furthermore, these bonds between families through arranged cousin marriages were also strengthened by the reciprocal marriages of brothers and sisters with their cousins, the concept of *dawati* or *atta satta*, as previously discussed with the lay community members, a form of providing security that one relationship was forever linked with the other, a failure in one would threaten the failure of the other.

“You know (if) my marriage breaks, my sister's marriage would be in the same jeopardy, (vice versa) it brings my wedding in jeopardy (because we are married in an atta satta).” - Imtiaz, Male, 30-49

“My brother, and my sister, they're both married in cousins. First cousins. They're both in my mom's side. They're like what you call it Atta satta (dawati). Basically in our family, my parents were the only one who had two daughters and the others, like my husband, they're like five brothers, and my other uncle, he's got like one daughter, two sons. So, there's only like three girls and ten, eleven boys in the family. So they were trying to take us in the family, rather than take us out. This was our grandparents wish. It wasn't really our mom and dad, it was our grandparents that pushed us to get married into the family.” – Reem, Female, 16-29

There was also displeasure shown for marriages that occurred outside the family, such

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marriages were deemed doomed to failure, suggested the participants.

“For example, we just had my brother-in-law's marriage and he got married to someone from outside the family, and they had studies together and knew each other well, and we even told them, that your caste does not match, you should not marry, but they didn't listen and their marriage has now ended. It was a love marriage. We told the girl so much, to let it go, stay with us, we'll work it out, but she didn't listen. There was just one problem with the boy, he didn't have a job at the moment. Now he has everything, job and all. They even had a house then, but now, because of the break-up, that house is gone because of that girl, from court. Then there is my brother-in-law's marriage, my other cousin. His marriage also didn't work. The girl was very clever.” – Samar, Female, 16-29

“Because that's the only one, that's the best choice you have really (to marry a cousin). You get married from other places and then all of a sudden, somebody can do black magic on the girl or the boy.” – Ismail, Male, 30-49 Mixed Discussion

The marriage discussions focused not only on arranged marriages, but also on forced marriages. Some felt that in their opinion, their marriage may indeed have been forced, because they were too young to know any better, as Faizan, who was only 15 when he was married to his cousin with disabilities, explains below.

“I think that (forced) goes hand in hand (with cousin marriage). The thing of that is with cousin marriage, they (parents) want to get their kids get married younger, and they don't realise that... some kids, they are like very straightforward (naïve), good in that way (and they just follow their parents without protest).” – Faizan, Male, 30-49 Mixed Discussion

There was also discussion of family pressure in the way of emotional blackmail exerted within some of the arranged marriages, which has been described as another facet of forced marriages (Gangoli *et al.*, 2006, Hossain and Turner, 2001).

“There are cousin marriages that take place to keep the rest of the family or the biraderi happy, to keep the mum's and the father's side happy. I mean obviously it wasn't forced like you were gonna (sic) be killed, shot, but you still felt the pressure. It's emotional blackmail. To be honest, when I talk about arranged marriage, arranged should be when both children and both parents are happy and everyone is happy about it and everyone is fine. That's what an arranged marriage is, because everyone, all parties should be happy. Forced is when some of the parents are happy and kids have been forced into it. But my situation, it was arranged because, (well) there should be another title. It's arranged because my parents arranged it and everyone else let it happen but it wasn't forced. There wasn't a gun to my head but emotional blackmail was so bad, it was pretty much forced. Although later on because it was done in such a way that there was idea afterwards (to end

it). Because lot of girls I know, they have been through very similar things, but they mentioned they annulled the marriages.” – Nosheen, Female, 30-29

One participant, Adeel, however felt that there was equal blame to be placed on those being forced into such marriages as well as the ones doing the forcing. He felt that there were many avenues of assistance available here in the UK for there to be any justification for forced marriages, and hinted that it was probably something else that was displeasing about the marriage but it was now being blamed off as a forced marriage.

“To be honest with you, I have no sympathy for those people who are from forced marriages, why? Because, what's the point of crying after you've been forced? Then, you know you get married, okay our parents forced us? Just because they didn't like their husband or their wife, they changed their mind and they can say yeah okay well, if you enjoy it, let's not report it, if you enjoy it, it's having good sex, but if you don't, then it's just a rape! Well, I think there are cases I've seen where initially the girls or the boys they agreed, but afterwards they say it was a forced marriage. Because they didn't like their other side, they didn't like their husband or the husband didn't like the wife. This thing can happen. So, forced marriage, I don't know, I don't take it, I'm very careful when somebody says that you know, they're a victim of forced marriage. I'd say well, you accepted it then, but now you're accepting it. You are saying that you know you want to come out of it. Why did you accept it in the first place? You're still the same person, how come you've become so strong within a few weeks, or a few months?” – Adeel, Male, 32

Even though this issue of falsely claiming a forced marriage has been brought up in the media by some opponents of a law against forced marriages, amongst the participants however, this was a minority view of one participant, while the majority felt that it was a legitimate issue within this discussion about cousin marriages.

“No one should be forced to marry against their will. I mean, the thing they're doing where young kids are taken to Pakistan to get forced to marry someone, and they ring the British Embassy and they send people over to get them, I think that's brilliant. There should be no forced marriages. I mean, the parents are supposed to be the child's protectors, if they're not safe with them, then they're not safe with anyone.” – Ruba, Female, 30-49

The intention of such marriages, as participants suggested was to bring families closer and that such marriages were more secure, still some of these forced marriages failed. There were at least three participants who had either been through a divorce or were going through one currently.

There were also other participants who were the second spouse for a person who had previously divorced another cousin, showing again the strength of the arranged marriage systems that exist within the community.

“He (her husband) came here on a settlement visa. He’s a cricketer. He had his first marriage here (with a cousin), she was British, but because of some circumstances that they couldn’t work out, it didn’t work out and then he married me.” – Laiba, Female, 26

Some of these marriages broke down because of domestic violence, an issue that was exasperated because the abuser was also a cousin, making the victim feel an added pressure to remain in an abusive marriage for the better or *izzat* (honour) of the wider family (Gill, 2004).

“There was a lot of violence in the marriage as well. A lot of it! That’s the reason why we separated, because he nearly killed me. And when he got his indefinite (indefinite leave to remain in the UK legally or in other words, permanent residency), his attitude changed towards me. Before when he was violent, he would actually say sorry. And at that point I thought okay, he’s been brought up in Pakistan, not very educated, that’s how his mentality is. In time, I’ll weed it out of him, you know. It’s like a child, going to a new place, and trying to get him adjusted. It’s just after he got his indefinite, I realised, that wasn’t the case, and he wasn’t even sorry. After he’d hit me, he wouldn’t even say sorry. He beat me up quite bad, it became a police case. They didn’t charge him because they said there were no witnesses, although there was his hand marks on my neck and everything, but they didn’t charge him. But my family pulled me out. They said, you know, you’re an emotional wreck right now. You can’t think. But you know, we won’t let this go on. So, they pulled me out.” – Ruba, Female, 30-49

However, drawing a link between arranged marriages, forced marriages and domestic violence would fall into an orientalist, culturalist approach that blames patriarchal cultures for violence against women without examining the underlying factors that are similar to all marriages with domestic violence (Razack, 2004). Ruba was suggesting that being in a cousin marriage, as well as one where there is domestic violence, makes it particularly difficult to escape from such marriages.

Another aspect of cousin marriages that was a prominent in this theme was the issue of transnational marriages. The transnational marriages with cousins from Pakistan are also part of the arranged marriage tradition, according to participants. Most participants, when asked about their

family history told of how one of their parents was settled here and then they got married to a cousin and brought them over to UK. This has continued through to the next generations. It was described by one participant as an easy solution to the tightening immigration laws. Laws which some participants felt were in place only to limit cousin marriages and the number of Muslims coming over from Pakistan. Sabeen, 21, spoke about her struggles in getting her husband to join her in the UK, due to the ever changing immigration rules and requirements.

“No, he was in Pakistan, and I was in England. But when I come and go, we used to stay together and got to know him. Yeah, got married when I was 16, stayed with him for a month, came back, gave his case, got rejected, because, not enough documents. Then I went back to Pakistan after one and a half years, stayed with him for 20 days. Then, I gave his case next year, and that got rejected, then I went to Pakistan a year and a half after that for four months. Then we did an appeal for the second rejection, made new papers, and that was rejected again. Then, I was 20 and they changed the rule to 21, so I had to wait for a year. And then, they made another law about English test, by that time I was in my third year of Uni (sic) finishing. And I said to my husband, I've got a couple of months, you learn English then we finish my uni, I look for a job with you. So then now, after that, because the laws kept changing and stuff, then I had to working from July till now, and his case is in again, now I'm 22. Then now, they've changed the law again to 18. So, I've applied again and am now waiting. In so many marriages, I've seen with my own eyes, they are their direct uncle's son, and they come here and, I'm not saying that every guy or every girl does that, but sometimes, he comes here and he gets the visa and then he goes off. And he has that disloyalty.” – Sabeen, Female, 16-29

Some participants suggested that these cousin marriages are in fact only for the purposes of gaining a UK nationality, a sentiment that is in common with some of the lay community members' responses.

“The main issue, is that girls come from Pakistan, boys come from Pakistan, they're just gonna (sic) come. The whole community isn't it. Yes, of course. It's the red passport. There's nothing else.” – Adeela, Female, 30-49 Mixed Discussion

Others spoke of a feeling of obligation felt towards relatives back home to call them over to the UK, to give them a chance at a good life. This feeling of obligation may in part be due to the fact that their extended family may have aided, financially or otherwise, in their migration to the UK in the first place, as discussed earlier in Chapters 3 and 7 (Ballard, 1994, Shaw, 2001).

“People are getting arranged marriages were happening and the UK boys and girls

were being told you get married to your cousin in Pakistan. You give them a chance as well. They are your blood, give them a chance to come here just like you were given a chance because your father gave you a chance to come here.” – Imtiaz, Male, 30-49

However, transnational marriages were sometimes used to assert more control over the relationship as the incoming migrant family member will be more inclined to stay in their debt, since they had him or her brought over to the UK. This may have been an opinion stated by some participants in the lay community members’ discussion, but it was experienced by Adeel, a participant in the consanguineous community. He grew up in Pakistan, was married to his cousin in the UK at age 17, and when he came here, only then did he find out that she had a terminal genetic disorder. Adeel’s wife died a year later leaving him behind with their infant child, who has a mild learning disability. Adeel’s brother-in-law, who has the same fatal disease, is now set to be married a second time to a cousin from Pakistan in the hope that she would come and take care of him in his final days. This expectation from one’s kin, on the one hand to expect a relative in Britain to call over (through marriage) a relative in Pakistan to give them the opportunity to lead a better life, and on the other hand to expect that relative to come to Britain and be indebted to them, serve as some of the underlying reasons for marrying a cousin for the participants.

7.2.4 Factors encouraging cousin marriages

The feelings of obligation to help other family members come over to the UK are an extension of the process of migration discussed earlier in Chapter 1 (section 1.2). Migration involves the larger family or *biraderi* investing in one person and that person can sometimes then feel an immense obligation to repay the favour, usually through marriage of a son or daughter to that of a relative back home, to also give them an opportunity to make a better life in the UK (Ballard, 1994, Shaw, 2001). As explained above, this obligation can then lead to a seemingly mutually beneficial arrangement for both parties, as Adeel’s narrative below illustrates.

“My cousin, who's not well at the moment (also his brother-in-law), this is his second marriage (also to a cousin). First marriage, I told my auntie and all, they

were going to get married, I know the kind of condition he's in (terminal genetic disorder), I know his wife won't stay with him. And my auntie, she's kind of straightforward, she said no no, we're going to do it. Obviously, they needed somebody in the house (to take care of him and the house) too, so. So, they got married and brought the girl over and she was there for two years and then after two years she's got freedom (her immigration) and she just left.” – Adeel, Male, 30-49

Adeel’s cousin’s first wife came over from Pakistan and took care of his cousin and his family for two years, which the family wanted, and then she moved on to make a better life for herself after she received her immigration (right to stay in the UK legally), a move which may make some feel betrayed and exploited for purposes of immigration (Shaw, 2001). However, Adeel’s cousin’s family then had him married to another cousin from Pakistani, who would now come over and take care of his cousin, who is suffering from a terminal genetic disorder. Some see these types of cousin marriages as a means of limiting the risks involved in marriage (Charsley, 2007, Shaw, 2009), whereby, marrying a known entity can reduce the chances of a marriage failing, or property and possessions going out of the family (Proctor and Smith, 1992). Keeping land or property within the family or easing the dowry negotiations were also strong reasons for the preference of cousin marriages in the consanguineous community member responses.

“Sometimes it is because of that. Sometimes people have lots of inheritance to give away and they want to keep it in family. Our people, they are only interested in making wealth and property and then keeping it in family, even though the property just lies there in waste, you can’t take it with you.” – Laiba, Female, 16-29

While others saw cousin marriages as a cultural practice that allowed participants to maintain both cultural and physical links with Pakistan.

“I don't think there's a link religiously for marrying first cousin. I think it's more of a cultural thing and it's always been a cultural thing. And it's been brought from Kashmir, with our parents and them (to maintain their culture).” – Ahsan, Male, 16-29

“So one day we were going to the city and there were our three paternal uncles there in London and so four brothers including my father. So first they had very tight link but slowly and gradually as chachas (paternal uncle) died including the last one, one night my dad thought that his link has finished from that family. So it’s better to do a marriage in their family and then we were just sitting there and

watching TV and he said it that our link is broken and he mentioned my uncle's name that he has passed away and his wife has also passed away and (the) new generation doesn't know the oldies, knows us but everyone is busy in life and your link is finished and I started thinking to revive this relation, I started thinking that I should do a marriage there. So that's how it started.” – Salman, Male, 50+ Discussion

Along with a feeling of obligation, as in Adeel's example, his in-laws expected their daughter-in-law to come in and take care of their son and the family, and it was more than an expectation, it was a belief that she would, which is why they chose to marry their son to another cousin the second time around. This was explained by the participants as the benefits of closeness, the altruistic feelings that kin have for one another, a major factor encouraging cousin marriages (Denic *et al.*, 2010, Hussain, 1999) and a feeling strong enough to be quantified (Jeon and Buss, 2007). The participants suggested that the strength of the bond of “blood” usually means that the married cousins have more feeling for their in-laws, this altruism is something that would be hard to find from an outsider. It was said that cousin marriages bring families closer together, bridging gaps across the miles. These positives held more weight with the older respondents, who also felt that because of the close nature of the relationship, some disputes between the husband and the wife could be assuaged with the assistance of the extended family. These views were not dissimilar to the lay community responses and they were summed up quite bluntly, yet appropriately by Ruba who said, *“There is a common saying that my mom taught me, you know when, they say if you get married to a cousin, if he's gonna (sic) kill you, if you had married someone from outside, if they kill you they'd throw you out in the sunlight, your body will just burn, if it's your cousin he'll have something in his heart, and he'll throw you in the shade.”* Ruba did not share this view with her mother as she had to separate from her husband who physically abused and assaulted her. Nonetheless, this closeness, a sense of security in knowing that someone from their own blood would be kinder to them, was a feeling that resonated with the majority of the participants.

“Marrying in cousins, they will care more. My wife, she really takes care of my boys, and even my cousins in Pakistan that are married to their cousins, they're all

really happy and close. That's what family is about.” – Faizan, Male, 30-49 Mixed Discussion

“They cooperate with you more. They are there with you and are sensitive towards your problems. Outside girls are not that sympathetic.” – Munawwar, Male, 50+ Discussion

7.2.5 Negatives of Closeness

There is another side to closeness within families, a side that has a negative impact on cousin marriages. When these close marriages fail, it is not just the couple alone that is affected, the entire extended family gets engulfed, something that the participants said was perhaps the most negative part of being so close, an inevitability in cousin marriages, as are “family politics” according to Reem, 28. This view was not different from those of the lay community, and both sets of participants felt that when such close unions lead to separation or divorce, entire families are torn apart. Moreover, they also put strain on the marriage’s survival in the first place, due to the nature of the close relationships, any negative situation can be amplified due to the emotions involved, a complexity of such relationships which has previously been documented (Khuri, 1970).

“Negatives are like you know when the family they split up. Like the parents, if there are any problems with my parents, then it would be really difficult for us two. Us two are sometimes, you know struggling with these things (sic). (And) Family politics becomes worse! We used to have them (fights due to politics). But now, it doesn't come down to us anymore. Before it used to. When we were young, obviously we used to take it really to heart, 'why did your dad say that?' or 'why did your mom say that?’” – Reem, Female, 16-29

“See, the disadvantage is, if you marry from within the family, cousins, if there is someone, and if something goes wrong, then it's the whole family which... the chances are that your other side, they won't be happen, because nobody really takes it well. It's always, somebody else to blame. So, it won't be just between two people, there would be other people who will be involved.” – Adeel, Male, 30-49

The close nature of the relationship can sometimes be an even bigger issue and become a deterrent if the cousins grow up together and have had regular interactions throughout childhood, which makes them feel like brother and sister, complicating things when they are arranged to be married. The feelings of natural aversion and the incest taboo theories were discussed earlier in

Chapter 3 (section 3.3), and the responses of the participants seem to point towards this natural aversion that develops between people in closed quarters, as they felt closer to their cousin in situations where they had grown up together and this issue was less important when they barely knew their cousins, making an argument against a biological avoidance of such relationships.

“No, no (would not marry cousins she grew up with). Because then you end up seeing them like a brother and sister thing. That's how it is. I mean, we've got cousins here and we always ended up seeing them as brother and sister.” – Adeela, Female, 30-49 Mixed Discussion

This factor was mentioned by the lay community as well in their hesitation to marry a cousin, however, amongst the consanguineous community members, some of the participants carried on with the arrangement despite holding such reservations.

“There are cases where I have seen, where actually the family brought somebody from back home. They sort of brought somebody here as their son, and they were staying in the family as their son, and the girls took him as their brother, and later on their dad decided to get them married. This was a few years ago, when I spoke to a girl and she said that this is the situation... they said yeah I look at him as a brother and that and then they marry him, they keep saying that but at the same time they are having kids, they have a family and all that, and I'm thinking if you took him as a brother, you shouldn't marry him in the first place.” – Adeel, Male, 30-49

7.2.6 Current Trends of Cousin Marriages

While mentioning the negative and positive aspects of cousin marriages, it became apparent that there seemed to be a difference in opinion between the majority of the older and younger generations. The older generation seemed to defend arranged cousin marriages, while the younger participants usually mentioned the negative aspects of such marriages more and with more emotion. There was one aspect that all participants seem to agree on and it was also seen in the lay community responses and that related to the current trends of marrying cousins. The lay community responses showed that most participants mentioned how cousin marriages would be a moot point in the coming years as in the recent past the trend had moved away from wanting to marry in the family. This point was made by the participants not in response to a question about the current state or rate

of cousin marriages; rather it was brought up during discussions in general about the advantages or disadvantages of cousin marriages, and they seemed to be brushing aside any concerns because these trends were now changing. This phenomenon was repeated within the consanguineous community as well, as illustrated by the following narratives.

“I think now the trend (is) to marry slightly outside the family. I can’t see that happening, second and third generations marrying in Pakistan bringing people over like they used to (sic). I think there has been a change of thinking.” – Nosheen, Female, 30-49

“They’re doing it now (marrying outside family) because they’ve got no choice because the kids are saying that now. A lot of families are growing out of it now. I think because they’re realising that children. I mean, I’ve seen it happen many times, that children get married in family, and marriages are messed up.” – Ruba, Female, 30-49

Perhaps another factor contributing to this suggested trend is the rising level of education in the newer generations, something that was relayed by the participants. They felt that because kids these days were now educated and had their own minds, they tended to decide for themselves about marriage, which was increasingly in the form of “love marriages” to boys and girls outside the family and even *biraderi*. Education was closely linked with elements of urbanisation and increased contacts with boys and girls outside the close relatives.

“One of my cousins in Pakistan, she’s quite educated, she’s not gotten her children married inside the family.” – Ruba, Female, 30-49

“I just in terms of, I’ve seen, places like Islamabad, Lahore and Karachi for example, those places are a lot more advanced. Most of them they marry outside.” – Sabeen, Female, 16-29

This was not however seen as a positive by some participants, who felt it was the increasing amount of sex education that had now been introduced into the schools which was in a sense corrupting these young minds.

“Now when kids go to school, they say that (marrying cousins is bad). But understand this has recently happened. This has happened because they started extra sex lessons and all in school. Now our daughters are just 8, they go to school but this wasn’t before. Ten years ago no one was talking about it. Kids were being born even then (but no one said anything). I think it’s coming from schools.” – Yunus, Male, 50+ Discussion

As previously mentioned in the lay community findings, this trend suggested by the participants in both groups, the move away from cousin marriages, is not supported by literature or national statistics (Shaw, 2001, Shaw, 2009, Ahmad, 2006). This is not to suggest that the participants' claims are not true, they are perhaps just unproven as yet. Indeed, in countries like Norway, which also have a large Pakistani diaspora, there has been a steady shift away from cousin marriages attributed to rising education levels, especially female education (Grjibovski *et al.*, 2009, Stoltenberg *et al.*, 1998). However, there are differences in the Norwegian Pakistanis and the British Pakistanis, with the latter having a distinct Kashmiri influence, which brings with it a unique identity, as previously discussed (Ali, 1999, Werbner, 2004). Moreover, participants such as Yunus above, have shown suspicion towards education and information in general, which they feel is state-sponsored and targeted against Muslims and Muslim ideals. This distrust has led to diversity issues that go beyond issues around marriage alone.

7.2.7 Diversity Issues

While education was labelled as a deterrent to cousin marriages by the lay community members as well, the distrust shown for the education system by the consanguineous community members was strong and embedded within issues of diversity and ethnic strife. Besides feeling that sex education was possibly a ploy to curtail cousin marriages, some participants also felt that the tightening immigration laws were meant to limit the growing population of Muslims in the country.

“Within the last ten years they have lifted this up so first they took up arranged marriage and then about us being brutal and now this. Maybe they don't want our people. In London, I went there I was a young kid, I was talking to people there and heard there were 17 mosques in London itself. But now there is no comparison. There are 19 in Luton itself. It's so small but in very corner there is a mosque. And English people get troubled with that as this is spreading of Islam. There was a time we were thinking our generation, in the 50's, 60's, mosques will close down like churches as our young generation didn't care much (about religion) but looking at things (now), 400 kids are there in the mosque at the times of Fajr (early morning prayer). It's all full! Maybe this is what is in their minds that Islam is spreading in the young generation and I feel they have been successful in hindering it.” – Gauhar, Men, 50+ Discussion

Some felt that the media was biased against the Muslims and linked them to forced marriages, whereas things like this happen in places like India as well, with Hindus and Christians, but it's the Pakistanis and the Muslims that get the blame in the media. In response to Baroness Deech's comments on cousin marriage resulting in "disabled babies in the immigrants from Pakistan", and how raising it as an issue is feared as not to offend Muslims, the participants were critical of her choice of words and questioned the proof she may have to back up such statements. They were more upset that Deech included all Muslims in her comments, and less concerned at the finger pointed at Pakistanis.

"There may be stereotypes where people think that only Muslims get married (to cousins). I think that's wrong. Going back to the point, I'm sure that happens in India as well, and there aren't only Muslims in India, there's Hindus also and Christians." – Ahsan, Male, 16-29

However, there was a general feeling that White people or British people rarely understood their point of view regarding cousin marriages, and some felt it better to just hide the true nature of their relationship from co-workers, teachers and friends, who found cousin marriages abnormal, showing a divide forming based on cultural gaps.

"Yes (White people think it's) disgusting and just to make life a bit easier it was easy not to mention (at work) when I got married that he was a cousin. It just made life easier because then you don't have to explain why and everything else. People that I have been around, like in your community and in your family, it's not a big deal marrying your cousin is no big deal, it's a normal (thing) but when your science teacher or when you are at College and you meet other people that don't actually marry their cousin and you realise that they don't (think) it's normal. For them it's not normal. It can take quite an offence, as soon as you mention they say oh my gosh, she is one of them!" – Nosheen, Female, 30-49

"No, no. The English, they also have, their kids are also disabled. They don't even have cousin marriage concept, but they can have brother sister! They all do it." – Laiba, Female, 16-29

This mistrust and gap was exasperated further by communication gaps that existed when new immigrants could not speak English well enough resulting in alienation, as Nosheen continued.

"Britishers (sic) would come to have a mixture of everything but even when I take

my little girl to school, there were barriers for me and there were barriers for other women who don't speak English or are British by marriage, and they don't communicate with the other mums. The English or the Black parents won't talk to them and they won't talk to me because they are not sure where I am from or just because of the colour of my skin and that makes me think that if they are segregated on those issues, then what hope do we have for future of our children?" – Nosheen, Female, 30-49

There was yet another layer to these cultural differences, between those coming from Pakistan, who were sometimes deemed as clever and having an agenda, with the ones who have been in the UK for more than a generation. This level of distrust however, could be attributed to the previously mentioned feelings of betrayal family members feel when their relatives from Pakistan do not remain in a marriage once they receive their immigration (Shaw, 2001).

"I don't want to sound prejudice when I say this, it's not going to be racist because he is Muslim but I think they're very crafty in Pakistan. And they know exactly what words to say to the person to get them to like you and that's what he did. They make you fall for (them). To be honest with you, even when you call someone from Pakistan, when you get married to someone from Pakistan... you see my views have changed now. I think they need to be educated to a certain level; they need to know this language. They need to, but before I didn't think that but of course, I learned through my experience." – Ruba, Female, 30-49

There were issues with diversity between cultures but also within cultures, more specifically gender power dynamics that existed in a relationship or a family. Not only was male dominance in these relationships evident in the example of Ruba, 31, who was a victim of years of domestic violence and yet felt obliged to remain in the marriage for the sake and *izzat/sharam* (honour) of the family, but male dominance was also buried within the narratives of the participants. Some participants stated that it was difficult to marry outside of *biraderi*, especially when it came to giving a girl outside the *biraderi*.

"It does matter (biraderi). For the girls I suppose, boys it doesn't. I tell you why, because they wouldn't give the girl out of the biraderi for some reason. But we have, it was a similar caste, then they do. I have a friend her family doesn't give her out of biraderi." – Reem, Female, 16-29

There was also this sense that somehow health risk would be reduced if it was only the mothers that were related in the previous generation, suggesting that the female contribution was

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either less important or weaker. Some even asserted that sometimes marriages breakdown because female cousins who come over from Pakistani after marriage find a lot more freedom and hence abandon their marriages because they feel they can now do better on their own.

“Women have a lot of independence. They go all over, do things for themselves, drive etc. For men, it's a problem. For women it's also a problem, when they see that in Pakistan they didn't have the security etc., but here, they think that they'd be more beneficial if they live on their own.” – Adeel, Male, 30-49

These feelings of male dominance were also present in the lay community responses when Abid from the 16-29 men's group said that boys get married to girls from Pakistan so that they would cook and clean for them and take care of their parents as well. This was not a strong sub-theme in the lay community but within the responses of the consanguineous community members, it has emerged as an important aspect of cousin marriages within the community. Earlier, when some participants mentioned the need to keep property within the family as a reason for marrying a cousin, Samar, 29, opposed this because in their family, the females were not given inheritance at all, something contrary to Islamic beliefs, but not uncommon (Khuri, 1970).

“There are a lot of people who think that if a girl comes from outside, then she'll come and take our inheritance and all that. But that's not an issue anyway because in our family, they don't give inheritance to girls anyway, so they don't think like that.” – Samar, Female, 16-29

While issues of male dominance play a role in the overall dialogue about cousin marriages, to define the practice of cousin marriage and culture through male dominance, as some have done (Talbani and Hasanali, 2000), would be an over simplification and contrary to the point being made by the participants, which was to discuss all of the cultural and social issues that affect and influence cousin marriages within the community. These diversity issues seem to have an impact on the everyday life of some of the participants, but ethnic and gender barriers were less of an issue when interacting with the healthcare professionals and service providers, as discussed in the next section of health services issues. Diversity issues and ethnic strife lead to trust deficits which can only complicate further the lives of these participants who have already highlighted a range of other

cultural and social issues that are having an impact on their lives, which are complex enough with the dynamics of arranged transnational cousin marriages, male dominance, and a widening gap in education and mind-set between the younger and older generations of British Pakistanis.

7.3 Genetics, Healthcare Services and Consanguinity

In the previous two chapters, the findings of the service providers' study and the lay community members study showed differing foci, with the former discussing health issues surrounding consanguinity in much detail while the latter focused on the cultural and social aspects in greater detail. The participants of the consanguineous members of the British Pakistani community in Luton will have had more interactions with the health and social services being offered in the area than the lay community, mainly because an effort was made to speak to some parents of children that have complex needs and are receiving specialised care. So, it was expected that there may perhaps be a different or more diverse perspective on offer than the lay community members, in terms of their knowledge of genetics, health beliefs and service use.

7.3.1 Knowledge of Genetics

However, when it came to knowledge level about genetics, the responses were not far apart from that of the lay community members. Some participants in the older group discussions had never heard of the word, but this could have been due to the language barrier. Both of those group discussions were held in Urdu, and the literal translation of genetics in Urdu, *geeniyat* or *ilm-e-ikhlaqi*, is perhaps even less common than the English word. A language barrier was not necessarily the case with Farhan, a participant in the mixed 30-49 year old group discussion who stated "(I've) never heard of that word (genetics)." The group discussion that Farhan was a part of was held with parents of children with disabilities, making it more likely that he may at some point have spoken to a genetic specialist, yet he claimed to have never heard the word before.

There were still others who had heard of it, both in general and in relation to cousin marriages. One female participant in the 16-29 age group, spoke of an increased risk level when

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there had been no “cross” marriages outside the family in the generation before.

“There should be more awareness against it (genetics). Especially in instances where there has been no cross marriage (outside cousins) in the generation before, because when they have that cross marriage and then their kids have cousin marriage, then you have less side effects.” – Laiba, Female, 16-29

Moreover, almost all the participants had heard of disabilities or problems in children linked to cousin marriages, either through the media or the doctors.

“Yes, I’ve heard it from people, I’ve seen it on TV a few times. I’ve read it in books, that if you marry within cousins, then you get girls being born and all that, but I don’t believe in that. This is that person’s luck or fate, and that’s what happens.” – Samar, Female, 16-29

“Yes my doctor he mentioned that you know this was way back in after I got married and (had our) first kid, and he said you know, you are married in cousins and this is very dangerous what you people do and you don’t understand (sic). You know your genetics, you have the same genetics, alike and then your kids are born and that it could make more problems for you. I said how does that work? He said because you are from the same blood and there could be problems. I said, you said it could be a problem, why you not saying what the actual thing is? Is there something wrong or is that blood if it collides or whatever? We are married and does that make a difference to our children? And he said yeah there could be more diseases and stuff. And I said how you know? Raise your facts. He said it’s being studied that’s why I am telling you. I said ok you know leave that conversation to another time mate and we left.” – Imtiaz, Male, 30-49

“I have heard, in fact I know that this happens, 90% of the time children are disabled.” – Laiba, Female, 16-29

As with the lay community members, a majority of the consanguineous community member participants had only heard of genetics or its relation to consanguinity through the media or through their GP. There was very basic understanding of genetic risk which was unexpected as at least some of the participants had previously dealt with specialist genetic services, including seeing a genetic counsellor. Yet it seemed, much like the lay community, the little knowledge of genetics that the consanguineous community participants possessed was gained through the prism of its linkage to cousin marriage, in the media and through the health professionals, something which can in fact act as a barrier in understanding genetic risk (Ahmad and Bradby, 2007, Ali *et al.*, 2012).

7.3.2 Disputing the Evidence

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Among those that had heard of genetics through their doctors, there were doubts about the evidence that was available to link genetic disorders to cousin marriages, as noted above by the aggressive tone in which Imtiaz demanded for such proof from his doctor. While some participants mentioned the presence of repeat still births and even other rare genetic disorders in acquaintances of theirs who happened to also be married to cousins, they felt that that could in fact happen to anyone. The overwhelming response was focused again on the presence of disabilities in children of other ethnicities who normally did not marry their cousins.

“The English, they also have, their kids are also disabled. They don’t even have cousin marriage concept, but they can have brother sister. They all do it.” – Laiba, Female, 16-29

“This is one of the big debates, in dealing with this debate that we had, why are there millions of marriages that are outside, why are more people disabled in that sense? Why are there more disabled babies in outside marriages than cousin marriages? And then the debate comes, when you go to such places (disability centres), there’s only kids who’s from cousin marriages, why are there a whole set of ones from outside marriages? Why are they all disabled?” – Sabeen, Female, 16- 29

Furthermore, some of the respondents stated that there was little or no history of any issues in their own families even though most of them were married to their cousins, familiar argument used in disputing genetic links to consanguinity by lay people (Richards and Ponder, 1996, Shaw and Hurst, 2008, Darr *et al.*, 2013).

“My Mrs has mentioned it to me as well. She said doctors mentioned this as well that you are married in cousins, first cousins and it could be dangerous you know. What’s the danger? We have four kids now and my brother has 6 and then he got married again and he got another 4, (that’s) 10 kids altogether (with no problems).” – Imtiaz, Male, 30-49

One participant, Laiba, noted that she believes that people like to hide these disabilities, so as not to be stigmatised. There of course exists a debate in literature on the choices some parents of children with disabilities have to make in terms of the visibility or invisibility of their children’s disabilities, especially when it comes to minority populations (DePauw, 1997, Gouvier *et al.*, 1991, Todd *et al.*, 1990). When asked about the possibility that perhaps the disabilities were not seen in

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other family members married into cousins was due to matters of confidentiality, most respondents dismissed this idea. However, Adeel, 31, talked about how he was unsure of the exact nature and progression of his cousin and brother-in-law's genetic condition because they wished not to discuss it with anyone.

“He never tells (us about his condition). Especially within the family, he never gives you the full picture. He just hints you here or there. To us, he doesn't tell us anything. The doctor can't either. So, we don't know really about him.” – Adeel, Male, 30-49

Even though the participants have dismissed the idea that perhaps information about disabilities and genetic disorders are suppressed from others in the family and the community to avoid stigmatisation, it has been suggested (Shaw and Hurst, 2009, Karin, 2003). Perhaps it has to do with the perception of disabilities, where some do not believe a condition is a disability unless there is a physical deformity present, making these conditions a type of hidden disability (Fitzgerald and Paterson, 1995). Imtiaz, 32, had mentioned during his interview that there was no history of disabilities or genetic disorders in his family, however, after the interview he stated that he in fact had a daughter who had a hearing problem from birth. It is possible that Imtiaz did not mention this during the interview for fear that it may be linked to his cousin marriage, but it was more likely that Imtiaz did not perceive this to be a disability, given his blasé demeanour about the matter. Nonetheless, it is beliefs and behaviour such as this that have an impact on access and use of health services, which formed another sub-theme in the responses from the participants.

7.3.3 Service Utilisation

In the absence of satisfactory proof, the consanguineous community members often sought theological explanations for these disabilities or still births. One participant spoke of an evil eye or black magic as the reason why some disabilities occur in the community. Conversely, a majority of the respondents cited either fate or Allah's will in explaining the problems faced by their children. Certainly this has been reported before (Bryant *et al.*, 2011, Bywaters *et al.*, 2003, Croot *et al.*,

2008), and the service providers findings from chapter 6 also show that they believe the community members avoid services because of their health beliefs.

“I think it wouldn't matter. Because I'd be scared of the answer. Because I would just say, look, leave it to God. If I were to find out there was a definite issue, I would be concerned, but I would leave it to God.” – Sabeen, Female, 16-29

“Strongly I believe it was meant to be for me. It was a test. It was a very hard test.”
– Adeela, Female, 30-49 Mixed Discussion

While these answers may point directly to the person's fatalistic health beliefs, it may also point to a lack of understanding of the disease or perhaps the fact that some of these participants were referred to genetic counselling and screenings, but were not given a definitive explanation about genetic risk. Furthermore, as previously discussed in Chapter 6 (section 6.2.5), religious explanations of health ailments serve as coping mechanisms, and sometimes wrongly get characterised as a barrier (Atkin and Ahmad, 2008). The limitation of available genetic services and the nature of rare genetic disorders may in fact act as barriers in patients' use of these services.

“My whole family, we've had genetic like test, we've had blood test, we've had everything. Yes, we went to Dr. W (identity protected) at the L&D hospital. So, we've had some tests and everything. And they wanted to do another research study for us, but it was too much of forms filling and everything. And when the first test was done, it was nothing to do with our genetics. It's just, the doctor said that it's one of them things that they've got no reason what's wrong with my kids and why they're like that. I've had two pregnancies that were terminated so. They were for no reason.” – Adeela, Female, 30-49 Mixed Discussion

Additionally, some participants indicated that these tests or discussions about children with GPs become meaningless to them once they are already married.

“I go and see a GP, most couples do too. But by then it's too late isn't it?” – Adeel, Male, 30-49

This could serve as another reason why the majority of participants turn to find comfort in religious explanations of disease and death. Nevertheless, much like the lay community participants, the participants in this study were also open to pre-marital genetic testing as in the example given to them of the Greek-Cypriot and Ashkenazi Jewish communities using pre-marital genetic

screenings to negate the impact of thalassaemia and Tay-Sachs disease respectively.

“Yeah, why not? They should have the blood test before they get married.” – Reem, Female, 16-29

“That’s down to individual families but I think if that’s an option available to you then why not take it? You know, to be on the safe side there is no harm in it. If you go through a blood test, I personally don’t see anything wrong with that at all. Like I said, times have changed and we need to change with the times to certain extent but not compromising our faith (sic).” – Haris, Male, 30-49

Religious beliefs or explanations were also given as the reason why some participants may refuse testing and other services. Most such cases have to deal with abortion; due to unclear understandings about Islam’s position on abortion, parents sometimes opt to take the pregnancy to term, even when they have been informed of the remote likelihood of the child’s survival or a normal life span or a life without disabilities.

“I think it should be up to them (to do genetic or pre-natal testing). If they feel that they need to, then they should. Me personally? I wouldn’t. No. Because, I’ve made my decision, I’m now married to a first cousin. The way I see it, for me, if I have children, if God gives me children, then He gives me children. And whatever they’ll have, they’ll have. From me speaking to somebody, that’s not going to change anything. At this stage, that’s impossible.” – Ahsan, Male, 16-29

“We do not believe in termination obviously. Allah has given you something and it doesn’t matter if these guys have a system to find out like you said (baby) would last for a year only but problem is we don’t believe in these things. Another thing is that if that kid is sick, and 6 month, a year or 2 years and then poor guy would die so in Islam even that thing is good. Like obviously patience only Allah gives but our belief is that in next world he (that child) will not go into jannat (Heaven) till his parents go too. This is our belief so we don’t think like that.” – Akram, Male, 50+ Discussion

This is perhaps also fuelled by stories of miraculous survival of babies that have been shown to have life threatening cancers, but once the parents opted to continue with the pregnancy, the child survived and grew up to go to college. This story was narrated by a couple of users, although it is short on specifics, it seems to resonate with some participants.

“I have seen such a case, where there was a six month pregnancy, the child was to be born with a cancer in the back and they were very worried that the baby will be as the scans show, with this thing on the back. So, they took medicines and tried to do an abortion, but the baby was still alive, and now the baby is in University!” –

Laiba, Female, 16-29

Some participants, however, were open to termination services if they were provided with enough information and given religious guidance on the matter.

“I don’t really know much about these options but I would probably speak to an Islamic scholar and see what they recommend. We will go from there. Because I didn’t have to deal with anything like that but if I had to I would definitely speak to a scholar. Different scholars say different things. It depends what circumstances are. I think certain circumstances yes and others no.” – Nosheen, Female, 30-49

Sometimes, the desire to have a normal child or another child usually results in parents wanting to go ahead with more pregnancies even when they have had several still births and children with physical and learning disabilities, as exemplified by Adeela. Even though she had already had an abortion, a decision she deeply regretted, and now completely discounts the experience and did not include it in her stated “seven” pregnancies.

“As a mother, I mean, you get pregnant and there's something wrong with the child and they say, would you like to abort it? I mean, you can't make that decision easily. I mean, I did, when I was very young and I still regret it today. But I think Allah is forgiving. I think it's a very very hard decision. Mashallah, I've had seven pregnancies, I've got two children with special needs, two that died, one that was born alive but then died, one was like still born (sic), and even after my last child, people said, the doctor said don't get pregnant, you might have another child with disability. And Allah gave me a beautiful daughter, and I can't thank Allah enough.”
– Adeela, Female, 30-49 Mixed Discussion

Respondents in the service provider study gave examples of other patients who have refused intervention and chosen to carry on with such pregnancies for the desire to have a normal child, and certainly under-utilisation of services has been reported (Randhawa and Owens, 2004), but these responses from participants do not indicate a lack of willingness to undertake services rather a lack of understanding of the available services, such as in-vitro fertilisation along with pre-implantation genetic diagnosis, which can sometimes assist parents in avoiding fatal pregnancies and genetic disorders (Handyside *et al.*, 1992).

While health beliefs and behaviour may have contributed in creating some barriers to service utilisation, there are other barriers to service access according to the participants. Much like the lay

community, appointments were seen as the biggest barrier in access to services.

“It's just that sometimes it's just a hassle to get an appointment. Which is, or may factor into why I don't really visit the GP. Because it's such a headache to get an appointment.” – Imtiaz, Male, 30-49

There were mentions of both language and racial barriers, but not in a matter that made them feel stigmatised or biased against, rather it was felt that speaking in the same language allowed patients to better relay their condition and sometimes a doctor from the same ethnicity will understand the complexities of their situations better and will deal with them with the appropriate and sensitive words.

“Yeah, for my aunty, I have to go with her. It obviously doesn't matter who it is. But she would prefer, if there was nobody, then she would prefer somebody who could speak the same language and definitely a female.” – Adeel, Male, 30-49

“He was an Asian doctor and that's why I didn't mind him saying that, because he dealt with it very very subtly and he was very very good about that (cousin marriage).” – Nosheen, Female, 30-49

There were still other barriers like transportation, family support network, and shyness due to gender, which were mentioned by the participants as barriers to their access to services.

“Some people think that how to discuss things according to Sharia, but a doctor is a doctor, and you should discuss everything with a doctor. Islam gives permission for this, that you can share these (sensitive) things with doctors or teachers. Islam does give us this permission, with a doctor, or teacher, or another profession I can't recall now, it's no sin to discuss with them. When you have confidence, support from family and friends (then you can share with the doctor). When I had a problem, I had to discuss with a doctor, I just went, but I have a friend who hasn't, she's shy. I keep telling her that it is okay to talk to a doctor, we are supposed to talk to a doctor, if we don't tell the doctor, how else will they know if there is something wrong.” – Laiba, Female, 16-29

One participant spoke about the cutbacks in the disability services that has had an impact on his ability to easily take his children with disabilities to go see a doctor, something he has to do on a regular basis. His narrative also highlights the important issue of understanding hidden disabilities, as mentioned earlier.

“They have cut down a lot for children with disability. Cut down a lot of costs. Children used to get mobility (services). You know when you get the disabled badge

(for car). When you go to hospital appointment, you used to get to park close. They've now made it so strong (stringent), that your child has to be not walking to get that badge. With my children, they walk, but my younger one, and my older one they've got no sense of danger. I have to pick my 6 year old up and hold my 11 year old's hand (at the same time), and it's very hard. I've applied for a blue badge inshallah I'll get it, because what he does, he's got no sense of danger, he'll run. And the forms are so complicated, does he walk, how many lines does he walk, how many years has he...And you can't really explain your feelings because either you say that you've got a disabled child, you don't really mean, physically disabled. Mentally if they are disabled, I think that's worse.” – Fiazan, Male, 30-49 Mixed Discussion

Consequently, in order to choose a GP, these same factors came into play as participants spoke of overcoming those barriers of language, transportation and gender.

“Same language. It's more convenient. You can explain well the problem (sic). They (his parents) went to Caucasian doctors but they didn't properly understand them. It's more convenience than anything.” - Imtiaz, Male, 30-49

“It (distance and transportation) can be a barrier if you are not driving. I think I overlook these things because I can drive and I am quite independent and I have just grown with it but looking at our community, you look around and you see so many women who can't drive and are very isolated.” – Nosheen, Female, 30-49

“In certain situations, you would prefer to have a woman, you feel comfortable. But in terms of ethnicity, no (no preference).” – Sabeen, Female, 16-29

In terms of genetics and health services, the participants showed doubt about the existing evidence linking disabilities to cousin marriages. They also highlighted the importance of religion in coming to terms with their difficult situations. The participants mentioned barriers to services access, some of which were not previously emphasised in the lay community group discussions. They also showed a willingness to learn more about genetics and were eager to give their suggestions on strategic actions to improve the health profile of the community.

7.4 Strategic Actions

7.4.1 Promotion of Available Services

In discussing the steps the participants felt needed to be taken in order to improve the health profiles and services of their community, the responses were not dissimilar to those of the lay community. They also stressed the need to obtain more information about genetic disorders and any

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possible links to cousin marriages. Even though at least one of the participants had gone to see a genetic counsellor, it was found that almost everyone else was unaware of their services available locally or even their role. However, it was stressed that these services needed to be delivered in a culturally sensitive manner. The participants also called for additional and appropriate services to be made available to cater to the need of the local population, which had a large Muslim Kashmiri community.

“I think it would be good if there was a bit more information available out there. Having said that, if we could be bothered to actually go out and find the information ourselves as well. But I think still, if there was more information out there then it would be slightly easier. That could be done through the media, that's one of the main things, one of the main sources. Even if it wasn't, if you were to go to the GP, I don't know how it would work to be honest, I don't know how the GP's and the NHS Direct, and the other sources available, how they are linked together. Maybe even if you go the GP there's some information available at the GP, something on the board or something that you can read while you're waiting or something, that would say that there are other alternatives or places you could go or whatever, you know. Yes, I don't think there's anything wrong with educating people. As long as they're portrayed in a correct way and discriminate anybody and say that make any party look bad. See the figures and say that's wrong that's wrong. Just see the figures and that's it, just leave it at that! Let people make up their own mind and what they want to do.” – Imtiaz, Male, 30-49

“I think there should be more research, definitely. They need to bring it out and they need to talk about it. They need to be very careful what they say, in front of the media. Keeping in mind that there are people out there who might just dismiss it because of how you put it in front of them.” – Adeel, Male, 30-49

“I think (more) health services, they need to look at the town as well, the needs and communities that reside in there and if within (Luton the) Pakistani Kashmiri community is the largest then they need to make sure adequate services are available to reflect the community (in terms of) staffing, language, female doctors. Not disregarding the other communities but if largest community doesn't have representation then there is something wrong. Like Urdu would cater for majority of (the) Bengali community as well and on top of the Indian community as well. So you are catering for 2-3 (communities) while catering to one (of the) largest ones.” – Haris, Male, 30-49

7.4.2 Community Involvement and Service Delivery

Some participants felt that this information was best delivered either by the religious leaders or in conjunction with them and discussions with the community. The majority of the participants

however, felt that this information was in fact best delivered by the GPs, with whom they have developed a longer standing relationship. It was also mentioned that the GPs should also receive detailed information about genetic conditions, so that they are better equipped to deliver this information to them.

“It’s better if community organises as we understand and get better things.” – Yunus, Male, 50+ Discussion

“If it’s done in Colleges etc., Centres, then its better, it’s needed here (more information on genetics). Even the doctor should have the knowledge to give to us.” – Samar, Female, 16-29

“I think the GP has a more of a one-to-one relationship, and in most cases it's only you and the GP sitting there. And you do feel more open, and you could possibly have more intimate conversation with your GP, than sitting at the hospital. Yeah, I think I could see that happening. You going and sitting there and the GP you know, generally providing you with the information.” – Ahsan, Male, 16-29

“I say that they (GPs) should get the most information. Because people mostly listen to their doctors, even if they something wrong, they will listen to them. They will not listen to you or me and definitely not parents, they say they are just old, they don’t know anything.” – Laiba, Female, 16-29

7.5 Summary

The main themes emerging from the discussions with the consanguineous community members, as presented in this chapter, were once again focused on culture, genetics and healthcare, as well as the strategic actions needed to improve health and healthcare. The emphasis of the responses with these participants was on the sociocultural implications of consanguinity, especially in discussing the nuances around cousin marriage as an institution. The participants spoke of systems of arranged cousin marriages that were inescapable. Another feature of these arranged marriages was the family tradition of marrying a first cousin through generations. The reasons given by the participants for preference of cousin marriages included the desire for a sense of security, in old age by depending on altruistic feelings of a loved one, in inheritance by keeping property within the family, and in avoidance of risk of divorce. There were other reasons like immigration, as participants suggested that there was a feeling to want to help family members back home by getting

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their children to immigrate to the UK through marriage. Although these did not guarantee successful marriages, with evidence of abuse and broken marriages prevalent in the participants. Perhaps owing to these experiences of failure and the ensuing hurt, or an increased level of Western education, the current generation is shying away from cousin marriages, according to the participants.

There was a poor overall understanding of genetic and health risks. In the absence of better understanding, participants often cited seeking explanations through religion. It was however, more than health beliefs that perhaps acted as barriers to services access and use, as participant responses indicate there were a host of other barriers which included a lack of culturally and demographically appropriate services. The participants were eager to improve the situation by asking for more services and information about these services and the relative risks, although again the information should be delivered in a culturally sensitive manner through the proper medium that is in conjunction with both the doctors and the community leaders. The consanguineous community discussions presented in this chapter, along with those of the lay community (chapter 6) and the service providers (chapter 5), have provided an insight into the understandings of consanguinity as experienced by those in Luton. In chapter 8, the key findings from these chapters will be discussed in light of the literature and the study objectives.

CHAPTER 8 – DISCUSSION

8.1 Introduction

Chapters 5, 6, and 7 have presented the findings from the discussions with service providers, lay members and consanguineous members of the Pakistani community, respectively. This chapter turns its attention to a discussion of the cumulative findings arranged according to the major themes that emerged from the findings. The aim of this research was to examine the sociocultural impacts of consanguinity along with any implications for healthcare, with specific objectives of:

- exploring the consanguinity discourse globally, nationally and locally;
- examining the views and experiences of consanguinity in Luton’s British Pakistani community;
- ascertaining the health service providers’ knowledge and views towards consanguinity in Luton.

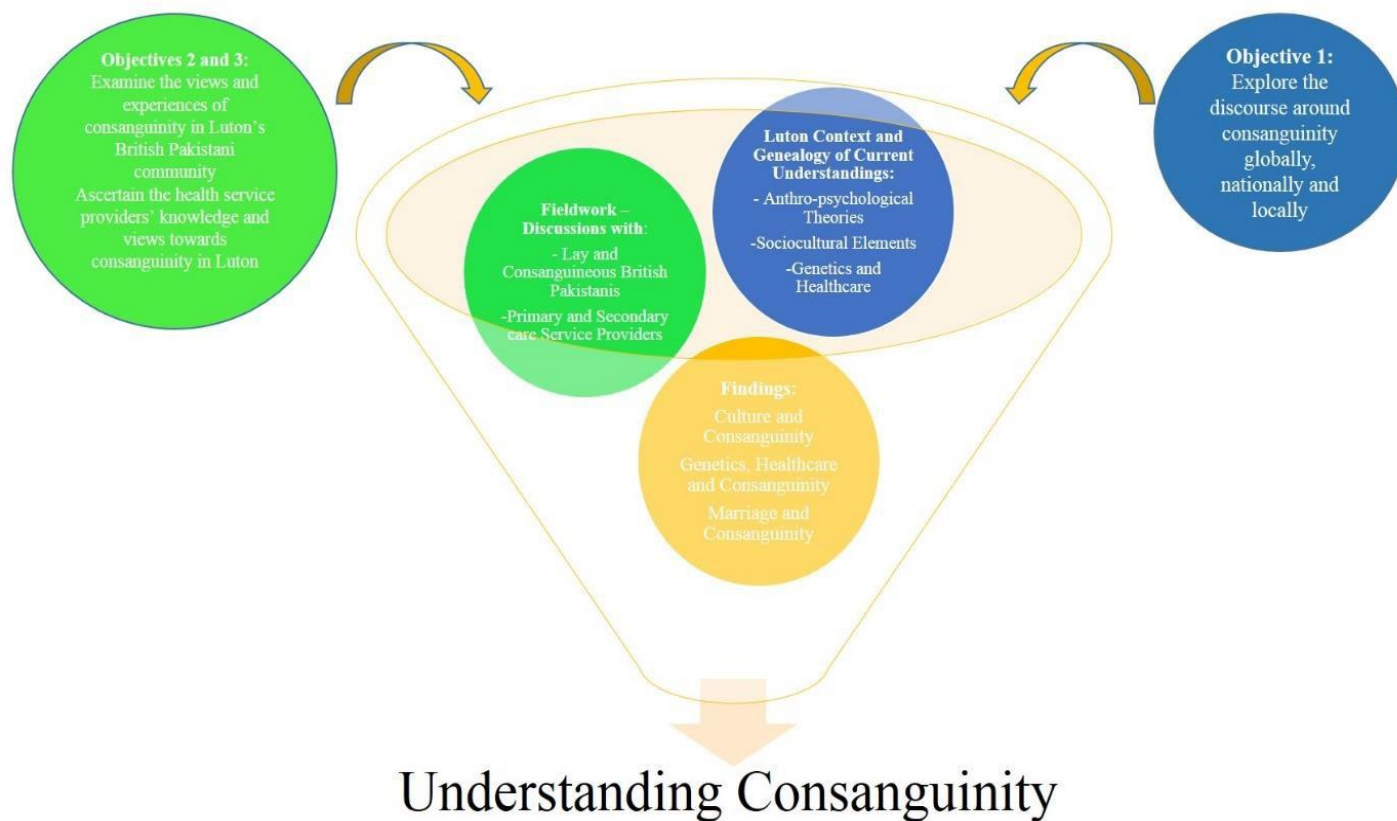


Figure 8.1 Understanding Consanguinity - This figure shows how the study objectives (colour coded to correspond to how they) were achieved and the findings of which have constructed an understanding of consanguinity being discussed in this chapter.

While the first objective was achieved through the literature review of current understandings of consanguinity, the second and third objectives were answered through fieldwork discussions with the service providers and the British Pakistani community. The main findings from these discussions are analysed together as per the case study design, and help to construct an understanding of consanguinity which is based on a critical analysis of current knowledge and experiences of this discourse, as represented by Figure 8.1. This chapter then, presents a discussion of these main findings which are organised according to the major themes that emerged from the analysis, namely culture and consanguinity, marriage and consanguinity, and genetics, healthcare and consanguinity. Given the power of discourse in formation of knowledge, it is no surprise to see that these major themes corresponded well to the sociocultural elements, anthro-psychological theories and knowledge of genetics and healthcare, which form the basis of current understandings of consanguinity. The discourse around consanguinity positions the Pakistani community in the UK as the ‘other’ and this has implications for service provision and utilisation, which will be evident throughout the discussion on the findings of this thesis. The discussions begins with the sociocultural elements of consanguinity, represented here by the major theme of culture and consanguinity, which encapsulated issues around social, religious and ethnic categorisation of consanguinity.

8.2 Culture and Consanguinity

Key findings:

- Service providers did not believe that consanguinity was linked to religion, but in Luton, consanguinity was mostly seen in the Pakistani community
- Service providers saw a clear link between consanguinity and negative health outcomes, specifically high rates of infant mortality and children born with disabilities and/or abnormalities in Pakistanis, while the community did not subscribe to this view

- Labelling of Pakistani patients as high risk could lead to institutional racism, creating barrier to accessing care
- Lack of understanding amongst the service providers about heterogeneity in Pakistani population, failing to recognise the Kashmiri identity of the local population, which is important for cultural competency as well as crucial in accurate genetic/health risk assessment
- Lack of cultural competency evident amongst the service providers through their use of negative/discriminatory language associated with consanguinity

As previously discussed (section 1.3), social categorisation for the purposes of description and intellectual debates can be useful (Barre, 1975, Bateson, 1958), but when these categories are used to define, identify or explore causation of health problems, the consequences can be significant and usually unproductive (Nazroo, 2012, Ahmad, 1994). This categorisation has been applied at times in the past with regards to consanguinity and South Asians, mainly Pakistanis (Morton *et al.*, 2002, Ismail *et al.*, 2004, Wijeyaratne *et al.*, 2002). This ethnic categorisation of consanguinity can result in feelings of stigmatisation amongst the community (Ahmad and Atkin, 1996, Modell and Darr, 2002a), creating distrust which eventually contributes to poorer health outcomes, as the community becomes hesitant to report health problems for fear of being stigmatised or lack of trust in the doctor's assessment of their health being impartial with regards to their consanguinity (Darr *et al.*, 2013, Ali *et al.*, 2012, Ahmad and Bradby, 2008). The service provider responses in this study show that they understand that consanguinity is not linked with religion and is seen in people from different ethnicities globally; however, they felt that in the local context of Luton, cousin marriages mostly occurred in the Pakistani community. This response was also echoed in the findings of both community groups. The difference, however, was seen in the service providers' clear linkage of consanguinity with negative health outcomes, with which the community disagreed. This link was

then expanded upon by the service providers and essentially used to label Pakistani patients that came in for treatment as high risk due to the possibility of a consanguineous relationship. While the inclination that consanguinity is prevalent mostly in Pakistanis would not offend the community, deeming from their responses in the findings, labelling them as high risk would be seen as pathologisation of their culture. This was indicated by the response from one participant in the community findings, who felt that the doctors would see them differently because of their cousin marriage and this would then become a barrier for them to access health services. Ethnic categorisations can lead to other hegemonic representations of a community or group (Werbner, 2004). In the UK, and in Luton, the Pakistani community has a distinct Kashmiri identity, and the Kashmiri diaspora, which already feels displaced without control of their territory (Ali, 2002), such categorisations can become even more problematic leading to feelings of discrimination. Ethnic categorisations may indeed lead to discrimination in the form of institutional racism (Nazroo, 2012), which need not be intentional (Atkin, 2006), feeding into the overall discursive construction of consanguinity as an ethnic condition effecting the other, with the threat of spreading and effecting the indigenous (Ahmad and Bradby, 2007). While the service providers would argue that their intent is not to categorise, their language feeds into the popular discourse, which then transcends their personal sphere of understanding into what Foucault referred to as the circle of knowledge distribution which eventually reaches the micro levels of society (Inden, 2000).

Categorisation, as suggested earlier, can be used to identify and explore ethnicities for removal of disparities, such as Putnam's ethnic models for use in population based studies (Sturgis *et al.*, 2011, Nazroo, 2012). The service providers were generally knowledgeable on the differences in behaviours between the local Pakistani and Bangladeshi populations, both Muslim, but the Bangladeshis do not generally marry within cousins, delinking religion with cousin marriages and recognising the influence of culture on the practice. However, when it came to the heterogeneity present within the Pakistani community, it was only the South Asian service providers who were

well informed of the distinction between Pakistani and Kashmiri. As discussed above, the Pakistani community in Luton is pre-dominantly from the Azad Kashmir region of Pakistan, making them culturally distinct from a majority of Pakistanis from other parts of the country with a unique identity (Ali, 1999, Ballard and Banks, 1994), a Kashmiri identity about which the community feels strongly (Ali, 2002). This lack of recognition amongst the service providers may possibly limit their ability to connect with the local community. In fact, a majority of the service providers had no interaction with anyone in a cousin marriage outside of work, meaning the only exposure they had to cousin marriages was in the medical context, usually a negative interaction, which had a limiting influence on their cultural competence and increased their negative perception of consanguinity in linking it to disease.

As suggested above, a lack of cultural competence amongst the service providers was noticeable in their use of negative language associated with consanguinity. When some service providers equated consanguinity to inbreeding and raised the issue of uncle-niece marriages in the context of consanguinity, a practice common in South India, but not so in a largely Muslim Pakistani local population, who consider it *haraam* or a sin as it is not allowed in Islam, as confirmed by the community studies' findings, it showed a poor understanding of the sensitivities involved in talking about consanguinity. Hahn and Inhorn (2009) contend that because public health has become part of the sociocultural process, it is important to understand people's values, concepts and behavioural norms, playing close attention to sociocultural rules for interaction and gathering information. Associating words like inbreeding with consanguinity is unhelpful (Bittles, 2012), and implies poor knowledge of the local population which feels stigmatised when such words are used to describe their relationships. The use of appropriate language and understanding the cultural context of a patient's condition is crucial to achieving healthcare objectives, as without these basics, the rest of the care process is destined to fail (Johnson, 2004). As one participant in the consanguineous community study suggested, it led her to hide the true nature of her relationship, which can lead to

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poor history taking and possible misdiagnosis, a form of institutional racism that leads to poorer health outcomes based less on disease and more on discrimination and misdiagnosis (Gee, 2002, Patel and Hegginbotham, 2007, Nazroo and Iley, 2011).

The failure to recognise the distinctness of the Kashmiri identity and the heterogeneity in the Pakistani community is relevant not only in terms of cultural competency but also in terms of recognising the importance of *biraderi* system in marriage customs as well as genetic risk assessment. This risk assessment can be exaggerated, as discussed in chapter 3 (section 3.4.3) without accounting for endogamy and population stratification which is very relevant in the Kashmiri diaspora in the UK. However, this oversight is not unique to service providers in Luton, as a recent study in Bradford (Sheridan *et al.*, 2013), published in the *Lancet*, faced similar criticism (Bittles, 2013) on possibly exaggerated risk values associated to consanguinity because of failure to account for population heterogeneity. Nonetheless, failure to understand the sociocultural dynamics of a local population can lead to impacts on healthcare, either in the form of service delivery and access barriers or incorrect genetic/health risk assessment.

8.3 Marriage and Consanguinity

Key findings:

- Consanguinity is most commonly recognised through cousin marriage
- Consanguinity thus gets linked to arranged marriage and forced marriage
- The community members suggest natural aversion as a deterrent to cousin marriage
- Cousin marriage driven less by incest taboo and more by alliance theory and gift-exchange theory, described mainly through a sense of security
- Male dominance in community responses may be a means to further stigmatisation
- Immigration laws further fuel cousin marriages through transnational marriages
- *Biraderi* is an important concept in consideration of marriage partners
- Risks associated with marrying within *biraderi* (endogamy) even less recognised

than that of cousin marriage, both by the community and the service providers

Findings under this major theme, marriage and consanguinity, relate directly to some of the sociocultural elements and anthro-psychological theories which have informed the current discourse on consanguinity, discussed earlier in chapter 3 (sections 3.3 and 3.5). The discussions with the service providers and community members of Luton indicate that these understandings of consanguinity are represented in relation to the tradition of cousin marriages. Indeed, consanguinity is most commonly referred to as cousin marriage, be it in the media, health setting or the dinner table (Darr *et al.*, 2013). This was confirmed as such in the findings of both the service providers' and community members' studies. However, as previously discussed, this definition not only is incomplete scientifically (Hoodfar and Teebi, 1996, Bennett *et al.*, 2002), it may also be privileging marital unions over all other types of sexual relationships that may occur under consanguinity; consequently shielding incestuous relationships from the popular discussions, but still using the incest taboo to define, predict and identify consanguinity and in essence cousin marriages. It also serves to associate consanguinity, rather cousin marriages, to more "traditional" cultures, which for the most part have sexual relations only after marriage, yet carrying forward the underlying links to incest and inbreeding, both in popular culture and scientific models (Bennett *et al.*, 2002). Of course it is entirely plausible that this association stems from mere numbers, as in the majority of such unions happen to be cousin marriage, but this does not make it either responsible or exclusive, and the repeated usage of the term cousin marriage aides the discursive formation of consanguinity by associating it with traditional societies, making it an ethnic condition (Ahmad and Bradby, 2007), as discussed earlier (section 8.2). The expansion of this construction of consanguinity into arranged and forced marriages, as highlighted by the findings, only serves to augment this association, so much so that it has come to define those societies' own interpretations of consanguinity.

None of the participants in the community discussions had heard of consanguinity, but most were familiar with cousin marriages, as previously discussed. The links to incest or inbreeding were

only mentioned in terms of how others (Whites) viewed them. As such, there were no discussions that could explore hidden incestuous feelings as suggested by Freud, but there was proof that sociocultural elements, religion in this group, played a role in enforcing this incest taboo, since most respondents proclaimed it was forbidden in Islam to have such relations. Clearly, incestuous relationships do not define consanguinity in this group and referring cousin marriages to incest was seen as a Western construction. There was however, credence given to Westermarck's theory of natural aversion as most participants proclaimed that growing up with a cousin made them consider them as a sibling rather than a cousin and creating a natural feeling of disdain for any talks of marriage with this person.

Both arranged and forced marriages were linked to cousin marriages by the community members. Their responses highlighted the multiple facets of both arranged marriages and forced marriages, in terms of assisted marriages and emotional blackmail (Ahmad, 2006). The underlying elements of such marriages, be it bridging families, property ownership, dowry, immigration or altruism, seemed to be related to the Lévi-Strauss' alliance and gift exchange theories (Vandenberghe, 1980), but not as a way to avoid incest (Lévi-Strauss *et al.*, 1969), rather it was more for reasons of security, or a sense of security, according to the community members. This sense of security they felt was provided through cousin marriages; security from potential failed marriages with unknown outsiders, security of possessions by keeping property in the family, security for extended family through transnational marriages against ever restricting immigration laws, or security from threats to culture from Western traditions. While discussing the elements of seeking this security, the community responses pointed towards the power dynamics of gender in the community. Women, essentially were used as the "gifts", in the gift-exchange to form alliances (Vandenberghe, 1980), hinting at male dominance. Some participants, who were subject to domestic abuse in their marriages would agree with such an assessment of a male dominant patriarchal society, while others would see this as another stigma associated to consanguinity

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(Michaelson and Goldschmidt, 1971). Similarly, the purpose of laws against forced marriages are described as the empowering of women, but some have doubted the true inclination to tackle these laws as being based on colonial and racist tendencies of the State to police South Asian communities (Wilson, 2007). Furthermore, the complex and restricting laws of immigration, as discussed in chapter 1 from the history of migration and settlement of the British Pakistanis, have further fuelled cousin marriages and perhaps even forced marriages. The tightening of these rules was seen as a racist agenda and Islamophobia by the older generations of the community members, to limit the number of Muslims in the UK. Linking Islamophobia to cousin marriages has come up in the media recently (BBC News, 2008), however, the Islamophobia discourse speaks more to the larger identity formation and migration discussion of the British Pakistanis (Ali, 1999) post the Rushdie affair and post 9/11 (Abbas, 2004), which in turn has influenced the overall construction of the meaning of cousin marriages when it comes to the British Pakistani communities, and as such has been identified by the participants. Whether Islamophobic or not, this sub-theme in the findings, of the ethnic strife that exists in Luton, is a by-product of the consanguinity discourse that positions the Pakistani community in the UK as the 'other', as suggested above (section 8.1). This discord impacts the behaviour of the community, in terms of trust deficits and social exclusion in a reaction to marginalisation (Frost, 2008). This also relates to the sense of security the community may feel in marrying from within, if not the family then the *biraderi* or the geographical area and so on, as suggested by the results.

The importance of *biraderi*, or clan systems, in cousin marriages has been highlighted before (Shaw, 2001, Shaw, 2009, Bittles, 2013), and was stressed in the findings of the community responses as well. The potential health risks of an endogamous population (Hamamy *et al.*, 2011) (see section 3.4.3) were even less recognised than those of first cousin marriages within the community. It was not a prominent feature in the service provider findings either, with only a few participants speaking on the potential influence of geographical isolation on the health outcomes,

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which speaks more to the knowledge deficit for genetics in primary care and to a lesser extent in secondary care. However, the assertion of one of the secondary care participants that cousin marriages were on the decline was backed up by the community members in their responses, although the literature is perhaps not as certain on this decline (Darr *et al.*, 2013, Shaw, 2001, Shaw, 2009). Nonetheless, these responses do speak to the growing inter-generational divide in opinions of cousin marriages amongst the British Pakistanis (Ali *et al.*, 2008, Salway *et al.*, 2012), with the younger respondents shying away from the traditional cousin marriages. The British Pakistani construction of consanguinity has historically been through the sociocultural implications of cousin marriages and this shift in attitudes of the newer generation may represent the growing influence of a wider discursive construction of consanguinity that has been discussed throughout this thesis, and has resulted in privileging the role of genetics.

8.4 Genetics, Healthcare and Consanguinity

Key findings:

- Genetics knowledge in community is limited and is mainly from media and through the prism of cousin marriages
- No difference in knowledge of genetics between lay community members and consanguineous community members
- Insufficient genetics knowledge levels in service providers, especially primary care service providers
- Additional training requested by GP's for genetics and genetic services
- Excessive workload for local genetics' service providers
- Limitation in available genetic diagnostic services, especially in relation to consanguinity
- Lack of understanding of referral pathways amongst service providers and community members

- Disconnect between service providers and community members in terms of perception of genetic disorders and in terms of barriers in access to care
- Health belief and risk assessment dependent more on sociocultural elements rather than genetics and health in community responses
- Social deprivation acknowledged by service providers but given less importance than cultural factors in terms of the impact on negative health outcomes
- Community participants' demographics hint at an impact on health outcomes based on social deprivation

As discussed in chapter 3, genetics has been used in medicine to understand and treat a number of hereditary diseases, and this has brought the focus on consanguinity, historically as a tool for studying hereditary diseases (Bittles, 2003) and perhaps as an indiscreet focus for explaining causation. The local community had limited knowledge of genetics, but apart from those over 50 years of age, most of the community members had heard of genetics, either through the media or through visits with the doctor. All participants had heard of a link between cousin marriage and disabilities, usually caused by genetic disorders, or as participants simply called it, genetics, again mostly through the media or through their doctors, a pattern similar to what has been reported elsewhere (Darr *et al.*, 2013). It was expected that those members of the community who had previously been referred to a genetic counsellor will have had more knowledge about genetics, but the findings suggest that their understandings of genetics are not much better than the ones who had never even heard of a genetic counsellor. They tended to equate genetics with “same blood,” which could be a literal translation of consanguinity (of same blood), meaning that unknowingly, they were equating genetics with consanguinity. The patients had only heard of genetics in relation to consanguinity or cousin marriage, and hence they tried to understand genetic risk through this prism, which not only propagated the view that consanguinity was linked to genetic risk, but also prevented the patients from understanding genetic risk in depth (Ali *et al.*, 2012).

This lack of understanding of genetics could also be a direct result of two other significant findings, one to do with the workload on secondary and tertiary genetic services, and the other on a lack of in-depth understanding of genetics within some of the service providers. The genetic counsellor who took part in the study spoke of the various different regional clinics she and her team of three other counsellors serve along with a consultant clinical geneticist on a bi-weekly or sometimes monthly basis, and with appointments lasting forty-five minutes each, the waiting list for appointments in one of the clinics is up to three months long. Furthermore, diagnostic services are not locally based, but are sent to regional diagnostic centres based in North West London or sometimes in Cambridge. At a time when health officials are calling for a focus on genetic medicine (Human Genomics Strategy Group, 2012, Emery *et al.*, 1999, Godfrey, 2003) and when service providers in this study see a clear link between the local Luton population and genetic disease, it would be logical to have more services available locally, a suggestion made by the community members as well. However, diagnostic services available even at the tertiary centre are not state of the art, this according to a personal communication in June, 2012 with clinical geneticists and cytogenetic technologists. These genetic professionals worked at one of the tertiary diagnostic centres, and cited the lack of a next-generation sequencing (NGS) machine at the facility as an example of their limited capability. NGS is the latest tool used in mapping gene locations used for diagnostics and research, and the method of choice in cases of rare genetic variants, which could be more common in consanguineous marriages (Zlotogora *et al.*, 2007, Bittles and Black, 2010a, Choi *et al.*, 2009).

The lack of availability of these advanced techniques, and minus an ‘all-encompassing’ genetic screen which can detect every negative genetic change (an insinuation by one secondary care service provider that was negated by the genetic counsellor during discussions), means that there will be limitations to the effectiveness of genetic services. This was noted in the responses of some of the community members, who suggested there was a lack of proof regarding the link to

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genetics for the disabilities experienced by their children, because service providers were unable to provide them with a definitive diagnosis or in some cases an answer in response to the simple question of why it (genetic disorder) had not occurred in their family before or why there appeared to be more White children at disability centres? Whether these were valid assertions by the community members or not (dismissed by one service provider as patients not knowing the differences between diseases and disabilities), what was valid were the patients' feelings of not getting a proper response to these questions, creating barriers in access to care. As suggested earlier (section 1.4), clear communication and understanding the patients' perspectives is key to the success of healthcare plans (Johnson and Cert, 2004).

While the genetic counsellor and the consultants, for the most part, had sufficient knowledge of genetics, the nurses, midwives and GP's in the study appeared to be less informed. Even though the midwives and some GPs felt that this knowledge was more suitable for specialised departments who are trained in genetics and counselling, it has been shown that due to the frequency and point of contact with sometimes non-genetically trained medical staff, lack of communication or miscommunication from these medical staff about the patient's condition may create doubts, fear and potential barriers in the further treatment and diagnosis for these patients (Raz *et al.*, 2003, Eldahdah *et al.*, 2007). This was also seen in the responses of the community members who felt that such information should be delivered by the GPs, citing their longstanding one to one relationship with them. Hence, it has been recommended that even ancillary staff in these situations be trained to provide support to the patients in helping them make informed choices (Bittles, 2012). Despite asserting that this knowledge was better suited for specialised departments, a majority of the GPs did state that they require additional training in genetics. This may serve to help reduce the trust deficit that was mentioned by some community members which has developed between them and their GPs, as community participants considered the GPs as having little knowledge about such matters. It may also alleviate concerns by some GPs of not wanting to tackle such complex

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discussions due to their own lack of depth in knowledge of genetics or a similar possible lack of knowledge or willingness to learn in the local community (Fry *et al.*, 1999).

Another pseudo-limitation of genetic testing that creates a barrier in service access is the late stage of presentation for patients who require screening. Both service providers and community members agreed that pre-natal screenings are sometimes too late for the patients of this community to have an effect on possible negative health outcomes. This is mainly due to the lack of clarity on the religious rulings of termination and the cultural taboo against it. For this reason, the example of the Greek Cypriot and Ashkenazi Jewish populations was given, who have reduced disease levels with pre-marital screenings in consanguineous couples (Triggs-Raine *et al.*, 1990, Angastiniotis and Hadjiminias, 1981). Both the service providers and community members felt that this was a better option because the alternative of pre-natal screening becomes an unquestionable point for most as they have already married someone by then. However, it should again be noted that these screens maybe limited in their effectiveness in a highly consanguineous population or one that displays genetic variations leading sometimes to no clear diagnosis (Plon *et al.*, 2008).

Given the lack of knowledge amongst some service providers about genetics and genetic services, it was somewhat surprising to see a majority of the service providers place the blame of genetic disorders mainly on the community members and their health behaviours. They mentioned a lack of knowledge and a lack of willingness to learn about genetics on the part of the community, termed as denial by one participant, as a result of a health belief system that was increasingly fatalistic and a closed culture not open to interventions. These views are not uncommon amongst some service providers (Ahmad and Atkin, 1996, Darr, 2009), but which have been ultimately countered as stigmatisation, pathologisation or misconceptions (Nazroo and Karlsen, 2009, Werbner, 2004, Ahmad, 2006). This represents an orientalist view of the other, where conceptions of culture are based on discursivities rather than reality, which may or may not conform to the presented truth (Atkin, 2006, Sayyid, 2004), as previously discussed in chapter 2 (section 2.4). This
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misconception was also cleared when the majority of participants of the community studies expressed a desire to learn more about genetics and in particular the links that may exist to cousin marriages. This should be a mutually beneficial endeavour as the service providers stressed at length about promoting health education amongst the local community, both about genetics and available health services. However, the community members also stressed the importance of culturally sensitive delivery of such information, lack of which results in barriers, some of which were not addressed by the service providers in their discussions, which focused mainly on health beliefs, as stated above.

The service providers and the community members were asked about barriers that may exist in access to health services; the service providers, as mentioned above, stressed the impact of health beliefs, but also language, ethnicity and gender as barriers, while the members of the community mostly agreed with these barriers, as does the literature (Ahmad *et al.*, 1989). However, the community members focused less on ethnicity and gender barriers, and more stress on appointments (lack thereof), transportation, and distance away from doctor surgeries. Furthermore, some participants in the community discussions highlighted racial barriers, feelings of being marginalised, and not necessarily from the White staff, but from South Asian ones, whose use of harsher language was lamented by some respondents. This is an interesting point as it was pointed out in one of the service provider discussions that White service providers hesitated in their communication with South Asian patients, based on some taboo areas that they could not discuss, whereas some South Asian service providers felt that they could get away with speaking about those issues, as they were from similar backgrounds. However, the responses from the community indicate that this ends up becoming a barrier to their access to care, because they feel that the South Asian doctors overstep their boundaries through use of such harsh language when discussing consanguinity or even other health concerns. However, having a doctor who speaks the language could certainly be an advantage, as other participants mentioned. This again highlights the

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importance of cultural competency along with an effective communication with patients, regardless of the service providers' ethnicity, to ensure best practice (Johnson and Cert, 2004).

These same barriers became important factors in choosing a GP, with older generation of community participants stressing the importance of gender, ethnicity and language. In terms of gender, all female community participants highlighted the importance of having a female doctor present for visits that were considered feminine matters, which has previously been observed (Farooqi *et al.*, 2000). Another issue that arose from the discussion of language barriers was the problem with using translators, as it was often seen that community dynamics or family politics were restrictive at times in the use of a close relative for translation, when such services were not presented by the medical facility, something that unintentionally aids institutional racism (Bhopal, 2001). The need for secrecy and the taboo nature of disabilities may also act as barriers in proper diagnosis or even prevention, as in the case with couples that have been identified as being carriers of a disorder and who may not allow the geneticist to approach other family members who may potentially be at risk based on the findings. The geneticists have no authority to seek out the other family members due to doctor patient confidentiality in such cases. Other barriers included the confusion in terms of which doctor to see, how to get an appointment with a specialist, the lack of clarity within the service providers in terms of referral system to tertiary care and the recent cutbacks in disability care, a concern raised mainly by parents of children with disability but also by the service providers. Most of these suggested barriers are not contrary to existing literature (Dimitrova *et al.*, 2006, Hussain-Gambles, 2004, Raghavan, 2009, Fry *et al.*, 1999), the only major difference between the groups' assertions of barriers lies in the service providers' suggestion of health beliefs as the biggest barrier and the community members' assertion that appointments were the biggest hurdle. However, neither groups mentioned the impact these barriers can have on the overall health profile of the local population which has been highlighted as being below national levels, with consanguinity playing a modifiable role in this statistic (Taylor, 2011, Taylor and Whiterod, 2011).

How do the barriers listed above by study participants and other sociocultural factors, including deprivation statistics from the council report itself, influence the negative health outcomes of the local population? Without discounting the legitimate numbers of infant deaths and other morbidities, forwarding the conclusions of such numbers without the perspective of these other “modifying” or “modifiable” factors would be akin to continue contributing to a discursive construction of consanguinity.

As suggested in chapter 1 (section 1.3) and earlier in this chapter, ethnic categorisation, when used to define causality without addressing the full causal pathway, when association is inferred as causation, the result is a magnification of health inequalities (Nazroo, 2012, Nazroo and Karlsen, 2009). Race is a social construct that has a negative impact on health, not due to biological inference, but sociological deprivation (Jones, 2001). The service providers did mention the impact of social deprivation in the context of consanguinity, but there was an attempt to marginalise this impact by suggesting a larger role played by culture in certain countries, alluding to British Pakistani culture in Luton. However, this is where statistics without context can be misleading, as this logic fails to address the full causal pathway (Collins and Johnson, 2009). Consanguinity may be a contributing factor to poor health outcomes, many studies have suggested that this seems to be the case (Abdulrazzaq *et al.*, 1997, Bittles, 2001, Farag *et al.*, 1993, Güz *et al.*, 1989, Sanderson *et al.*, 2006); however, social determinants of health are also a part of that same pathway (Bittles, 2012, Hamamy *et al.*, 2011, Marmot, 2010). Even though a recent large study on consanguinity in the British Pakistanis in Bradford by Sheridan *et al.* (2013) claims to have controlled for social deprivation in their association of elevated risks of congenital anomalies due to consanguinity, the statistics in the study in fact show the largest numbers of anomalies occurred in the most deprived cohort. Suggesting that the culture of British Pakistanis is more important in diagnosis than social determinants misconstrues the statistics, because the example given by one participant of a similar number of infant deaths in South America, where there is little consanguinity, shows in fact that

social deprivation plays a bigger role in determining poor health outcomes than consanguinity or culture. Nevertheless, when evaluating factors impacting health, all factors must be considered, none should be privileged or marginalised, as it is not the absence or presence of such factors that cause poor health, it is the interaction between such factors that has an impact on health (Solar and Irwin, 2007, Shi and Singh, 2011, p. 43).

In chapter 1, it was shown that Luton ranks amongst the most deprived regions of England, and within the town, the British Pakistanis have the highest population in two of the most deprived wards. The demographic data that was collected from the community participants as part of the discussions to contextualise the participants and the setting showed the differences in the demographics of the community members. While this is not a quantitative study and generalisations should not be made from this small data set, it however can be used to add perspective to the situation with the British Pakistanis in Luton, which were identified as having poorer health outcomes than others (Taylor, 2011, Luton Borough Council, Council, 2004). The community members who were married to their cousins were older, less educated and underemployed as compared to the lay members of the community. Studies have shown time and again that social factors, such as education, employment, age and even issues with ethnicity can have an impact on health outcomes, and in the Strategic Review of Health Inequalities in England Post-2010, the Marmot Review recommended that in order to reduce inequalities, focus must be on the underlying social determinants of health and the wider elements that were the cause behind the cause of poor health outcomes (Marmot, 2010). Moreover, it has been argued that any data presented in terms of the negative health impacts of consanguinity without normalisation for socio-economic factors should not be considered good data (Bittles, 2010b, Bittles, 2012, Hamamy *et al.*, 2011).

The health beliefs of the community members were a major theme in the findings and they play an important role in the social context of health determinants (Sias *et al.*, 2011). In chapter 1 (section 1.4), the health belief model was discussed as a model that states people's health behaviours

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depend on their perceptions of the severity of the disease and the risk of them contracting it, the benefits of partaking in prevention behaviour, and the barriers they will face in accessing or implementing that prevention behaviour, the self-belief that one can actually execute the behaviour required for prevention and the cues that can trigger action (Champion and Skinner, 2008, Skolnik, 2012). Some assertions of this model were tested in the discussions with the community, as health beliefs were also brought up by the service providers as potential barriers in accessing healthcare. This was done in part by asking the participants questions that addressed how they factor in the potential health risks of consanguinity with the potential social benefits to be gained by continuing it (Shaw, 2009, Bittles, 2012). Overall, the findings showed that cultural issues relevant to consanguinity were of more importance to the community members than the health issues. It was also seen in the findings that it was the lack of understanding of risk, as well as a lack on the part of the service providers in defining these risks without ambiguity, such as the response by a senior GP that asserted a non-scientific approach in highlighting potential risk in consanguineous patients, that may have played a role in the community members discounting the risk factors, as discussed earlier (section 5.4). The cultural benefits of cousin marriages outweighed the risk factors in the eyes of some participants, whereas for others, the sometimes negative sociocultural impacts on family and marriage of consanguinity outweighed any health risks deterring them from consanguinity.

8.5 Summary

In this chapter, the combined findings of the three different groups used in the case study of Luton were discussed through the major themes that emerged from the data. It was shown that while the overall focus of the service providers and the local community in terms of consanguinity may be divergent, one focusing on health and the other on sociocultural implications, the underlying themes that they use to comprehend consanguinity are related and primarily follow the dominant discourse. While health beliefs play some role in creating barriers to access, the barriers that exist

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due to ethnic categorisation or other social determinants of health hold equal importance in terms of both service access and health outcomes, and spending resources on part of the causal pathway from consanguinity to negative health outcomes is not efficient healthcare provision. The sociocultural constructions of cousin marriage, both for the community and the service providers, have an impact on behaviour and ultimately health profiles. There is common ground in terms of the direction participants would like to take with respect to improving the highlighted health and trust deficits, with both groups calling for better health and genetic education, further training, improved services and access to those services, and a culturally competent and combined approach to healthier communities. At least in terms of healthcare, there is a need to address the inequalities that go beyond sociocultural categorisations. It is said that health outcomes are decided not by the genetic code, rather by the postal code. While that may be a simplistic or even debatable approach, addressing inequalities in a comprehensive, inclusive and culturally competent manner is not only appropriate in a globalised society where race is a social construct not a biological one, and where medical care is taking a more personalised approach, it is also efficient healthcare. So, whether consanguinity is seen as a health issue or a sociocultural issue, an approach grounded in local recommendations to address all aspects of this discourse is needed. In the conclusion to this thesis, some personal reflections of the journey of this research are presented next, along with a reflection on the understandings of consanguinity presented through this work, and recommendations based on the findings.

CONCLUSION

In this thesis, the constructivist-interpretive paradigm was chosen to answer the research question. This constructionist paradigm calls for a relativist ontology in which reality is deemed to exist in multiple forms based on subjective constructions and experiences of social meanings (Guba and Lincoln, 1998). So, reality depends essentially on who experiences it and how they experience it. Later, a critical lens was applied to this approach through Foucault's ideas on discourse and use of power in generation of knowledge, such that realities are inspected for the influences of the time that help shape and construct them (Hall, 2001). These realities emerge from social processes and can be seen as social constructionism (Appleton and King, 1997). The overall approach then allows the researcher to construct an understanding based on interpretations of the experiences of groups, the subjectivities of literature and the discursive formations of the times that influence these experiences and subjectivities. The methodological approach that was deemed most suitable for this purpose in chapter 4 was a hybrid qualitative instrumental case study, incorporating elements of phenomenology and ethnography, while using focus group discussions and in-depth interviews with Luton's British Pakistani community and service providers as data collection tools. In qualitative research, the researcher is a tool of the research itself, and this becomes more important in a constructivist-interpretive research, in which the researcher attempts to construct an understanding based on interpretations of literature, observations and participants. It is impractical to remain objective and counter-productive to try not to be influenced by the research. In this final section of this thesis, I will further reflect on my personal journey through this research and add to section 4.7, using field notes and observations in describing how this research aided me in constructing an understanding of consanguinity, and what I would like to see come out of this research and the consanguinity debate in Luton. This reflection is based not only on reflexivity but on the triangulation that was evident throughout data collection, with multiple sources of data, from

multiple locations, in multiple settings, discussing the same research questions and in analysis of the findings, by combining results and discussing issues that were most prevalent in all discussions (Krefting, 1991).

I. Reflections on the journey

I had a personal interest in learning more about consanguinity, having been familiar with it due to my own cultural background. I also felt that my background in genetics and public health would make it easier to undertake this research. While my background certainly helped in understanding some of the concepts, the depth of this discourse still seemed overwhelming at first. While consanguinity remains a global phenomenon, it engages local environments in unique ways. In Canada and the United States, where I have done most of my past research, consanguinity is most closely linked to incest taboos within religious minorities, but not necessarily ethnic minorities. This slight difference negates the inclusion of important aspects of this discourse that are evident in the UK and elsewhere in Europe, aspects dealing with sociocultural elements of ethnocentrism, racism and immigration. This is not to say that those religious minorities in North America do not face hurdles, including discrimination, it is quite the contrary as evident from literature (Bennett *et al.*, 2002, Ottenheimer, 1996). However, the geo-politics of this debate in the UK are amplified with the inclusion of ethnic strife, as a majority of the consanguineous populations here were visible minorities as opposed to North America, where the issue is most relevant only amongst Whites. I immediately found out the significance and polarity of this debate in the UK just as I started my research and I was first greeted with surprised faces of people in the university and the community when I mentioned that my research would look into the impacts of consanguinity, or cousin marriage as it is commonly called here, and most people warned how I would not find many participants for my research.

Once it became apparent that this was a subject that ignited passionate responses from

people and how publicised this issue was in the media⁸, I decided to use a theoretical approach that would be critical of popularly held beliefs being presented as facts. I knew my study would have to be qualitative, because numbers could only tell part of the story and this was a subject that required an in-depth exploration. I chose to take a constructionist approach as it would allow me to build an understanding based on a relativist and pragmatic style, accepting multiple points of view, including that of the researcher. The critical evaluation of current literature was made possible by incorporating Foucault's methods, which were more idealistic than didactic, but useful in dissecting current constructions of consanguinity. My methodology choice and methodological tools were chosen based on compatibility with the overall approach and flexibility in data collection from multiple sources. After analysis of the data as a whole, in light of the critical analysis of literature that preceded it, I was able to focus on the emerging meaning of consanguinity from my research, where I saw both novelty and limitations, and felt that some recommendations could emerge from my personal overall experience of consanguinity. I also offered the participants a chance to learn more about the topic and discuss the findings of this research, for which purpose I gave them my personal contact information for each of them to contact me personally, as a group feedback session would have compromised the confidentiality of the participants. However, none of the participants to date have contacted me or the rest of the supervisory team directly. I was asked by the Research and Development Department at the Luton and Dunstable Hospital to write a short report on the findings with the service providers for inclusion in their newsletter, and I intend to do that after the thesis is published. I am content that the information from the thesis will be fed back to the community through journal article and follow up research projects that are already starting based on the findings of this thesis.

⁸ During my first few weeks of research, there was a documentary on Channel 4, Dispatches – When Cousins Marry. This programme was emotionally draining and focused on debilitating genetic disorders that a family was suffering through apparently because the parents were cousins. While the programme may have been factually correct, it presented only one side of the debate, the one that ostracises cousin marriages by linking them to genetic disorders without explanation of genetic risk.

II. Contributions to the Field

There is little research looking at consanguinity in Luton and overall, studies looking at the perspectives of service providers on consanguinity is also limited. This thesis contributes to both these areas as well as presents a comprehensive study with a critically devised methodology, a representative study population, and findings relevant to local and national health policy:

- The literature review on current views of consanguinity was based on a critical genealogical approach discussed not only the contents of the views but looked beyond at the historical context in which they were presented and what influences might have had an impact on the views presented in the research.
- While there has been research into views and impacts of consanguinity in other cities of the UK, no such research had been conducted in Luton with the British Pakistani/Azad Kashmiri community.
- Another advantage of conducting the research in Luton was the benefits of examining consanguinity impacts within a town that had a highly consanguineous population, with similar socioeconomic status, and a relevantly similar history of settlement in the UK, providing good controls for study participants, a criticism that has been labelled on previous studies into consanguinity from other cities in the UK.
- A major contribution of this thesis to the field is the inclusion of views of the service providers on consanguinity. While other studies have looked into service provider views in the care for South Asian patients, in which the discussion on consanguinity has risen, I could not find any studies that specifically looked into consanguinity from the service provider perspective, who are most relevant in terms of healthcare delivery, outcomes and policy.

- The participation from different age groups, both from males and females, with diverse educational backgrounds was also important. Previous research has shown the differences in inter-generational attitudes towards consanguinity, the findings in this thesis confirmed some of these views but also showed a difference between literature and participant views in terms of the trends of consanguineous marriages, which participants felt were declining, a finding contradictory to literature.
- With the inclusion of both community and service providers, some differing perspectives were also seen in their responses, not only on consanguinity where the focus of the service providers was on the biomedical model of health and that of the community members was on the sociocultural model.
- Moreover, the discussions on the barriers to service provision (not specifically related to consanguinity) showed the difference in focus of the two cohorts, with the service providers focusing on health beliefs of the community and the community focusing on the logistics of appointments, structural and language barriers.
- There is a large body of literature that focuses on the genetics of consanguinity and by presenting this largely social research at international conferences and seminars focusing on the genetics aspects, this thesis attempts to bridge the gap between the two separate arms of research into consanguinity.
- Provides the Pakistani community and primary care service providers with ‘realistic’ information on the genetic risk associated with consanguinity.
- Calls for improvement of information for primary care service providers on referral routes for consanguineous couples.
- Similarly, calls for an increase in the availability of information and provision of

genetic services

- Highlights the need to develop cultural competency in the delivery of services related to consanguinity.
- Debates the links between consanguinity and cousin marriage. While taken for granted as synonymous words, the differences in definition are explored in a critical constructionist way, and a separation in use of these words is recommended to prevent negative connotations
- The results from this thesis have the chance to impact future health policy with participation from and communication with members of the local clinical commissioning group

III. Limitations of the Research

As with any research, there are limitations that are evident from the beginning or become apparent during the research, some of which have already been discussed. Perhaps the biggest limitation to this research was the lack of comparison of the Pakistani community views in the UK with those that they are often culturally linked with, which is in Pakistan itself. I would like to highlight that there would be different social dynamics at play in the Pakistani settings, based on the socioeconomics and healthcare systems, but the comparison of views nonetheless would have added to the richness of this study. The other limitation deals with the use of the word Pakistani as well, because as has been highlighted throughout this study, a large proportion of the Luton residents, as well as the participants in this study, have a unique Kashmiri identity. As such, there was a debate to change the use of the word British Pakistanis to Pakistani/Kashmiri community; however, I believe that because of the debates presented in this thesis around ethnic categorisation being mainly an artificial application used for better intellectual communication rather than implying characteristic meaning, using British Pakistani while describing the heterogeneity of the

sample in their origins from different regions of Pakistan and Kashmir were sufficient, but any future application of the findings of this work will have to ensure this distinction, which is why it can be perceived as a limitation.

There were also limitations in the sample of the service providers, with very little participation from the social care services, even though they were heavily recruited. It would also have been useful to incorporate a mixed focus group discussion with representation from both primary and secondary care. While the approach applied in my fieldwork was based on best practice of other research, after looking at the finding of the research, it would have been interesting to see the interaction between the two groups on issues of referral pathways and the role of the GP in the care pathway in relation to consanguinity. It would also have been useful to interview the local faith leaders who play an important role in the community both as gatekeepers and influential leaders. The faith leaders were used as a means to recruit participants in the study, the chosen protocol did not call for their own inclusion in a discussion like the service providers. Although an attempt was made to hold at least one group discussion with imams from different mosques around the town in conjunction with the Public Health Luton representatives, the discussion never materialised due to hesitation from the potential participants. This however, would be an area worth exploring in future research, as studies have shown the influence faith leaders can have on the community (Ahmed *et al.*, 2006, Randhawa *et al.*, 2010), and the findings from this research show the impact of religious beliefs mixed in with cultural beliefs has on the health behaviour of the local community.

While this was a social research thesis, the limitations in this work pointed out by the academics in genetics field highlight the absence of any analysis on genetic data of British Pakistanis. In their view, this presented an excellent opportunity to recruit participants into a complementary study that analysed local genetic profiles, which would be beneficial for future diagnostic use. While they see this as a limitation, I believe this to be more of an opportunity for

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future research based on this thesis' assertion that local genetic services in Luton need to be improved for them to be useful in the context of consanguinity.

IV. Constructing an understanding of Consanguinity

These discussions with the service providers and the local community showed me the differing areas of focus in this dialogue on consanguinity. While the health researchers and doctors continue to focus on the genetics and health outcomes in this debate, the community members continue to grapple with the sociocultural fallouts. Literature on this subject has evolved from the early psychological and anthropological explanations of consanguinity, which sought to theorise this form of human behaviour. However, most of the evolution seems to have been towards seeking explanations in the genetics behind consanguinity. The common feature in both these approaches it seems is their intention, which appears to be the need to predict and even control consanguinity as a phenomenon. The most recent social science research has tilted towards treating consanguinity as an issue of globalisation, encompassing challenges of ethnic identities, immigration, integration, and indeed population health. At the end of this research, I too believe consanguinity to be an issue of globalisation, but I also believe that it has always been an issue of globalisation. I do not intend to get into a debate about the meaning of globalisation, which holds different meanings to different schools of thought, and has been described at times as the most dangerous buzzword of the late twentieth century (Wiseman, 1998). I use globalisation here in a very generic sense as a factor in culture and ethnic identity (Hall, 1997) and also as a sociocultural factor in global public health (Skolnik, 2012). In my view, globalisation can refer to the changing populations of regions and countries in the postcolonial era, and these population changes have introduced new challenges both in terms of sociocultural integration and public health. I believe consanguinity is one such challenge that engages both of these aspects. The challenge I refer to is that of understanding consanguinity as a cultural aspect of an integrated society that contributes to, but is not solely responsible for, a changing local health spectrum. In terms of the example in this research, the British Pakistanis

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represent the cultural aspect of consanguinity in an integrated British society, which encompasses challenges of migration, ethnic identity, racism, social deprivation and public policy, and all of this together with changing genetics has an impact on local health. I say local health because with globalisation, national and regional health policies are increasingly failing to address local concerns, a point made by some service providers in this research as well. Hence, a move towards localised and even personalised medicine is becoming necessary in a globalised society and certainly in terms of consanguinity and public health genomics (Bittles, 2010a).

V. Recommendations and Future Directions

The aim of this research was to explore consanguinity, but the objective was never to theorise it, rather it was to construct an understanding of consanguinity, which I believe I have detailed above. However, I would like to close my thesis with a set of recommendations and future directions I personally would like to see with regards to consanguinity, at least in Luton, based on both the findings of this research and observations from a public health and genetics perspective through analysis of local services and participation in multi-disciplinary and related international conferences and seminars relevant to consanguinity:

- Based on the strategic recommendations given by both the service providers and the community members in this study:
 - Health education and promotion programmes on genetic risk and available health services for all Luton residents and to have these programmes available in multiple languages, especially Urdu, Punjabi (Pahari, if possible) and Bengali (and Sylheti dialect), besides English.
 - Genetics training for all health professionals.
 - Cultural competence training for all health professionals.
 - Public involvement in localised clinical commissioning.
- Based on the recommendations presented at the Westminster Health Forum and July 2013

Westminster Social Policy Forum Keynote Seminar on Health Inequalities 2012:

- Larger focus on the social determinants of health and the need to address the full causal pathway both upstream and downstream of consanguinity in the impact on health outcomes.
- Based on the observations of best practices in caring for a similar British Pakistani consanguineous population, discussed at Raising Awareness of Genetics Amongst Culturally Diverse Communities Conference in Leeds, UK:
 - Recruitment of locally trained community health workers.
 - Availability of translation services at all doctor surgeries and local hospitals catering to the most commonly locally spoken languages.
 - Availability of health and genetics trained Muslim and other chaplain services offering religious advice to patients at local hospitals.
- Based on the learnings from the 6th Annual National Conference on Health Disparities in Little Rock, USA on tackling health inequalities faced by ethnic minorities and socioeconomically deprived populations:
 - Introduction of mobile health units that offer basic triage, health prevention tips and health promotion strategies to alleviate the workload on GP surgeries and to provide more options to the community in the absence of more appointments at local surgeries.
 - Increased funding for local community centres and recruiting private sector to invest in promoting healthier lifestyles.
 - Assist NGO's that are involved in health promotion, disability care, preventing domestic violence, advocacy services and half-way houses.
- Based on the learnings from the International Conference on Consanguinity in Geneva,

Switzerland, the Course on Statistics and Molecular Biology of Consanguinity in Bologna, Italy and observations and analysis of local genetic services serving Luton:

- Availability of a resident genetic counsellor at the local hospital.
- Increased funding for genetic medicine, including local diagnostic services with Next-Generation Sequencing capabilities that are crucial for detecting rare mutations.
- Commitment to genetic research, including GWAS studies to help build a local profile of the most common mutations in the local population, for better predictive testing in the future.

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Appendix 1 – Literature Review of Sampling Strategy

Study/Paper	Main Aim	Methods	Sample Size	Recruitment Strategy
Croot et al. (2008)	To provide a detailed account of how Pakistani parents account for and understand their child's disability	Qualitative/ Phenomenological; In-depth Interviews; Thematic Analysis	16 interviews	Formal Network (therapists and staff at Special schools); Opportunistic (through word of mouth to contacts of those selected through schools)
Hussain (1999)	To examine the relative importance of religious, economic and cultural reasons for consanguinity	Qualitative/ Ethnography;	294 Interviews (127 non-consang.; 167 consang.);	Mixed-Method, Larger preceding quantitative study sample (which was based on recruitment from Professional Network) used to randomly select 300 (for in-depth interviews);
Hussain (2002)	Explore lay perceptions of genetic risks associated with consanguinity	In-depth Interviews; Focus Group Discussions (FGDs)	15 FGDs (5 in each locality)	Stratified Purposeful Sampling (gain representative from each ethnic group and age group)(for Focus Group Discussions);

Study/Paper	Main Aim	Methods	Sample Size	Recruitment Strategy
Ali (1999)	To examine the enculturation and formation of identity in an ethnic minority (Kashmiris) in Luton	Mixed-Method; In-depth Interviews, Observation, Questionnaires (ISA)	75 in-depth interviews	Opportunistic; Snowballing
Ali et al. (2008)	To identify the attitudes and beliefs towards consanguinity in the Pakistani community of Birmingham	Qualitative/ Ethnographic; In-depth Interviews, Focus Group Discussions (FGDs)	8 interviews (only consang.); 8FGDs (only non-consang.)	Purposive; Professional Recruitment firm hired (Randomised within inclusion criteria); Compensation paid to participants
Kaur-Bola (2009)	To explore the needs of children with multiple, complex disability and learning difficulties from the	Qualitative/ Grounded Theory; In-depth Interviews;	14 interviews (10 with parents of disabled children,	Purposive; Not specified

Study/Paper	Main Aim	Methods	Sample Size	Recruitment Strategy
	Pakistani and Bangladeshi communities in Luton	Focus Group Discussions (FGDs)	with community/ religious leaders); 8FGDs (4 with lay community members, 5 with service providers)	
Shiloh et al. (1995)	To examine the impact of pre-marital genetic counselling in decision making of consanguineous couples for marriage and having children	Qualitative; In-depth Interviews	230 interviews (65 with consanguineous counselled; 40 with consang. Non- counselled; 125 non- consang.)	Purposive; Fonnal Network (genetic counselling records and nurse assisted recruitment by phone); Opportunistic (randomly at maternity ward)

Study/Paper	Main Aim	Methods	Sample Size	Recruitment Strategy
Darr (1990)	To help improve service provision for thalassaemia major affected British Pakistanis	Qualitative/ Ethnography; Observation	Not specified in numbers	Purposive; Snowballing
Atkin and Ahmed (2001)	To explore the strategies and resources young people use to cope with thalassaemia and sickle cell	Qualitative/ Phenomenological; In-depth Interviews;	51 interviews (26 with Thai. and 25 with SCD)	Purposive (to include all young cases of Thai. or SCD); Formal Network (paediatrician and haemoglobinopathy specialists)
Rhodes (2008)	To explore attitudes of the Pakistani community towards epilepsy	Qualitative; In-depth Interviews; Focus Group Discussions	30 interviews (20 from sample frame and 10 of their carers); 2 FGDs with lay community	Purposive; Formal Network (City's Epilepsy Register for Interviews, Community Centre for FGD)

Study/Paper	Main Aim	Methods	Sample Size	Recruitment Strategy
Greenhalgh et al. (1998)	To explore the experience of Diabetes in British Bangladeshis	Qualitative/ Phenomenological; In-depth Interviews; Focus Group Discussions; Narratives; Pile Sorting; Structured Vignette	50 interviews (40 Bangladeshis with Diabetes, 10 control, non-Bangladeshi, with Diabetes and similar socio-economic background); 24 of 40 chosen for 3 FGDs as well ; All respondents also gave narrative	Purposive; Formal Network (3 different GPs registrars) and Opportunistic (through reception at GP)
Bywaters et al. (2003)	To explore whether negative stereotypes regarding health beliefs of ethnic minorities regarding disability are valid	Qualitative; In-depth Interviews; Thematic Content Analysis	20 families	Purposive; Formal Network (City Family Support Unit)

Study/Paper	Main Aim	Methods	Sample Size	Recruitment Strategy
Khlat et al. (1986)	To gauge perceptions of consanguineous marriages and their genetic effects among a sample of couples from Beirut	Qualitative; In-depth interviews	200 (100 consang. and 100 non-consang. women)	Purposive; Formal Network (Hospital in Beirut)
Williams and Healy (2001)	To explore the perceptions of cause of psychological experiences among new referrals to a community mental health team (CMHT)	Qualitative/ Grounded Theory; In-depth interviews	34 (6 pilot members, 15 patients, 5 non patients, 8 purposely selected) 47 total interviews conducted, some individuals were interviewed more than once)	Purposive and Theoretical; Formal Network (CMHT)
Ritchie et al. (1994)	To gain an understanding of workers' priorities and motivations, and help develop better interventions	Qualitative/ Phenomenological; Focus Group Discussions	IOFGDs (119 participants)	Purposive; Formal Network;

Study/Paper	Main Aim	Methods	Sample Size	Recruitment Strategy
				Snowballing
Khanum (2008)	To provide insight and recommendations for assisting victims of forced marriage and for its eradication	Qualitative/ Case Study; In-depth interviews; Focus Group Discussions	104 interviews; 4 FGDs; 15 case studies	Purposive (specifics not listed but possibly opportunistic)

Appendix 2 – Topic Guides



Exploring Consanguinity

Topic Guide

(Service Providers)

1. Introduction

- Thank you.
- Introduce self and relationship to project.
- Give background to the project: we are looking at gaining a better understanding of consanguinity and want to understand the view of service providers.
- The aim of the research is to explore the many facets of consanguinity and to develop an understanding based on the experiences of the service providers.
- This project is sponsored by the University of Bedfordshire.
- Brief outline of the discussion:
 - After this introduction we will talk about the services you provide generally and specifically and if any for people in consanguineous marriages.
- Explain about the consent procedure, emphasise confidentiality, tape recording and length of discussion (approximately 90 minutes).
- The information from the research will be written up as a report and may be published in a peer reviewed journal.
- Any questions about the study or group discussion before we start?

2. Current Service Provision

I would like to ask you a little bit about you and the services you provide.

- Please tell me a little bit about your role.
 - Probe: department, seniority/mangers, ethnicity
- Do you know how many patients/clients you see on a daily basis?
 - Probe:
 - Knowledge of the figures, access to figures, knowledge of ethnic composition
 - Ask for rough percentages of anecdotal information
- In your view are these manageable numbers?
 - Probe:
 - Why/why not?
 - Efficiency of services/inefficiency, staffing issues
- Do you or your department see patients/clients that may be consanguineous?
 - Probe:
 - For which services?
 - Any indirect referrals to your department?

3. Consanguinity

I would like to discuss consanguinity.

- What do you understand by consanguinity/cousin marriage
 - Probe: for levels of inter-relatedness e.g. first cousin, second cousin, cousin once removed, uncle/niece etc.
- How would you describe the link between hereditary disease and consanguinity?
 - Probe:
 - More relatedness/higher diseases?
 - Increase in prevalence of rare disorders?
 - Rate of reproduction- skewing numbers?
- Do you know anyone in a consanguineous marriage
 - Probe: nature of relationship e.g. only patients, friend, family, acquaintance etc.
- Which communities/ethnic group in Luton are in consanguineous marriages?
 - Probe:
 - Perceptions of differentiation/association between nationality vs. Religion
 - Where is this information from e.g. work experience, statistics, media, knowledge of local community, friends, family etc?
- Does the ethnicity of your consanguineous patients impact your role in any way?
 - Probe:
 - Positive/negative effects of same ethnicity/different ethnicity, diagnosis, disclosing difficult information/bad news
 - Fear of disclosure within the community etc.

4. Accessing Services

I would like to ask you a little bit about access to the services that you provide for consanguineous couples.

- What is the process of patient referral to your department?
 - Probe for information on the care-pathway e.g. GP referral, secondary care, genetic counselling services, social services etc
- What happens to patients after first point of contact?
 - Probe: progression and follow-up
- Can you think of any barriers that may exist in patients/clients accessing your services?
 - Probe:
 - Real vs. perceived (e.g. structural barriers vs. health belief) Age
 - Gender/ethnicity/language/social Class Physical/Environmental
 - Provider prejudice/fear of stereotyping lack of information about services)

- What factors help encourage service utilisation?
 - Probe language barriers, education, appropriate staff

5. Improving services and patient access

I would like to ask you a little bit about improving services and access for consanguineous couples.

- What service improvements are required to enhance access for consanguineous couples?
 - Probe: for views on how current services could be refined, new services required, partnership working etc.

I would like you to read the following patient case study.

(based on a true story quoted from a blog on a newspaper website):

Zalan 2011, 'A Cursed Lineage', *blog.DAWN.COM*, weblog post, 24 June, accessed 22 May 2011, <<http://www.dawn.com/201106/24/a-cursed-lineage.html>>

AK arrived at the hospital destined to die a slow and painful death. He had, in fact been dying for some time and this was not news to anyone. Over the last three years, his condition had drastically deteriorated; often struggling to breathe despite the oxygen that the doctors had arranged for him, his muscles were wasting away bit by bit because of his condition. Despite the battering his body was taking, he was a strong boy and would somehow make it to another day past another infection, something the nurses and doctors knew quite well now after his frequent visits.

His attendances in the hospital were becoming more and more frequent and each attendance had more to do with caring for the dying than for treating the sick. This was unbearable to watch for any parent, outliving their child. A few weeks earlier, the staff watched the female senior consultant have the 'conversation' with his parents. She must have struggled with it, as much as anyone would. How do you tell parents, that their son is going to die soon and it would be cruel to try and revive him, only prolonging his misery?

The consultant was an expert; she had carefully discussed it with AK's family over many weeks. Her team would do their best to treat any illnesses and make sure AK was comfortable to the end; but he was not to be resuscitated if his heart stopped beating. Initially his father understood, but his mother struggled with the discussion, over the weeks she finally came around and would say '*it was for the best*', a painful realization indeed.

AK didn't fully understand what was going on you see, he was only three years old. He was born with an inherited genetic disorder, a rare condition, but that was more

common in his family ... His condition meant his muscles were wasting away at an accelerated rate, to the extent that he could no longer breathe without support.

Tranquil, despite everything AK was a fighter that day, he fought off his latest infection. The senior paediatrician decided the next day that he could be discharged, but suddenly that afternoon, his breathing increased rapidly as he struggled to clear his lungs, the nurse desperately tried to suction the secretions before the oxygen was slowly cut from his brain.

The senior paediatrician shouted for his mother, she rushed from where she was standing nearby ...hesitated ...and then slumped in the chair next to AK's bed, refusing to look at her son. The doctor picked up AK, and carried him to her; his oxygen mask dragging behind. *'Mum your son is about to die, let his last sight and last touch in this world be y ours,'* the doctor said handing him over to his mother.

AK's mother held on to her three year old son for one last time. Soon after, he was declared dead. His mother wept: to call it crying is perhaps understating it, it was in fact something more primal, not a cry, something closer to a howl. Despite all the forewarning and discussions, nothing prepared her for the inevitable.

Follow up discussion:

- This story is based on a true account of a UK family. What are your initial thoughts on the story? What could you, in your role, have done to help this family?
 - Probe: more/less treatment options, future counselling, earlier screening, follow up care
- Knowing the family history and ethnicity, how would you have helped the family differently?
 - Probe: rareness of disease and consanguinity, endogamy, ethnicity and genetic diagnosis
- Are there specific areas you would suggest to improve in service provision of such cases?
 - Probe:
 - Clinical/Genetic services
 - Education (Health Promotion and CPD)
 - Social Services and NGOs
 - Research
 - Probe further: Preference for preventative care or treatment focussed services?
 - Screening for prevention, pre-marital counselling, pre-conception counselling, post natal counselling, patient education vs. screening for diagnosis, medicine for treatment.
- What professional development do you require to provide existing services to consanguineous couples?
 - Probe: sensitivity/cultural competency training, understanding genetics for better delivery of information.
- What professional development do you require to deliver 'new' services?
 - Probe: as above-more.

- Who should provide these 'new' services?
 - Probe: NHS, Local Council or GPs under new proposed changes.

6. Closing

I would like to ask you some final questions to bring the discussion to an end.

- Summary of suggestions/recommendations.
 - Probe:
 - You believe access to services can be improved by...
 - You have stated that further training need/need not be required
 - You would/would not like additional services provided

****Thank participant for their contribution, stress confidentiality.***

Exploring Consanguinity

Topic Guide

(Community)

**Note: Section in Blue only meant to be asked of people in cousin marriages

1. Introduction

- Thank you.
- Introduce self and relationship to project.
Give background to the project: we are looking at understanding cousin marriage.
- The aim of the research is to explore the many facets of cousin marriage and to develop an understanding based on the experiences of people living in Luton.
- This project is sponsored by the University of Bedfordshire. I am a student at the University of Bedfordshire and this research is being carried out as part of my PhD.
- Brief outline of the discussion:
After this introduction we will talk about your views, experiences and understanding of cousin marriage.
- Explain about the consent procedure, emphasise confidentiality, tape recording and length of discussion (approximately 60-90 minutes).
- Emphasise that this is not a question and answer session and that there are no right or wrong answers. Opinions are all valid and that is what you are interested in obtaining.
- The information from the research will be written up as a report and may be published in a peer reviewed journal.
- Any questions about the study or group discussion before we start?

2. Demographics

I would like to ask you a little bit about you and your links to Pakistan.

- Please tell me a little bit about yourself.
 - Probe: education, place of origin in Pakistan, profession, religious affiliation, *biraderi*
- How long have you lived in Luton for and do you have family back in Pakistan?
 - Probe:
 - When and how did you settle in Luton?
 - How strong are the links with family in Pakistan? How frequently do you or they visit? Majority in UK or in Pakistan? Do they plan to come over? Or do you plan to go back?

3. Cousin marriage

I would like to discuss cousin marriage.

- What do you understand by cousin marriage?
 - Probe: for levels of inter-relatedness e.g. first cousin, second cousin, cousin once removed, uncle/niece etc.
- You are married to your cousin, what is the exact relationship?
 - Probe:
 - e.g. first cousin, second cousin, cousin once removed, uncle/niece etc.
 - Is anyone else in your or your spouse's family married to their cousin?
 - Arranged/Love/Other? If other, any pressures or feelings of obligations?
- What does genetics mean to you?
 - Probe:
 - Any links to cousin marriages?
 - More relatedness/higher diseases?
 - More rare disorders?
- Besides yourself, do you know anyone in a cousin marriage?
 - Probe: nature of relationship e.g. only friend, family, acquaintance etc.
- Would you say that cousin marriages are confined to Muslims or Pakistanis?
 - Probe:
 - Perceptions of bias towards Muslims or British Pakistanis?
 - Where is this information from e.g. work experience, statistics, media, knowledge of local community, friends, family etc?
- In your view, what are the advantages of cousin marriage? Disadvantages?
 - Probe:
 - Positive/negative effects of same family as in-laws, in terms of familiarity, religiosity, cultural values and inheritance
 - Positive/negative effects on social issues like force marriage and immigration?
 - Genetics?
 - Marrying a cousin different than marrying within a *biraderi*?
 - Would you be more likely to marry a cousin if you grew up together or if for example they came from a different city/country and you rarely saw each other?

4. Accessing Services

I would like to ask you a little bit about access to the health services in your area.

- How often do you visit a GP for common ailments or regular check-ups?
 - Probe for information on GP preference e.g. same ethnicity, gender, area.
- Do you feel that you get all the support that you need?
 - Probe:
 - Referrals, progression and follow-up
 - Ever seen a genetic counsellor or had a genetic screening done?

Do you believe that a consanguineous couple should see a genetic counsellor?
 What other options do couples that know will be having a child with a disability have?
 (termination?)

- Can you think of any barriers that may exist in your access to services?
 - Probe:
 - Real vs. perceived (e.g. structural barriers vs. health belief) Age
 - Gender/ethnicity/language/social Class Physical/Environmental
 - Provider prejudice/fear of stereotyping lack of information about services
- What factors help encourage service utilisation?
 - Probe language barriers, education, appropriate staff
- Do you feel that a specific group of people use health service more than others?
 - Probe:
 - Which groups (ethnicity,gender, age)? Are consanguineous couples a part of this group?
 - Is that a concern for you as a tax payer?

5. Situation in the UK

I will now read a section of a news story to you and will then ask some related questions.

"Baroness (Ruth) Deech (Professor of Law at Gresham College, London) believes first cousins who marry are far more likely to have disabled babies, and that the practice is far more common among immigrants from Pakistan. However she says that the dangers are not spoken about by politicians or doctors in case Muslims are offended. Lady Deech contrasts this approach to the Government's attitude to health problems such as obesity or smoking, which are the subject of aggressive publicity campaigns."

Beckford, Martin 2010, 'Baroness Deech: Risks of cousin marriage not discussed for fear of offending Muslims ', *The Telegraph*, online news article, 23 March 2010, accessed 24 October 2011, < www.telegraph.co.uk/news/religion/7497906/Baroness-Deech-Risks-of-cousin-marriage-not-discussed-for-fear-of-offending-Muslims.html >

- What is your opinion of Lady Deech's position?
 - Probe:
 - Are married cousins more likely to have disabled babies? Is this more pertinent in Pakistanis?
 - Are you aware of any publicity campaigns for or against cousin marriage? And are they helpful or discriminatory?
- Other prominent politicians, like Ann Cryer, have called for a ban on cousin marriage, what is your opinion on that?
 - Probe:
 - Your views? Plausible? Uncalled for? Is it discriminating? Links to racism?

- What are the feelings of the Pakistani community in Luton (at least the people that you know) about genetics and dealing with genetic disorders?
 - Probe:
 - Hesitation?
 - Feelings of being targeted?
 - Other communities like Greek-Cypriot and Ashkenazi Jews have dealt with Thalassaemia and Tay-Sachs Disease aggressively, why not the Pakistani community?
- Locally, in Luton, do you feel things are different than they are in the rest of the UK or even Pakistan?
 - Probe:
 - More/less cousin marriages?
 - More/less disabilities, medical problems?
 - More/less focus politically?
 - Mixed in with other geo-politics or race/religion/crime?

6. Improving Services

I would like to ask you some final questions to bring the discussion to an end and these will relate to your ideas about any needs to change current services.

- In terms of cousin marriages, do you feel that it is something of concern?
 - Probe:
 - In terms of healthcare or social issues?
- Are the current health and social care services available in Luton adequate for the community?
 - Probe:
 - For those in cousin marriages?
 - If not, what do you feel is lacking?
- Do you feel that there is a need for further education in terms of genetics and genetic disease for the general population?
 - Probe:
 - For those in cousin marriages?
 - If not, then why do service providers believe there is a need?
 - Is the local atmosphere conducive to discussions on this subject? With council, service providers, community?

****Thank participant for their contribution, stress confidentiality. Offer vouchers and ask to sign sheet confirming voucher has been received.***

Appendix 3 – Service Provider Research Protocol

UNIVERSITY OF BEDFORDSHIRE



Exploring the Social, Genetic and Healthcare Impacts of Consanguinity

RESEARCH PROTOCOL

Mubasshir Ajaz

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1.0 Overall Research Title

Exploring the social, genetic and healthcare impacts of consanguinity

2.0 Aims and Objectives

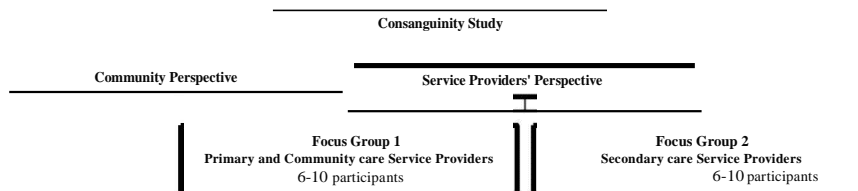
2.1 Aim

Explore the health and social service providers' knowledge and views towards consanguinity in Luton

Objectives

1. Collect service providers' knowledge and perceptions about consanguinity;
2. Discuss ideas for improving continuing education for professionals on consanguinity;
3. Identify current service provision available local health services relevant to the needs of consanguineous population;
4. Obtain service providers' views on the improvement of services for the needs of the consanguineous;
5. Discuss strategies for improving uptake by local population of health services.

3.0 Rationale



This is a qualitative study looking at the social, genetic and healthcare impacts of consanguinity from the local perspective of Luton. This protocol pertains to the service providers' perspective portion of the study for which NHS ethics approval is being sought. The study will involve up to 20 service providers who will be asked to participate in two focus group discussions. The aim is to build an overall understanding of consanguinity based on the real life example of Luton's service providers. The research has the potential to serve as both a health promotion study and one that highlights potential inequalities in health for a minority population, as well as identify areas of improvement for the efficiency of healthcare delivery.

4.0 Study Context

Consanguinity is defined by the World Health Organization (WHO) as the union between individuals who are related as second cousins or closer (Teebi and El-Shanti, 2006). The practice of consanguineous unions has a long history in the West, and has been part of the aristocratic and royal

societies since the Middle Ages (Bittles, 2009). One of the pioneers of science, Charles Darwin, was also married to his first cousin, and it was during this period that initial scientific exploration into consanguineous unions and their offspring started (Bittles, 2009). This change in the discourse of consanguinity is even more prevalent in recent years, as the practice is often ostracised in the Western cultures, even though it is prevalent globally at an incidence of at least 20% (Modell and Darr, 2002). Marriage within cousins has been reported as the preferred mode of union across the Middle East, North Africa and South Asia (Bittles, 2001, Bennett et al., 2002).

In studying consanguinity, it would be important to identify a study population that would allow exploration of all three aspects under research in this study: genetic, healthcare and social. Although consanguinity is a global phenomenon, some of the highest rates of consanguineous marriages take place in Pakistan, where the rates are reported as high as 77.1%, as well as up to 62.5% first cousin marriage rates (Bittles, 2001, Hussain, 1999). This tradition or trend or practice of consanguineous marriages is also evident in recent migrants from Pakistan or communities with origins from Pakistan, in Britain (Hasan, 2009, Modell and Darr, 2002, Shaw, 2006). Research suggests this practice is on the rise in Britain in successive generations of Pakistani communities (Shaw, 2001, Darr and Modell, 1988, Hasan, 2009) as opposed to other European countries like Norway where studies suggest that there has been a successive decline in the numbers of consanguineous marriages from generation to generation (Stoltenberg et al., 1997, Stoltenberg, 2009, Grjibovski et al., 2009). In Luton, the British Pakistanis are the largest ethnic minority group (Khanum, 2008, ONS, 2004). This sets a good boundary for the study population that a community exists locally that is known to practice consanguinity in a town with apt healthcare infrastructure which will allow the researcher the means to explore all facets of the study in a manageable manner. Previous studies on consanguinity in the UK have been conducted in areas with high South Asian populations like Bradford, Birmingham, Leicester and areas of London. The reason why Luton has been chosen for this study rather than these other locations is due to a combination of reasons. Luton is a smaller town compared to the other cities mentioned above, and as such the populace is situated closer together, making it easier to do community based research in terms of logistics, geography and socio-economic dynamics. Moreover, Luton has enough similarities in terms of the history of the British Pakistanis and their migration, as well as their composition, with the bigger centres that a study conducted in Luton, acting as a microcosm of these other areas, will possibly have relevance elsewhere. There have been a number of studies already conducted in the other locations and there may be a case made for the over-studying or at least the feeling of being over-studied, within the Pakistani diaspora in those regions (Githens- Mazer et al., 2010, Henderson, 2010), whereas previous studies in Luton (Kaur-Bola, 2009, Khanum, 2008), relatively fewer in number, highlight the need for further research in this subject area. Furthermore, it is appropriate for practical purposes as the researcher is linked with the local university and is also accustomed to the language and culture of the study population, making it easier in certain situations to connect with the community (Darr, 1990).

One of the main arguments used by the critics of cousin marriages is of adverse genetic effects. It is acknowledged that certain autosomal recessive genetic disorders can occur more frequently in the progeny of consanguineous couples, due to the limited nature of the non-disease related alleles in the available gene pool (Bennett et al., 2002, Bittles, 2001, Hoodfar and Teebi, 1996, Miguel and Jose, 2005,

Modell and Darr, 2002, Teebi and El-Shanti, 2006, Woods et al., 2006, Clarke, 1997). There is evidence of its effects on pre-reproductive mortality rates and adult-onset disorders (Bittles, 2001). There are however serious misconceptions that sometimes label all sick children of consanguineous couples as being in that state due to the nature of their parents' relationship (Darr, 1997). While this is certainly not the case with every such patient, children of consanguineous couples are at a higher risk of developing genetic disorder, albeit highly variably (Bittles, 2001), but the same can be said about other factors, like smoking or drinking during pregnancy and advanced maternal age at birth. However, the fact that a higher risk does exist, coupled with the fact that most consanguineous unions take place amongst populations that may be challenged socio-economically, it is an area worth exploring from a healthcare perspective. As healthcare strategies have moved away from focusing on curing health issues as and when they come up to focusing on improving overall health and preventative care (Deeter, 2000), it is important to address issues that may possibly impact the health of a population or specific groups within the population. And when that group happens to be one of the largest minority ethnic groups in the UK (ONS, 2004), it becomes an even more important issue locally.

In light of the indications above, Luton will be used as a case study in understanding the phenomenon of consanguinity and this study will focus on the experiences and knowledge of the service providers in Luton in dealing with a consanguineous population. The result will be to construct a comprehensive understanding of the discourse of consanguinity and its impact in terms of society, genetics and healthcare.

5.0 Methodology

5.1 Research Questions

Research questions that will be probed through the focus group discussion with the service providers will focus on the specific objectives listed above. They will include:

What is meant by consanguinity? Is it a disease, disorder or medical term? Do you approve/prefer this word or would you rather use another?

Is every genetic disorder indicative of a consanguineous union? If not, what percentage? How much do you know about genetic testing and screening? Are these services available in Luton?

Which services do you feel are most directly involved in dealing with a consanguineous couple or their child? How do you feel your profession links with this topic?

Are there any indirect relations to other services?

Are these services readily available to users? (referral system and accessibility) Why or why not?

What are your personal views/beliefs about consanguinity? Do you believe that these beliefs impact your work or ability to work in dealing with consanguinity?

Do you believe there should be laws and regulations associated with consanguinity? What and why?

Is there a specific group of people mostly associated with consanguinity? Why?

Do you believe it is a choice related to religion/culture/ethnicity?

Do you believe that the level of consanguinity in a community significantly impacts the usage of health and social services?

What disadvantages would you attribute to consanguinity? Advantages?

Do you believe there is adequate knowledge or resources available to staff about genetic disorders and the topic of consanguinity? If not, how can it be improved?

How about for the public? Any strategies you would suggest to improve access to information and to services?

Are you aware of the referral system in place for genetic counselling? Do you believe it is adequate?

Is there enough staff to cope with a) diagnostics b) counselling c) disability services? How closely linked are social services with other NHS services?

What role can NGO's play in this system of care?

5.2 Study Design

This study will follow the qualitative methodology, in order to build an understanding of consanguinity with the study participants, in this case the service providers in Luton. More specifically, 6-10 service providers will be recruited to participate in each of the two focus group discussions, lasting approximately 90 minutes each, questions for which have been listed above. For this part of the study, focus group discussions have been used as the research tool for the main fact that focus groups are useful in generating large amounts of data through singular sessions because they involve group interaction that allows participants to state and justify their views in ways that is usually not possible in individual interviews. Focus groups are best utilised when trying to retrieve a range of opinions on a specific issue, or obtain a social context for how people talk about an issue, and how group interaction may shape responses (Hennink et al., 2011, Lewis, 2003). They can also provide participants with a liberating feeling to discuss a sensitive topic, as others are also doing a similar act. Focus group can be used to expand on issues generated through other methods, like interviews and literature review, and prove useful in discussing strategic solutions, particularly useful in health studies (Hennink et al., 2011, Finch and Lewis, 2003). Group composition is an important aspect to consider when designing focus groups and while a little heterogeneity for the purposes of sparking a conversation is important (Finch and Lewis, 2003), one of the reasons to attain similarity in group composition is to keep the focus on the questions being asked rather than individual differences of the sample (Ali et al., 2008). Previous studies with service providers have divided groups based on roles, whether clinical or social, and on level of care, either primary or secondary (Billings, 2003, Dimitrova et al., 2006, Woo et al., 2011). Since the NHS is divided structurally into primary and secondary care services (NHS, 2010), the two focus groups in this study will also be divided by one each for primary and secondary care, with the primary care group also including community and social care service providers.

5.3 Participants and Recruitment

This study will include up to twenty service providers, who will be asked to participate in two focus group discussions. The aim is to build an overall understanding of consanguinity based on the real life experiences. For this reason, health and social services providers in the local Luton community will be recruited and will include professionals from doctors, nurses, midwives, genetic counsellors, social workers, and clinical leads. As mentioned earlier, they will be divided into two separate focus groups, depending on their level of service provision, either primary or secondary.

The participants will be recruited through advertisement at the Luton & Dunstable Hospital in Luton (for which a Research Passport has been obtained by the researcher and a Site- Specific NHS Ethics approval will be sought from the hospital's R&D department), through telephone contact at 25 local GP practices (identified by NHS GP practice finder within 2 miles of LU1 postcode) and social service centres (see Appendix 1 for full list), and through direct invitation in person from the chief investigator at both the Luton & Dunstable Hospital and the GP practices and social service centres. Once the participants show interest in the study, through verbal or electronic communication with the chief investigator, they will be provided with the participant information sheet (in person by the chief investigator or electronically through email). They will be given the opportunity to ask further questions about the research from the chief investigator by telephone (01582 743738 or 07775 932925) or through email (mubasshir.ajaz@beds.ac.uk). If they would like to continue and take part in the study, initial consent will be assumed and they will be asked to sign an informed-consent form when they arrive for the focus group discussion. This will be followed by the approximately 90 minutes of focus group discussion which will be held at a mutually convened venue.

5.4 Analysis

The analysis will be inductive in nature using data familiarisation, coding, and categorizing to perform a thematic analysis (Trochim and Donnelly, 2007). This type of analysis is in line with the constructivist-interpretive approach of the study and will be done using Atlas.ti software.

6.0 Ethical Issues

The topic of consanguinity is a potentially sensitive issue. However, all participants will be ensured that the aim of this research is to understand knowledge and perception of consanguinity and how services can be better geared to improve care to people in or about to embark in a consanguineous relationship. All participants will be given an informed consent form, as well as an information sheet, which are modelled after the NHS Research Ethics Committee's requirements. All results will be reported anonymously, with aliases being used to replace real identities, and the results will be available to all participants once the study is completed. All personal data recorded will be kept confidentially in a password protected and encrypted hard-drive within an alarmed building at the University's Putteridge Bury campus. Participants will also have the opportunity to contact the research team or

administrators if they require further information or if they have a complaint or comment about the study. Research will only progress once approval is received from both the University of Bedfordshire Ethics Committee and the NHS Research Ethics Committee. As well as R&D approval through the Site- Specific NHS Research Ethics form from the Luton & Dunstable Hospital of the NHS Trust.

7.0 Impact

This study will contribute to an overall understanding of consanguinity based on the knowledge, perceptions and experiences of the local service providers in dealing with people in consanguineous relationships. The research has the potential to serve as both a health promotion study and one that highlights potential inequalities in health for a minority population, as well as identify areas of improvement for the efficiency of healthcare delivery.

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9.0 Appendix 1-List of Recruitment Sites

GP & HOSPITAL SITES:	Dr. Kanchandani & partners The Blenheim Medical Centre 9 Blenheim Crescent Luton, LU11HA Phone: 01582 404012	Town Centre GP Surgery Luton NHS Walk in Centre 14-16 Chapel Street Luton, LU1 2SE Phone: 01582 709290
Bute House Medical Centre Grove Road Luton, LU11QJ Phone: 01582 729428		Whipperley Medical Centre Whipperley Ring Luton, LU1 SQY Phone: 01582 744870
Cardiff Road Surgery The Surgery 12 Cardiff Road Luton, LU11QG Phone: 01582 722143	Dr. Prasad & partners Conway Medical Centre 49 Westbourne Road Luton, LU4 8JD Phone: 01582 429953	Dr. Ward & partners Farley Hill Medical Centre Luton, LU1SRD Phone: 01582 722525
Dr. Ali-Khan & partners 12 Westbourne Road Luton, LU4 8JD Phone: 01582 483344	Dr. Sadhev & partner Medici Medical Practice 3 Windsor Street Luton, LU1 3UA Phone: 01582 875500	Dr. Mirza & partners 177 Biscot Road Luton, LU3 1AP Phone: 01582 572817
Dr. Choudhury & partners Bell House Medical Centre 163 Dunstable Road Luton, LU11BW Phone: 01582 723553	Dr. Saleh Wenlock Surgery 40 Wenlock Street Luton, LU2 ONN	Dr. P.S. Bath Surgery 49 Ashcroft Road Luton, LU2 9AU Phone: 01582 391 831
Dr. Dhabuwala 31The Corssway Farley Hill Luton, LU1 SLY Phone: 01582 728826	Dr. Verghese & partner Liverpool Road Health Ctr 9 Mersey Place Luton, LU11HH Phone: 0845 2265603	Dr. Khan 278 Dunstable Road Luton, LU4 8JN Phone: 01582 453155, 01582
Dr. Hoda 53 Leagrave Road Luton, LU4 8HT Phone: 01582 404967	Dr. Ward & partners- Lea Vale Medical Group Lea Vale Medical Group 9 Mersey Place Luton, LU11HH Phone: 01582 722525	Dr. Shah 170 Ashcroft Road Luton, LU2 9AY Phone: 01582 727192
Dr. Howard & partners (addington Surgery 33 Manor Road Luton, LU1 4EE Phone: 01582 725673	Dr. Zaman 2a Malzeard Road Luton, LU3 1BD Phone: 01582 481700	Dr. Subramony 3 Medina Road Luton, LU4 8BD Phone: 01582 722475
Dr. Kanchandani & partners The Link Surgery 10 Wetherne Link Luton, LU11BE Phone: 01582 420788	Kingsway Health Centre 385 Dunstable Road Luton, LU4 8BY Phone: 01582 847808	Dr. McGill & partners 39 Castle Street Luton, LU1 3AG Phone: 01582 729242

**Luton & Dunstable Hospital
Departments:**

Paediatrics
Paediatric Reception &
Enquiries
Tel: 01582 497224

Gynaecology and Obstetrics
Switchboard
Tel: 0845 127 0127 ext. 2082

*Haematology and Blood
Transfusion*
Tel: 01582 497214

Diabetes
Diabetes Centre Receptionist
Tel: 01582 718050

**DISABILITY AND SOCIAL
SERVICES SITES:**

FRIENDS OF BRIGHT EYES
P.O. Box 2463
Luton, Bedfordshire
LU4 8WN
Phone : 07871 500 706

**The Disability Resource
Centre**
Poynters House
Poynters Road
Dunstable, LU5 4TP
Physical Disabilities team
Phone: 01582 470940

Alban Neve Deaf Association
49 Old Bedford Road

Luton, LU2 7NX

Fax Number Only:
01582 519124
Email:
info@andaluton.org.uk

Samaritans Luton
33 Cardiff Road
Luton, LU1 1PP
Phone: 01582 720666

Headway Luton
41 Cardiff Road
Luton, LU1 1PP
Phone: 01582 876729

Appendix 4 – Research Advertisements

RESEARCH STUDY

EXPLORING THE SOCIAL, GENETIC AND HEALTHCARE IMPACTS OF CONSANGUINITY

Doctoral Research being conducted through University of Bedfordshire, with NHS Ethics Approval



WHAT IS THE RESEARCH ABOUT?

Consanguinity refers to the marriage between cousins. This will be a qualitative case study and opinions will be sought from health and social services providers in focus group discussions about their knowledge and perceptions of consanguinity based on their experiences in dealing with patients/clients that were in a consanguineous relationship. The aim will be to explore the possible impacts consanguinity may have on healthcare, genetics and society. This study will also be beneficial in identifying possible gaps in policies and procedures for the care providers, with potential national and global implications.

WHAT DOES PARTICIPATION INVOLVE?

- Taking part in an approximately 90 minute long focus group discussion
- There will be two focus group discussions and you will be asked to take part in only one based on your service provision area (primary or secondary care)
- Participation is voluntary
- Information collected will be confidential
- Published results will be anonymised

WHO CAN TAKE PART?

You are eligible to participate if:

- You are a service provider such as a doctor, nurse, midwife, counsellor, social worker or clinical lead
- Your service area includes the local Luton community

WHOM TO CONTACT?

Mubesshir Ajaz
 PhD Researcher, University of Bedfordshire
 07775932925 (m)
 01582743738 (o)
mubesshir.ajaz@beds.ac.uk



For further information regarding NHS Ethics Approval for this research, please contact Diane Hardy in R&D at the Luton & Dunstable Hospital. For more information regarding the research itself, contact the chief investigator listed above or the Research Graduate School at the University of Bedfordshire.

MAKE YOUR VOICES HEARD ABOUT COUSIN MARRIAGE

Doctoral Research being conducted at the University of Bedfordshire



WHAT IS THE RESEARCH ABOUT?

We are interested in understanding your views on cousin marriage. We are asking people from Luton's Pakistani community to come and take part in a discussion about what they know and what they think about cousin marriage. We are asking people who are in cousin marriages to talk about their experiences and also people who are not in cousin marriages to give us their valuable opinion. The overall aim of this research is to understand cousin marriage and possibly improve healthcare services in Luton.



WHAT DOES PARTICIPATION INVOLVE?

- Taking part in either a 60-90 minute discussion or a 60 minute one to one interview
- Participation is voluntary
- Information collected will be confidential
- Same gender interviews can be arranged upon request
- Published results will not contain any names
- You will receive a £20 gift card for the **Acadale Mall** as a thank you for taking part in discussions

WHO CAN TAKE PART?

You are eligible to participate if you are:

- A Luton resident of Pakistani origin
- Aged 18 years or older
- Either married to your cousin or not married to your cousin

IF YOU ARE INTERESTED IN TAKING PART, PLEASE CONTACT:

Mubasshir Ajaz
PhD Researcher, University of Bedfordshire
07775 932 925 (m)
01582 743 738 (o)
mubasshir.ajaz@beds.ac.uk

For further information regarding Ethics Approval for this research, please contact the Research Graduate School and the Institute for Health Research at the University of Bedfordshire. For more information regarding the research itself, contact the principal investigator listed above.

Appendix 5 – Sample Information Sheet and Consent Form (Service Providers)



Participant Information Sheet

Service Providers

Exploring Consanguinity

I (Mubasshir Ajaz) would like to invite you to take part in a research study which forms part of my PhD. Before you decide, I would like you to understand why the research is being carried out and what taking part in it would involve for you. I will go through the information sheet again with you before the focus group discussion begins and you may contact me beforehand through phone (01582 743738 or 07775 932925) or email (mubasshir.ajaz@beds.ac.uk) should you have any questions. I would suggest that this should take no more than a few minutes. Talk to others about the study if you wish.

Please, ask me if there is anything that is not clear.

What is the purpose of the study?

Consanguinity is the term used to describe marriage between cousins. This is widely practiced around the world and it is also common among some communities within Luton. However, there are many misconceptions about consanguinity that are unhelpful in recognising some of the issues surrounding consanguinity. There have been inconsistent results in studies linking consanguinity to various medical conditions and genetic risks, with disparity in the levels of risk associated with children resulting from such marriages. Moreover, previous research has pointed at a possible disconnect between health services being offered that may be useful for a consanguineous population and the actual uptake and need of these services. Through this research, it is hoped to learn the views of those who deal with the health and social services of the local community. The goal is to learn as much as possible while also identifying areas in need of addressing.

Why have I been invited?

Service providers are at the forefront of treatment and care for consanguineous families. Their knowledge, perceptions and experience is vital to understanding the way in which services currently respond and should respond to people in consanguineous marriages. You have been identified as a service provider for health and social services in Luton, and I am keen to seek your knowledge, experience and perceptions of consanguinity, genetic disorders and disability care, based on your role as a service provider.

Do I have to take part?

It is up to you to decide. I will describe the study and go through this information sheet, which I will then give to you. I will then ask you to sign a consent form before the focus group discussion starts to show you have agreed to take part. You are free to withdraw at any time, without giving a reason.

What will I have to do?

You will be asked to take part in a focus group, which will have between 6 and 10 participants and will last approximately 90 minutes. Participants will be asked to discuss topics surrounding consanguinity, NHS and non-NHS services covering a range of areas including: knowledge of consanguinity, perceptions and attitudes about consanguinity, service uptake, and any improvements that may be needed in services.

Will my taking part in this study be kept confidential?

Focus group discussions will be tape recorded, transcribed and then coded for analysis. I will be responsible for transcribing the tape recordings. All names will be removed and false names (pseudonyms) will be used to ensure complete anonymity. The tape recordings will then be destroyed and all transcriptions will be kept on a password protected, desktop computer located at Putteridge Bury, University of Bedfordshire. Research notes that are kept will have no personal names, identifiable places, issues that can trace the conversation to you. Transcriptions will be stored for 10 years as per University of Bedfordshire research policy. Only I and the immediate research supervisory team will have access to read the anonymised transcriptions for reviewing and analytical purposes.

There is the risk that confidentiality may be broken by another member of the focus group as discussed, however, to minimise this, the researcher will highlight at the beginning of the focus group that what is discussed should remain confidential. Also, it is important for you to know that the researcher will be obliged to disclose personal information to the appropriate person if anything is disclosed at any time that would indicate someone is at risk of harm, or there has been some form of professional misconduct.

What will happen if I don't want to carry on with the study?

If you want to withdraw from the study then I will ask you if you want your data removed. If you do then all data attributed to you will be withdrawn. However, as it is focus group research it may prove difficult when trying to identify the person through the tape transcription. As such before

focus groups take place all participants will be asked for their names (either your true name or false) so that your voices can be matched.

What will happen to the results of the research study?

The results of this study may be published on the University of Bedfordshire website or by the researcher in a peer reviewed journal article. Findings may be disseminated at relevant international conferences. In this case false names (pseudonyms) will be used to ensure complete anonymity.

Who is organising and funding the research?

This research is sponsored by the University of Bedfordshire.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by NHS research ethics committee and by the local Research & Development Department at the Luton & Dunstable Hospital. Moreover, this research is reviewed regularly by the Research Graduate School at the University of Bedfordshire and has also passed the approval of the University Ethics Committee.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (see below). If you remain unhappy and wish to complain formally, you can do this through my supervisor Professor Gurch Randhawa, Director of the Institute for Health Research, University of Bedfordshire, who can be contacted on 01582 743797 or through email at gurch.randhawa@beds.ac.uk or through the NHS Complaints procedure.

Further information and contact details Mubasshir

Ajaz, BSc, MSc
 PhD Researcher
 University of Bedfordshire Putteridge
 Bury
 Hitchin Road
 Luton
 Bedfordshire LU2
 8DL
 T: 01582 743738
 M: 07775 932925
 E: mubasshir.ajaz@beds.ac.uk



Consent Form

Title of Project: Exploring the Social, Genetic and Healthcare impacts of Consanguinity

Name of Researcher: Mubasshir Ajaz

Please initial box

1. I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.

3. I understand that relevant sections of data collected during the study, may be looked at by my supervisors from the University of Bedfordshire. I give permission for these individuals to have access to these records.

4. I understand and consent that the focus group discussion is audio taped, transcribed and verified by the named researcher.

5. I understand and consent to the recordings and transcripts being stored on a University password protected computer held at Putteridge Bury campus, University of Bedfordshire. I also understand that the data will be kept in a locked office which can only be accessed by the named researcher.

I agree to take part in this study.

Name of Researcher

Date

Signature

Name of Participant

Date

Signature

Version 1

1

20th July 2011

Appendix 6 – Sample Information Sheet and Consent Form (Community Members)



Informed Consent Form

Informed Consent Form for local community members of Luton, who are invited to participate
in the study titled “Consanguinity: Exploring the Social, Genetic and Healthcare Impacts”

Principle Investigator: Mubasshir Ajaz
Organization: University of Bedfordshire
Supervisors: Prof. Gurch Randhawa, Dr. Nasreen Ali
Sponsor: Self-sponsored
Project: Exploring the Social, Genetic and Healthcare Impacts of
Consanguinity

This Informed Consent Form has two parts:

- Information Sheet (to share information about the study with you)
- Certificate of Consent (for signatures if you choose to participate)

You will be given a copy of the full Informed Consent Form

Part 1: Information Sheet

About me

My name is Mubasshir Ajaz, and I am a PhD student at the University of Bedfordshire. I am carrying out research to understand cousin marriages in our local Pakistani community. I will provide you with information about my research and invite you to participate in this study. If you would like any further information that you feel was not provided in this information package, please feel free to ask questions of myself or my supervisors, Prof. Gurch Randhawa or Dr. Nasreen Ali.

Why are we doing this research ?

Cousin marriage is common in different parts of the world, including Luton. However, there are many different opinions about cousin marriage that are unhelpful in recognising and addressing some of the issues surrounding it. Through this research, we hope to learn the views of the local Luton community to understand cousin marriage and possibly improve healthcare services in Luton to meet the needs of the local community.

How will information be collected?

In this research, you will either be asked to participate in a group discussion about cousin marriage which will last 60-90 minutes or you will be asked to participate in an individual one hour interview.

Why have you been asked to participate?

We have chosen British Pakistani members of Luton for this study as cousin marriage is common in the community and as such, you are the best source of information about this topic. We feel that your experiences and knowledge will really help us in filling the gaps in terms of knowledge, communication and services that are needed for the local community.

Voluntary Participation

Your participation in our research study is completely voluntary, and you may choose to not participate at any point before or during the research. You are also allowed to change your mind if you decide to not participate at a later time even if you had agreed earlier. You will receive a £20 gift card for the Arndale Mall as a thank you for taking part in discussions and adding to our understanding of consanguinity.

Confidentiality

This research will be completely confidential. All information collected will be kept in a secure location and when it will be published, all names will be replaced by aliases or numbers. All information collected within a focus group will be known only to focus group members and no one outside the group will be informed about the discussion from the research team.

Further Information

This research is being conducted as a PhD thesis and all results (confidential and anonymous) will be available through the University of Bedfordshire. If you feel that you require further information about the research topic and procedures, or if you wish to make a comment or complaint, please feel free to contact Prof. Gurch Randhawa (gurch.randhawa@beds.ac.uk) or Dr. Nasreen Ali (nasreen.ali@beds.ac.uk). You may also reach them via telephone at 01582 743797.

Part II: Certificate of Consent

I have been invited to participate in a study attempting to better understand cousin marriage in a social, genetic and healthcare context. I have read and I fully understand the information given above about the research. I have asked any questions that I had regarding the research and they have been answered to my satisfaction. I voluntarily consent to take part in this study.

Print Name of Participant _____

Signature of Participant _____

Date _____

Day/month/year

Statement by the researcher/person taking consent

I have presented the information to the potential participant to the best of my knowledge. I have ensured that the participant understands they have the choice to opt out of the study at any stage if they do choose to participate. Participants are aware that all information will be kept confidential and all results reported will be done so anonymously. I also confirm that the participants have had the opportunity to ask questions about the study and that they have been answered to their content. The participants have not been forced to participate and I declare no conflicting interest in undertaking this research.

Print Name of Researcher/person taking the consent _____

Signature of Researcher /person taking the consent _____

Date _____

Day/month/year

Appendix 7 – NHS Research Ethics Committee Approval Letter

NHS
National Research Ethics Service
NRES Committee East of England - Norfolk

Victoria House
 Capital Park
 Fulbourn
 Cambridge
 CB21 5XB

Telephone: 01223 597597
 Facsimile: 01223 597645

07 September 2011

Mr Mubasshir Ajaz
 PhD Student
 University of Bedfordshire
 Caretaker's House
 Institute for Health Research
 Putteridge Bury
 LU2 8LE

Dear Mr Ajaz

Study title: **Consanguinity: Exploring the Social, Genetic, and Healthcare Impacts**
REC reference: **11/EE/0359**

The Proportionate Review Sub-committee of the NRES Committee East of England - Norfolk Research Ethics Committee reviewed the above application on 05 September 2011.

Ethical opinion

The PRS Sub-Committee were unsure what the researcher would do if any of the participants were distressed through the course of the focus group. It was acknowledged that the participants are all professionals but the patient case study could potentially bring up any recent, distressing cases the professional is working with or has worked with. Members wondered if the researcher would feel confident in being able to deal with this and if further support would be available.

The researcher was contacted advised that if someone does become distressed and required further assistance, they will be referred to the hospital's Occupational Health and Safety Services (OHSS) team, who provide counselling services for staff. He also advised that he has had experience working in various cancer hospitals and with patients going through immense distress, as well as having sat in on several genetic counselling sessions and so believes that he is capable of dealing with such situations should the need arise and of course could refer to the OHSS team for further assistance.

Members were suitably reassured by this.

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

Ethical review of research sites

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

This Research Ethics Committee is an advisory committee to the East of England Strategic Health Authority
 The National Research Ethics Service (NRES) represents the NRES Directorate within
 the National Patient Safety Agency and Research Ethics Committees in England

the study (set3 "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

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

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

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

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

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

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

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

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

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.

Approved documents

The documents reviewed and approved were :

<i>Document</i>	<i>Version</i>	<i>Date</i>
Advertisement	1	20 July 2011
Evidence of insurance or indemnity	Letter from University of Bedfordshire	16 August 2011
Evidence of insurance or indemnity	Certificate- UMA L	01 August 2011
Interview Schedules/Topic Guides	Focus Group Topic Guide, 1	20 July 2011
Investigator CV	Mubashir Ajaz	16 August 2011
Other:Academic Supervisor CV	Professor Gurch Randhawa	16 August 2011
Participant Consent Form	1	20 July 2011
Participant Information Sheet	1	20 July 2011
Protocol	1	20 July 2011
REC application	Submission code 57376/241149/1/889	

Membership of the Proportionate Review Sub-Committee

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

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Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

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

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

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

Feedback

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

Further information is available at National Research Ethics Service website >After Review

11/EE/0359 **Please quote this number on all correspondence**

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

Yours sincerely

- <JA/c;£

ff

Dr Elizabeth Lund
PRS Sub-Committee Chair

Email: lynda.mccormack@eoe.nhs.uk

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

"After ethical review- guidance for researchers"

Copy to:

*Gurch Randhawa
R&D Room
120
University of Bedfordshire Putteridge
Bury
LU2 BLE*

*Ms Diana Hardy R&D
Luton & Dunstable Hospital NHS Foundation Trust
LewseyRoad
Luton
LU40DZ*

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NRES Committee East of England - Norfolk

Attendance at PRS Sub-Committee of the REC meeting on 05 September 2011

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Mr Ron Driver	Lecturer/Statistician	Yes	
Ms Leanne Groves	Psychological Therapist/Occupational Therapist	Yes	
Mrs Pamela Keeley	East Anglian Eye Bank Nurse Manager	Yes	
Dr Elizabeth Lund	Research Scientist	Yes	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Mrs Lynda McCormack	REC Co-ordinator

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