BAME NEEDS ASSESSMENT WEST SUSSEX: COMMUNITY ENGAGEMENT

THE YOUNG FOUNDATION
THINKING ACTION CHANGE

November 2015

ABOUT THE YOUNG FOUNDATION

We are The Young Foundation and we are determined to make positive social change happen. We believe inequality undermines the economy and corrodes our wellbeing, leaving its mark on communities, relationships, aspirations and self-worth.

The Young Foundation is working to create a more equal and just society, where each individual can be fulfilled in their own terms. We work with the public and private sectors and civil society to empower people to lead happier and more meaningful lives.

We believe little about the future of society is inevitable. Bound by our shared humanity, we believe we collectively have the power to shape the societies and communities we want to live in. We work closely with individuals, communities and partners building relationships to ensure that our thinking does something, our actions matter and the changes we make together will continue to grow.
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Our team

This project was managed by The Young Foundation and delivered in conjunction with a team of Community Researchers working with us. Special thanks must go to the Community Researcher team who worked hard to identify participants, carry out interviews and contribute to the analysis and without whom this project would not have been a success. They are: Paola Casati, Harjinder Chohan, Celeste Chung, Jignesh Gadhvi, Sabah Kaiser, Anikó Kormendi, Vignes Sivapathasuntharam, Lina Soblyte, Iryna Smith, and Maria Spiewak.

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EXECUTIVE SUMMARY

This summary reports the results of an independent community engagement and research study carried out as part of a Needs Assessment for Black, Asian and Minority Ethnic (BAME) groups within West Sussex.

The work was delivered by The Young Foundation, using a participatory approach with community researchers. Over 100 people from BAME communities were engaged with expert support from The Young Foundation. Community researchers also contributed to the analysis of the data and reviewed the final report.

The research had four main aims:

- to obtain a detailed understanding of the wellbeing and health and social care needs of the BAME population
- to identify gaps in service provision and the extent to which existing services meet the needs of the population
- to determine the barriers and enablers to accessing services and exploring what changes are required in order for those barriers to be overcome
- to identify priorities for action and indicators for monitoring progress towards change.

The findings and recommendations are summarised under four key areas of focus: Life and wellbeing in West Sussex; Using health and social care services; Tackling taboos (mental health and domestic abuse); and Community assets.

Findings

Life and wellbeing in West Sussex

West Sussex is broadly perceived to be a peaceful, safe and stable area in which to live and raise a family, benefiting from close proximity to scenic countryside and coastal areas. That said, many newer arrivals are feeling the effects of the housing shortage. The area has experienced considerable change as a result of immigration, particularly in the larger towns, and there is a sense from many people that the area has adapted in response

Although there were a number of positive aspects identified from the groups interviewed, a number of barriers and challenges remain.

There is largely a strong sense of belonging and integration with local society, with many actively involved in cultural and religious groups which help to reduce isolation and foster a sense of belonging. Conversely, many others feel more isolated and separated, with proficiency in English identified as major determinant of isolation. This is compounded by a lack of free or affordable local English classes.

Time constraints or a lack of access to transport, particularly in communities where there is a high prevalence of shift and night work, also hinder integration. Discrimination and racist abuse in public were reported, although described as isolated incidents caused by individual ignorance. Specific services were highlighted as sources of repeated discrimination, including a specific GP practice was and the care

home sector.

Local schools are perceived to be very good, with many praised for providing additional support to students for whom English is a second language. Concerns were raised by Eastern European families, about racist bullying in secondary.

Perceptions of the police differ significantly across communities; with Eastern European community attitudes shaped by negative experiences in home countries. Among the Asian community in Crawley perceptions have been shaped by a spate of crime directed at this group.

When problems arise, Citizen's Advice Bureaux are generally well-known and well regarded.

Recommendations

Commissioners of public services, (such as local authorities, the police, NHS England and clinical commissioning groups) should:

- Increase provision of and access to high quality, affordable English language and citizenship courses.
- Enhance support (including physical space and service based support) for formal and informal community groups.
- Embed a strategic approach in policy and services to target those most vulnerable and hard to reach.
- Work with community groups and informal networks to disseminate key information about health and social care services.
- Commit further resources from Sussex police to focus on building and improving relationships with some BAME communities.
- Work with head teachers and boards of governors to identify and tackle racially motivated bullying in schools.

Using health and social care services

Perception of health care services are typically shaped by experience of health systems in "home" countries, where, for those who can afford it, the service is more comprehensive and efficient, when compared with the NHS. Specifically, widespread dissatisfaction with GP services was reported.

The standard of dental care is considered to be poor. It is not uncommon for people to access more affordable and better quality services abroad.

Language barriers present a major challenge for accessing health and social care. On the whole, the majority suggest they neither want nor expect services to be tailored to the specific needs of their community. Their expectation is simply that they should have access to the same quality of services as the majority community. However, there are some specific religious/ cultural needs that some groups feel should be respected and accommodated.

Recommendations

Commissioners of health and social care services should;

- Embed active anti-discrimination policies and training at the core of procurement practices.
- Ensure that providers of residential care homes and home-care services are held accountable for discrimination in their services.
- Undertake, along with BAME community representatives, a review of culturally sensitive catering provision.
- Develop guidance for best practice at all points of contact with primary, secondary and social care services for those with language and communication barriers.
- Consider how the 999 emergency service system can better enable people to communicate with them, where there are language barriers.
- Ensure that there are clear and robust safeguarding mechanisms for safeguarding those with particular vulnerabilities and cultural needs.

Providers of health and social care, and voluntary services and the workforce should;

- Raise awareness of existing interpreting services to anyone for whom English is not their first language.
- Review provision of out-of-hours services.
- Ensure that GP surgeries mitigate the problems that could arise from accessing care.
- Ensure that services take into account the proportion of the BAME population who might require English language support.
- Ensure that information leaflets in GP surgeries are available in a wide range of languages.
- Work with BAME patients accessing care to manage expectations about the care they will receive in local health systems.
- Work with BAME social care service users to ensure that there is clarity and transparency in communicating what services people are entitled to.
- Increase visibility, availability and accessibility of talking therapies for mental health conditions for those for whom English is not their first language.

Tackling taboos (mental health and domestic abuse)

Many people with mental health problems continue to face stigma. Stigma has its roots in traditional attitudes and cultural beliefs, which vary among the different ethnic groups.

Religious and cultural leaders are generally considered to be poor at offering appropriate support for mental health issues, although at times they may play a role in signposting to local services.

Domestic abuse is often a source of shame and subject to high levels of secrecy. Reporting of domestic abuse is seen as an action of last resort and often only dealt with in the family, or in the immediate community, if at all.

Recommendations

Commissioners, providers, voluntary and community services and frontline staff should:

- Continue efforts to engage cultural and religious community leaders around supporting communities to deal appropriately with sensitive issues.
- Work together to create local campaigns and awareness raising activities.
- Increase support to the Voluntary Community Sector (VCS) to proactively engage BAME communities.
  Co-ordinate local activity with existing national anti-stigma campaigns.
- Ensure that training on domestic abuse and how immigration/residency status may affect disclosure is embedded into practice.
- Provide local leaders with evidence based and evaluated tools and resources to enable them to use opportunistic approaches to introduce sensitive issues in an appropriate way.
- Identify opportunities to approach and empower young people to champion change and raise awareness.

Community assets

Meeting places, local groups, neighbourhood activities and religious institutions provide important spaces and opportunities for people to socialise, and build social networks; which foster a sense of belonging and prevent feelings of isolation. They can be particularly important in maintaining the cultural and religious links that provide crucial support.

The community assets identified by the residents of Crawley mainly serve the Asian and Western European populations. Among the Asian community, assets such as religious and cultural institutions and groups are highly represented. In contrast the assets named by the Western European community are locations such as Tilgate Park, sports facilities, bars, restaurants and coffee chains, which provide spaces for making and meeting friends.

The residents of Bognor Regis identify fewer community assets, on the whole, but certain places are mentioned frequently, demonstrating their integral role in community life.

More than any of the other populations, Worthing residents cite the importance of their local library.

Recommendations

Commissioners and providers should:

- Consider investing in further asset mapping which may reveal clearer trends in the types of community assets utilised and hence offer opportunities to better target outreach work to different communities at ground level.
- Explore opportunities to capitalise on community assets as potential routes for health and public services to engage with specific groups.

CONTEXT

Over the course of 2014/2015, West Sussex Public Health Research Unit has been carrying out a Needs Assessment for Black, Asian and Minority Ethnic (BAME) groups within West Sussex. This forms part of the Annual Work Plan for the Health and Wellbeing Board and is one of several Needs Assessments for Health and Social Care.

The Needs Assessments combine epidemiological, corporate and comparative approaches as well as ensuring that members of the community have a prominent voice and opportunities to provide insights gained through their lived experience. The findings of the BAME Needs Assessment will inform future commissioning of health and social care services by Local Authorities, CCGs and NHS England across the region.

The purpose of this health and social care needs assessment is:-

- To examine current and estimate future health, social care and wellbeing needs of all distinct BAME communities currently residing in West Sussex;
- To identify existing services and provision in the community, primary and acute sector;
- To identify gaps in services or barriers to services including opportunities for prevention and building resilience;
- To identify provision of services against national guidelines / performance;
- To identify any staff training needs;
- To explore the occurrence of discrimination in the health and social care system and the level to which it deters service users from engaging with primary care and prevention strategies.

The majority of the BAME Needs Assessment was completed by Spring 2015, including extensive literature reviews, comparative work with neighbouring local authorities, a call for evidence, and consultation with stakeholders, commissioners and professionals as well as engaging with third sector organisations.

The evidence gathered uncovered a wide range of issues and themes including:

- Lower levels of engagement with many services, and a lack of trust in many public services;
- Particularly low levels of service take-up for dementia, learning difficulties and from the voluntary sector;
- A lack of culturally specific adult services;

- In other areas, a strain on services is noted, such as family services in areas with high numbers of migrants due to generally younger family structure
- The data also shows a significantly higher use of A&E services by some BAME groups;
- Challenges to service usage (including advice and support) include language barriers and gaps in outreach work and difficulties reaching groups with no established community groups;
- There are also some reports of experiences of prejudice, including hate crime, across West Sussex which affect overall levels of wellbeing.

An important part of the Needs Assessment is to listen to local residents from BAME communities and ensure that their voice is heard and understood so that the final output truly reflects the diversity of their views and experiences, and their future needs. This community engagement phase forms the basis of the research.

Community engagement objectives

At the heart of this community engagement was the need to identify those issues which are particular to certain communities within the BAME population, and that arise directly or indirectly as a result of specific ethnic, cultural or religious factors. The focus was on identifying gaps in services, barriers to accessing services, issues relating to staff training and issues of discrimination which are above and beyond those experienced or perceived by the wider non-BAME population. The aim was also to understand this information in the context of people's overall experience of living in West Sussex, and the implications of their experiences and perceptions of services for their overall wellbeing. We also wanted to gain some understanding of the community assets which people draw upon to help maintain their wellbeing and/ or improve their engagement with services.

Specifically, the objectives of this research can be summarised as:

- Obtaining a detailed understanding of the wellbeing and health and social care needs of the BAME population, testing and expanding the themes identified in the earlier phases of work;
- Identifying gaps in service provision and the extent to which existing services meet the needs of the population;
- Determining the barriers and enablers to accessing services and exploring what changes are required in order for those barriers to be overcome;
- Identifying priorities for action and indicators for monitoring progress towards change.

APPROACH

The overall research approach was defined by a number of factors: a need to uncover detailed and nuanced insights; the requirement to engage with a truly diverse group from across the various BAME communities within West Sussex, including in languages other than English; and a desire to ensure that the community engagement, was participatory in nature and reached beyond those who regularly contribute to public consultation and research. This latter point formed an essential part of the design as voluntary and community sector organisations and other established stakeholders had already been invited to share their views in earlier phases of the Needs Assessment. A qualitative research approach delivered in conjunction with a team of Community Researchers was selected as the optimum approach.

The community researcher team

An initial free, one-day course on community research was held by The Young Foundation and advertised through various channels across the region. This gave attendees the opportunity to understand more about the role and for their skills to be assessed. The Young Foundation recruited 10 of the15 attendees as paid Community Researchers for this project. The team then attended a second intensive day of training and were provided with weekly support and guidance by The Young Foundation team, including further face-to-face interim debrief days.

The team comprised individuals from Eastern and Western Europe, and several different Asian communities. Unfortunately, despite extensive outreach efforts, it was not possible to recruit a researcher from the Black African or Black Caribbean communities, although several Black African and Black Caribbean residents were interviewed. Collectively they speak fifteen different languages fluently: Bulgarian, Lithuanian, Polish, Hungarian, Russian, Ukrainian, Italian, Spanish, Gujarati, Hindi, Tamil, Urdu, Punjabi, Mandarin and Cantonese.

Qualitative methodology

Individual interviews were selected as the main method for research: they are appropriate for the relatively sensitive and personal nature of many of the issues to be covered, are more appropriate for the Community Researcher team in terms of the skill level required, and facilitate the capture of the greatest level of nuance and detail. It also ensures that a wide range of people can be included in the research at a time which is most convenient to them. In addition, three focus groups were conducted, led by The Young Foundation team.

A discussion guide was developed by the West Sussex Public Health Research Unit based on the existing evidence review and further refined in conjunction with The Young Foundation. The guide can be found in Appendix I. The final activity included in the interviews was a light-touch "asset mapping" to help uncover some of the local resources and tacit knowledge within the community which help people to maintain their health and wellbeing. It should be noted that the discussion guide covered a large number of topics and it was known from the outset that it would not

be feasible to cover all questions in every interview. Less information has been captured on social empowerment and influence, and asset mapping, both large topics which interviewers and interviewees found difficult to cover in the time available. Interviews typically lasted just over an hour, but some stretched to two hours.

Sampling

A sampling plan was developed based on the available Census data relating to the BAME population of West Sussex (see Appendix 1 for further detail). The plan set out loose allocations based on specific ethnic and linguistic groups across three priority areas identified by West Sussex Public Health Research Unit: Arun District, Crawley Borough, and Worthing Borough.

Individual research participants were identified by drawing on the local knowledge of Community Researchers who used multiple routes to reach these individuals including via temples, mosques, community centres, advice centres, and social clubs, and by building relationships with local businesses, cafes and restaurants that serve particular communities. This represents one limitation of the research – peer researchers were not always able to engage people from a full cross-section of BAME communities but all groups have been included. BAME populations are significantly younger than the general population, and so engaging older people proved to be the most challenging, along with men. However, all groups have been represented in the research and those in their 50s and early 60s also spoke of their experiences caring for older relatives to provide greater insight to those issues. All participants in the research were thanked for their time with a £20 shopping voucher.

Profile of research participants

A total of 116 West Sussex residents participated in the research. Table 1 provides the breakdown of participants by West Sussex region and Table 2 by age and gender.

Table 1: Research participants by region

	Arun District	Crawley Borough	Worthing Borough	Total
Asian	5	33	6	44
Eastern European	17	1	6	24
Polish	9	4	1	14
Other European	2	5	5	12
Black	4	7	3	14
Mixed/ other	2	2	4	8
Total	39	52	25	116

Table 2: Research participants by age and gender

	18-24		25-64		65-74		75+	
	M	**F**	**M**	**F**	**M**	**F**	**M**	**F**
Asian	-	1	10	22	4	3	3	1
Eastern European	-	-	7	17	-		-	-
Polish	-	1	3	8	-	2	-	-
Other European	-	1	6	4	-	1	-	-
Black	-	1		13	-	-	-	-
Mixed/ other	1	-	1	6	-	-	-	-
Total	1	4	27	70	4	6	3	1
	5		97		10		4	

Analysis

Interviewers wrote up detailed 'notes and quotes' of each interview which was analysed to identify salient themes, drawing on a grounded theory approach, which allows for the emergence and production of theories through the data and involves continual comparisons across cases, coding and identifying themes systematically. Two intensive group analysis sessions were also held with the Community Researcher team to debate emerging themes and findings, and add additional context and nuance from observations. The final report has also been reviewed by the full team.

This community engagement exercise produced rich and detailed data. Below we summarise the key findings of the research, looking at four major themes in turn:

- Life and wellbeing in West Sussex
- Using health and social care services
- Tackling taboos (mental health and domestic abuse)
- Community assets

FINDINGS

Life and wellbeing in West Sussex

Integration, Community and Isolation

Perceptions of West Sussex as a place to live and bring up a family tend to be largely positive with residents talking about the area as quiet, safe, and stable, and enjoying its natural features such as proximity to the sea and countryside.

Whether residents feel "integrated" into life in West Sussex depends very much on how long they have been here – our sample included second and third generation immigrants who have lived here all their lives and individuals who may have moved to the UK in the past few years, perhaps leaving spouses and children behind.

It is important to note that individuals were able to define and interpret 'integration' as they felt appropriate. Integration is not the same as assimilation. There are some individuals who feel strongly that they are part of a community made up of people from their national, cultural, or religious background, for example, and who feel that their social needs are fulfilled. Feeling part of **a** West Sussex community is not necessarily the same thing as feeling assimilated into the majority West Sussex community and culture.

Experiences of integration, community and isolation are complex and as a result, experiences and perceptions of integration and isolation differ considerably from person to person. While feelings of isolation are most prevalent amongst those experiencing language barriers, they can also be felt by those with a good level of English. Other factors which have a direct impact upon feelings of isolation and integration, and the extent to which people feel part of a community include the strength of family relationships and presence of family members in the local area, and the presence of cultural, religious or community infrastructure. One older woman described the television as her main form of company and couldn't name anywhere she goes except church and a local shop to call her sister back in Zambia, despite speaking English fluently. Another Ghanaian woman stated that whilst she is aware of a Ghanaian community group this is not something that she has ever attempted to engage with.

> Tamara is from Latvia and has been living in W. Sussex for almost a decade with her husband and two children. She likes the peace and quiet of the area and the fact it's safe for her family. She also likes that there are lots of independently owned businesses and the area hasn't lost its identity. Tamara has a high standard of English and often helps friends with translating their letters and paying their bills.

Additionally among some groups the kinds of work available may have an impact

upon time available to maintain social relationships, for example the large numbers of BAME residents who engage in shift work may find this difficult. Lack of time was also given as a reason why some people may find it difficult to learn English: *'I have a Russian speaking friend- who has 5 children and with such a big family does not have time to learn English- who feels isolated'* (Female, Estonia, 25-64). This in turn may contribute to a lack of ability to "integrate" and therefore to forge links within communities and engage with health and public services.

Occasionally negative comparisons are made between the overall sense of the community felt in the UK compared to that in home countries: *'people could live here all their lives in one house and still not know all the neighbours that surround them'* (Female, South African, 25-64). There is also some reference to difficulties engaging with the local population. This is particularly the case for those from Western Europe, who perhaps have higher expectations about how integrated they might feel: *'I'm a bit disappointed because I found it's very hard to make friends with English people. It's weird to live in a country where I don't have a close relationship with any local people".* (Male, Spanish, 25-64). Another states: '*it's difficult to make friends with local people, so with resignation I have to say it's almost impossible'.* (Male, Italian, 25-64).

Residents from Eastern European communities also tended to point out subtle ways they felt unwelcomed by local people. One comments that she feels 'aversion' from the other mothers in the playground (Female, Polish, 25-64); another notices that English parents at the school gate don't tend to say hello to her. Some people reported that it can be difficult to determine whether the difficulty of engaging with the local community is due to discrimination or because of peculiarities of British culture. One Georgian man (Male, Georgian, 25-64) , who has previously lived in Portugal, reported that he feels worried by the 'cold' attitude of those around him, particularly compared to his experience of Portugal. He wonders whether this is because British culture is colder or more distant.

In a similar vein, some Ugandan community residents suggested that, in Britain, the amount of time that people spend on their social relationships suffers as a result of a lack of time. *'In Uganda you can never be alone in your house for more than five minutes…it's a good thing.*' (Female, Uganda, 25-64), *'I think people don't spend too much time together in the UK because they all work very hard.'* (Female, Uganda, 25-64).

Language Barriers

Language barriers play a key part in levels of integration and this is particularly true for the Indian, Pakistani and Eastern European communities: *'it's hard for me – I can't do the simplest of things like do my shopping because I don't understand and people don't understand me – it's a lonely place to live without a common language'.* (Male, Indian, 25-64). Language barriers can have many impacts upon wellbeing including upon self-worth. Some residents explained that being unable to communicate effectively in English leaves them feeling embarrassed. One Hungarian woman described her attempt to get a national insurance card. The representative from the formal interpreting service that she made an appointment to use failed to turn up and this meant that she was left trying desperately to communicate in a language that she didn't understand. It left her feeling *'embarrassed and ashamed'* (Female, Hungarian, 25-64).

She stated that, now, when she has to do errands or go to the shops, if her husband is unable to accompany her, then she simply will not go.

Language has a significant impact on how people can engage both with public services and with the community at large. Indeed several respondents, particularly among the Polish and Eastern European communities, emphasised the importance of learning English if one wants to integrate and use public services. One Indian man stated that all people need to make an effort for integration to take place. It is not just the responsibility of the wider community to welcome, he argued, minority communities also have to make an effort to integrate (Male, Indian, 25-64).

The availability and quality of English language lessons is an important route to tackling obstacles to integration. Availability of these seems to be highly variable; one Latvian gentleman had two significantly different experiences. In one case his son's first school helped him a great deal by providing him with one-to-one language lessons. In another case he found that a language class he signed up to was conducted entirely in English: *'Try to understand an explanation of something difficult about a language you do not speak given in that same language which you are struggling to learn! We are not used to this system of teaching.'* (Male, Latvian, 25-64). The scarcity of affordable or free language courses from local providers is a major barrier for many people.

Those organisations that assist people with translating or interpreting are highly valued. Many people report needing help with everyday issues like applying for jobs or dealing with the welfare system. 'Connecting Communities'[1] was noted by members of the Eastern European community as a particular help when wanting to translate official letters or documents.

Presence of cultural and religious community links

Religious and cultural groups make an important contribution towards wellbeing for some communities. Among Tamil and Eastern European communities, the existence of cultural spaces and schools provide an important link to heritage and seem to be highly valued. For example the Tamil school at Hazelwick School and the Bulgarian and Polish schools are frequently mentioned as important 'hubs' for these communities. There is also some suggestion that the existence of these forms of cultural infrastructure might contribute to greater understanding and recognition of particular groups. For example, one man commented about the Sri Lankan community that: *'Overall the services have very much improved, culturally everything has vastly improved.... [before] we didn't have temples, we didn't have anything...people are well informed...yes you will get ignorance here and there and get remarks, but a lot has changed'* (Male, Sri Lankan, 25-64).

Madhu has lived in West Sussex for over 20 years and is an active member of the Tamil community. She enjoys attending events such as singing and dancing at the School. Madhu also regularly attends the temple which she finds is a great place for people to socialise, exchange information and learn about services that could be of help.

[1] Connecting Communities is a service run by Voluntary Action Arun & Chichester which helps local residents whose main language is Polish, Lithuanian or Russian, to access services, to help local service providers improve access to their services and to support integration. The Centre hosts CAB sessions, provides phone interpreting and written translations. It is currently at threat of closure.

Gaps in cultural provision were also noted as a problem by some – in particular shops selling goods from home countries and the lack of an Orthodox church in West Sussex: *"I drive and would go anywhere in West Sussex to be able to pray, light a candle for the health of my family in Estonia and to simply stand in silence in our church, where even the walls give you support"* (Female, Estonian, 25-64).

Key findings: Integration, Community and Isolation

- Perceptions of West Sussex as a place to live and bring up a family tend to be largely positive with residents talking about the area as quiet, safe, and stable, and enjoying its natural features such as proximity to the sea and countryside.
- The extent to which an individual feels isolation or integration is dependent on a range of factors and how those factors interconnect. These factors can include: language ability; cultural and religious community connections; relationships with family; and practical constraints.
- Proficiency in English can be a major determinant of isolation but the effects of this can be mediated to some extent through strong religious or cultural community ties and by family. The scarcity of free or affordable local English classes is a barrier to integration.
- Local connections, particularly to cultural and religious groups, can and do reduce isolation and foster a sense of belonging.
- Access to public services is dependent on the knowledge and skills of the family and community of those around an individual. It is not necessarily addressed by increase in local connections alone.

Experiences of discrimination

West Sussex has experienced considerable change as a result of immigration, particularly in the larger towns, and there is a sense from many people that the area has adapted in response. Several in the Indian and Pakistani communities note that the local area has become 'more accepting' and minority groups are 'becoming more a part of the community'. Similarly, one woman from Poland feels there is a '*big tolerance for foreigners'* (Female, Polish, 25-64) in the area while another from Ghana notes that *'I don't feel 'different' because of my background; people are generally very accepting and tolerant here'*. (Female, Ghanaian, 25-64). Another comments, '*with the high Black population in West Sussex, especially in Crawley...[people] have become more tolerant'* (Female, Gambian, 18-24).

Across all ethnic groups, there are reports of isolated incidents of feeling discriminated against in public. Indian and Pakistani respondents talk about examples of shouts of abuse from young people and disturbances after pub closing time. There is one instance of violent assault experienced by a Polish man: '*They walked across the road and just punched me in the face because they heard we were speaking Polish*'. (Male, Polish, 25-64) However, these kinds of incidents seem to be relatively rare. More common are reports of perceived subtle discrimination from public facing workers such as GP receptionists, bus drivers and people working in local council buildings. Many BAME people prefer to tolerate this 'everyday discrimination' as individual ignorance rather than institutional racism: *'Most of the people who are racist are not educated or have not travelled'* (Female, Ugandan, 25-64).

However, feelings about discrimination are complex. For example, a number of people from the Black community began the discussion about discrimination with initial positive statements made about tolerance and lack of racism. However, further on in the conversation contradictory examples were offered. A Ghanaian woman who spoke of tolerance also felt that the Black community is still perceived as a threat or 'troublemakers', commenting: *'[with a] Black African background, you are more likely to be stopped by the police or if you are in a group in an area you are most likely to be seen as you are doing something bad or [posing] a threat to individuals'* (Female, 18-24, Gambian). Another woman who describes herself as feeling very much part of the community now also noted that she didn't feel people in Worthing were used to minority groups, commenting *'I see the way people look at me'* (Female, South African, 25-64). Some people demonstrated a willingness to accept some levels of discrimination as inevitable: '*yes you will get ignorance here and there and get remarks, but a lot has changed'* (Male, Sri Lankan, 25-64).

It may be that Black people in West Sussex seek to maintain a positive stance, to focus on those experiences that support their sense of belonging and are resigned to a certain level of racism: *'I am used to racism... If I let racism affect me I would not move, I try my best not to be affected because there is no point'*. (Female, Namibian 25-64).

Many reports of discrimination in West Sussex appear to be based on random encounters. There were two clear examples, however, of more systematic, institutional racism. One is the experiences of some members of the Eastern European community who felt that one GP surgery systematically discriminated against foreign people with onerous conditions attached to surgery registration and misleading information about translation services.

The other example concerns an apparent issue specific to local care homes for both Asian and Black African workers: '*if you make a complaint, the English people stick up for each other even if they know they are wrong, so people like me have no hope'* (Male, Pakistani, 25-64). Several Black women working in care homes experience ongoing problems with their supervisors not taking the problem of racism against them, by the elderly residents and their

Anna is in her 40s, from Bulgaria, and has been living in Bognor Regis for less than 7 years with her husband and children. She feels that she has been subject to discrimination and that this has had a negative impact upon her job prospects. She would apply for all kinds of jobs but every time she mentioned her name, it seemed, the job was no longer available: "You just stop applying ... you stop trying and lose your confidence".

families, seriously. For some this has significant implications, for example one person explained that she changed her shift patterns to work at night to avoid interacting with families, many of whom didn't want to talk to her about their relatives. Another felt that the treatment she had from supervisors when she made a complaint was just as upsetting as the racial abuse itself. She concludes, '*the care home industry has a big problem with institutional racism, both in the private care homes and those funded by the NHS*' (Female, Namibian, 25-64).

Key findings: Discrimination

- West Sussex has experienced considerable change as a result of immigration, particularly in the larger towns, and there is a sense from many people that the area has adapted in response
- All BAME groups reported incidents of discrimination and/or racist abuse in public.
- Generally, there is a preference for describing the discrimination they encounter as isolated incidents caused by individual ignorance rather than something more systematic.
- In the care home sector some staff report high levels of discrimination from managers, residents and residents' families and feel disempowered to take any action.

Experiences of Public and Voluntary Sector Services

Experiences of public and voluntary services are very mixed and reflect a wide diversity of types of engagement with a broad range of services. Some services, however, are mentioned with greater frequency: public transport; schools; the Police; housing; and the Citizen's Advice Bureau.

Public transport

Public transport is mentioned a lot and generally there are positive comments about the frequency and quality of services: '*the transport services have improved a lot in the last 20 years*' (Male, Sri Lankan, 65-74). Some mentioned proximity to Gatwick airport as contributing to good provision of trains. Public transportation is a particularly vital service for older people in the Asian community, especially women, who rarely drive.

It is, however, felt to be expensive. One resident complained, for example, that the price for a short bus ride is the same as a long bus ride and that there is a general lack of flexibility on bus tickets (Male, Indian, 25-64). Another stated '...if it was a bit cheaper, probably more people would use it' (Female, Bulgarian, 25-64). There can also be comparisons to other places people know or have lived; *'If I lived in London I would have a bus pass by now but unfortunately not in Sussex because they have increased the retirement age for you to be entitled to have a free bus pass*" (Male, Sri Lankan, 25-64).

Schools

Schools are felt to be of good quality and improving. The high standard of education is an important reason for relocating to or remaining in the area for many families. Despite this, differences between experiences of education systems in 'home' countries and in the UK are, a source of concern for some residents. This seems particularly true in the Eastern European community. One resident feels that nurseries in the UK are not as good, stating that in Latvia they are open for longer hours, offer more structure to children's routines and they are not as expensive (Female, Latvian, 25-64). While the state provision of 15 hours of nursery care per week for children over three is viewed positively, people feel this is inadequate and that nursery services care is generally very expensive. One woman from Hungary explains that her 2 year old is not in nursery because the price is too high for her to manage. As a result of this she and her husband have to struggle to juggle their work commitments to ensure that they are able to be there for their child (Female, Hungarian, 25-64).

People across communities are broadly positive about the secondary school provision available. Many feel that additional provision for children who struggle, particularly as a result of language issues, is very good. One parent from Mauritius commented: *'My kids are so behind with education- they give them good support. They do their best to help my kids'* (Female, Mauritian, 25-64). Some residents commented that the schools try hard to cater to religious and cultural needs and that they seem interested in learning about the experiences that the children had in their native countries.

However, experiences were not universally positive. Some parents, particularly from the Eastern European community, are concerned about bullying in the schools and issues around drugs. Many cited examples about children experiencing racist bullying at school and in some cases this has caused considerable distress. One parent described how her son was bullied by a boy at school who called him a *'bloody foreigner'*. Her son got into a fight with the bully and was disciplined as a result. It was only after a dialogue between teachers and the parent that the bullying actually stopped: *'The first few years were difficult…there was a lot of crying. The children just wanted to go back to Bulgaria.'* (Female, Bulgarian, 25-64). While schools appear to take action against bullying when it is brought to their attention, some parents feel that schools are not proactive enough in the way that this problem is dealt with.

The Police

There are a number of positive experiences of engaging with the police but there are also examples of distrust. There has been a major series of robberies targeting the Asian community in Crawley. These robberies appear to involve Asian residents being specifically targeted as a result of the perception that Asian people keep large amounts of gold jewellery in their homes. Although most feel that the police are quick to respond to 999 calls and welcomed police engagement events, some feel they still do not take the problem seriously enough, '*they see it as an Asian Community problem'* (Female, Pakistani, 25-64). A lack of arrests for the robberies is seen as a clear indicator of its low priority for the police. This is having a knock-on effect with many Asian people, particularly older residents, becoming fearful and distrusting of callers and offers. For example, people are not taking up their entitlement to free home insulation because they fear that it is just a scam to gain entry to homes and that they are being specifically targeted as a result of their ethnicity.

Many in the Eastern European community also report not trusting the police but admit that this could have to do with attitudes towards the police in their own country. However, the 'Polish Policeman' in Bognor Regis is seen as a port of call for many in the Polish community.

Housing

There is a well-documented chronic shortage of housing the UK but finding adequate housing has been a particular issue for many in the Eastern European community. This has knock on effects for access to other services like healthcare: "*we cannot get a flat from landlord and agency because we do not have a permanent job and a contract from work, and as we cannot get a contract from the landlord, we cannot register with a doctor*." (Female, Eastern European, 25-64).

For many new migrants it is the process of finding a home when just moving to the country that is difficult. The complex issues of finding work, saving money for deposits etc. and understanding social housing systems can make housing a major challenge: *'It was difficult to find somewhere to live rent is very high.'* (Female, Indian, 25-64). One Bulgarian woman described how, initially finding a flat to live in was '*impossible'.* At first they lived with a friend who was going to help them set up a business but bureaucracy got in the way their friend backed out and they had no work and no money. (Female, Bulgarian, 25-64).

Citizen's Advice

Perceptions of the Citizen's Advice Bureau (CAB) are often dependent on the outcome of the interactions that residents had previously had. Where people had been to see the CAB, and they had not been able to solve their issue, the service is viewed negatively. One Pakistani gentleman stated that he had been to the CAB in order to sort out an incorrect gas bill but that they had ultimately not been able to solve the problem and he was left paying significant amounts of money. This left him with a poor view about the service: *'I have been to Citizen's Advice Bureau twice and I don't think they are a very helpful service.*' (Male, Pakistani, 26-64).

However despite some negative experiences, general perceptions of the Citizen's Advice Bureau appear to be very good. Residents cited them repeatedly as a place to go in order to access advice and assistance on a variety of topics from legal services to domestic abuse: *"if someone I knew was getting domestic abuse I think they would go to counselling or citizen advice bureau or social service"* (Male, Malaysian, 25-64). Many new residents also found that the CAB provided useful assistance in negotiating an unfamiliar legal procedures and systems: *"They do work hard, and it's nice to have the legal advice from a person who's actually knowledgeable and you feel more secure."* (Female, Belgian, 25-64)

Key findings: Experiences of Public and Voluntary Sector Services

- Experiences of public and voluntary services are very mixed and reflect a wide diversity of types of engagement with a broad range of services.
- The education system is perceived to be very good and a local asset. There have been particularly positive experiences of schools providing additional support, particularly for those students for whom English is a second language. The issue of racist bullying in secondary schools is a key concern for Eastern European families.
- Perceptions of the police differ significantly across communities.
    - In the Eastern European community perceptions are shaped by experiences in home countries. This often means people feel suspicious of the police and reluctant to engage with them. This appears to have been combatted to some extent among the Polish community in Bognor where a 'Polish Policeman' has established strong links
    - Among the Asian community in Crawley perceptions of the police have been shaped by a spate of crime directed at this group. Whilst the community appreciates outreach the fact that culprits have not been apprehended continues to undermine attempts by the police to make the community feel secure and reduce fear of crime.
- Eastern Europeans appear to be particularly vulnerable to poor housing due to temporary or circular migration patterns where people travel between the UK and their home country for seasonal work.

Using health and social care services

Attitudes to health and social care services

Primary health services are viewed very much in comparison to the norms and expectations of healthcare developed in 'home' countries. Many ethnic minority communities are used to a system where they pay for healthcare and therefore receive what they perceive as a higher quality service: being seen more quickly, having greater access to specialists, and developing a relationship with a particular doctor. However, there is some recognition that the system in home countries is only better for those who are able to pay: '*when we go back home the service is better as they resolve the problem, but we do have to pay for it'* (Female, Sri Lankan, 18-24).

Members of the Ugandan community tend to report that British healthcare compares favourably to what is available in their own country and feel that the valuing of healthcare is an integral part of British culture, valued more than personal relationships: '*British people value health above anything. They don't value friendship, or at least their social networks are rubbish-ish, but when it comes to health they are up there. You wouldn't have an accident and not have help'* (Female, Ugandan, 25-64). *'If you've been to Africa you can't complain, I know that people here say 'oh the NHS quality is going down'...but still, in the world the NHS is ranked as one of the best*.' (Female, Ugandan, 25-64).

Generally, most residents have a good level of knowledge of when they should be using a telephone service, GP, walk-in centre or Accident and Emergency department. However, understanding the message and knowing the 'right' answer is different to acting on it. Several people from across different communities talked about times they had used emergency services in non-emergency situations because they felt they had no other choice. Often this is related to long waits for GP appointments and a lack of appointments at times which are suitable for those who work. One Indian woman had used A&E at the weekend: '*illnesses do not take the weekend off*' (Female, Indian, 25-64). Another explained, '*simply put, if my health concern is immediate and GPs are anything but immediate with their care, I would go to a hospital'* (Female, Indian, 25-64). A young Greek woman similarly admitted that she had used A&E services on a weekend when she had no way of seeing her GP (Female, Greek, 25-64).

As a result of this many residents from across all communities also report using alternative forms of diagnosis and treatment at times, rather than visiting a GP. In some cases this seems to be a direct consequence of problems accessing services or getting services people feel are adequate. These range from options actively promoted by the NHS to others which could have dangerous consequences. There are, for example, several reports of going to a pharmacist as a first port of call to discuss medical concerns and get advice on how to address non-urgent medical problems. However, others are Googling symptoms and self-medicating. Others have a preference for using alternative medicine – there are reports of using medicine from Chinese homeopaths or using home remedies from local Polish shops.

Language barriers and interpreting services

Many residents from BAME communities speak English as their first language or are fluent and proficient. Others have language skills across the spectrum from sufficient to get by in daily life, to little or no English at all. People from all backgrounds agree that there should be special provision in relation to services for those who speak English as a second language and who lack a necessary degree of fluency. An ability to communicate effectively and understand information being provided almost always shapes perceptions, experiences and use of services.

This is a major issue for Asian communities in particular. Although some identify this as a problem that is diminishing with many second generation immigrants growing up speaking English, others pointed out issues for new immigrants, for example young Pakistani women who have recently moved here following marriage. At the same time, many older people, particularly women, speak only very limited English despite having lived here for many years.

There were some complaints about the lack of information leaflets and forms available in languages like Urdu and Hindi. Awareness and take up of interpreting services is very mixed. Amongst those from the Asian community, the consensus was that while the service is there, it is not well communicated: '*interpreting services are available just not everyone knows* it' (Female, Indian, 25-64); *'it is a matter of getting services known about in the public domain'* (Male, Indian, 65-74). However, there were individuals in this community with no awareness at all of interpreting services: one older person commented that they have been in the UK for 42 years and never been offered an interpreting service. Similarly, experiences in the Chinese community seem very mixed with one couple very knowledgeable about Language Line while another with extremely limited English had never heard of or been able to use any interpreting service.

In the Polish community there was evidence of formal interpreters being used for non-health public service experiences such as going to court, sorting out accommodation and trying to get a Sure Start maternity grant.

Where formal interpreting is not available, family support is the default option for navigating health appointments and other services. One Indian respondent explained how she tends to call her daughter (who is based in Birmingham) and ask her to interpret over the phone. This is also the method she uses to communicate with her husband's care home (Female, Indian, over 75). Across all groups there is often a preference for using a family member as a translator at doctor's appointments, rather than using a professional interpreting service. One Polish respondent says she likes taking her daughter because she doesn't have to explain everything from the beginning (Female, Polish, 65-74). Another prefers to take his son because *'he's family'* and therefore understands the situation (Male, Polish, 25-64).

> Tariq has lived in Crawley since the 1970s when he moved here with his family. He lives alone and was the primary carer for his mother who died recently.
>
> His own English is perfect and while his mother was alive, he made it his job to accompany her to all her doctor and consultant appointments, copying and taking notes between them because he lacked faith in the communications between different health professionals. Tariq describes himself as his mother's 'centre of consistency'.

However, significant downsides to using family to interpret are also acknowledged. Often when children are relied upon there is concern that family members may be unavailable at appointment times because they have work or study commitments. People also feel relying on them places a burden on family and friends.

There are also issues around whether family members relate everything that is said accurately. One woman had observed family '*putting words into their mouths'* and instances where meaning had been lost (Female, Indian, 25-64). In other instances, family members have been too embarrassed to communicate messages from health care professionals, for example telling a parent that they are obese and need to lose weight. Another feels that the quality of interpreting is much better when she used a professional service: '*the interpreter understands properly what I am saying and interprets*

it exactly, more than what my husband or daughter can do; it's not their fault but they cannot interpret properly'. (Female, Pakistani, 25-64). Finally, having to ask family members can constitute a loss of independence and privacy. *'My husband acted as my interpreter and this is not right because what I want to talk about is my personal business and I want someone who is not connected to me or my family to speak for me.'* (Female, Morocco, 25-64). In some instances, people report that they have not disclosed their symptoms as a result (e.g. gynaecological problems).

The consequences of not having language needs met are significant. They include delays in accessing treatment, incomplete or incorrect explanations of symptoms, a failure to understand questions and advice from healthcare professionals, and can ultimately lead to poorer health outcomes.

Davit, from Georgia, lives in West Sussex with his young family. They find it particularly difficult to understand written documents from the doctor. "The letter asking to make an appointment can be managed with help of Google Translate, but anything to do with medication, procedures etc. should be translated properly – it can be a matter of life and death". They have also given up on registering with a dentist as they did not understand the booklet given.

There are suggestions that people may avoid going to the doctor because they feel anxious about their lack of English, particularly in the Eastern European community. One Chinese respondent said if she was suffering from a mental health issue she would probably just try to read a self-help book as she anticipates communicating with a counsellor would be too difficult (Female, Chinese, 25-64). Many feel that health issues were more likely to escalate as people waited until they had no option but to see a doctor. Another described caring for a relative who didn't speak English and wasn't really able to benefit fully from care services because there wasn't always someone at home to provide interpreting (Female, Sri Lankan, 25-64). One Indian woman had a problem with her uterus that took two years to solve because she couldn't easily explain what was going on (Female, Indian, 25-64). She believes this could have been avoided if she had been given access to the translator she required at the beginning.

Language barriers also have consequences for emergency treatment. Inevitably the consequences for individual outcomes are potentially far more severe or even fatal. The difficulty of not being able to communicate in potentially dangerous situations was raised numerous times with people from both the Pakistani and Eastern European communities describing giving birth whilst their husbands acted as informal interpreters. One Hungarian woman described being scared as she gave birth. Whilst she was happy that her husband was there she did not feel it was good to be relying on him to interpret: *'I didn't feel safe. I don't know what I would have done without him' (*Female, Hungarian, 25-64)

Older Pakistani women reported that many people would call a family member before calling an ambulance, leading to dangerous delays. We also heard of instances such as

people having family members on one mobile phone translating to the emergency services on another phone.

Key findings: Language-related barriers to health care

- Inadequate interpreting services can potentially have serious implications for the health and social care outcomes of service users.
- Existing interpreting services are not adequately promoted. Both staff and service users are frequently unaware of their existence. The engagement of their services appears to be far from routine.
- Family and social networks are plugging the gaps and this can be unethical practice, as well as inappropriate and dangerous because of issues arising from omission and/or mistranslation.
- While some may choose to use family members as interpreters this is often done out of necessity rather than choice.

Primary care

There is widespread dissatisfaction with GP services. The appointment booking system involving speaking to a receptionist and getting a call-back from the doctor, now common in many surgeries, is often a source of frustration, especially for those with problems understanding or communicating: *'this new call on the phone service before your appointment to speak or see a GP is not suited for everyone'* (Female, Indian, 25-64). It means that it is harder to rely on family and friends. Rather than having someone make a call at 8am and confirming an appointment, they now need the person who interprets for them to be available for a longer period, to make both the initial call and take the call-back.

Having to wait for an appointment at all is disappointing for groups where walk in clinics are the norm in their own country: '*What is the point of seeing a person in 5 days when they are ill now? This would never happen in India, I would go to the clinic and see a doctor straight away, I don't need to make an appointment and wait for days*.' (Male, Indian, 25-64). Similarly, one Ghanaian woman feels: '*What could be a better system here is to have walk-in centres, this is how it works in my country*' (Female, Ghanaian, 25-64).

Whilst the process of registering with a GP was largely regarded as simple across communities there were some residents, particularly from the Eastern European community, who found the process overly bureaucratic. One Latvian woman recounted a story of an elderly woman with a brain tumour who, with no bank account and no proof of address, found the process of registering with a GP very difficult. The respondent found it shocking that the surgery would not take into account the individual circumstances of an elderly, ill patient (Female, Latvia, 25-64). This reflects a general dissatisfaction with the bureaucracy of GP surgeries which can be seen as uncompromising on issues like appointment times and home visits. There

are a number of residents, from across communities, who view reception staff in GP surgeries as a gatekeeper to their health: *'It's important to know how to get past the receptionist... you have to know how to beat the system.'* (Female, Ugandan, 25-64)

Amongst some women there is a preference for using sexual health clinics for gynaecological issues, partly because you can be seen on the day and but also because they believe it provides access to a specialist rather than a GP. This was mentioned by many different communities but seems particularly prevalent among the Eastern European community, where specialist appointments are more common in their home countries but also was reported by people from other communities. Whilst it is positive that women have found a place where they feel comfortable seeking treatment there are questions over the appropriateness of using sexual health clinics for purposes that are not related to sexual health or family planning.

A large proportion of residents in all communities are frustrated that they typically see different doctors each time they visit a surgery, making it difficult to build up a relationship or for the doctor to get to know their medical history: '*The only thing I miss is establishing a relationship with my GP. Every time, you see someone different, you don't have your 'GP friend' here'* (Male, Italian, 25-64). However, among some residents there is a more relaxed attitude to seeing the same doctor every time: '*it depends what is wrong. If I have pain in my breasts then I want to see my doctor but if I have pain in my wrists then I don't care which doctor I see'* (Female, Ugandan, 25-64).

In the Asian community there was particularly a sense that communications between doctors is not good and so patients need to explain their situation multiple times. This is a particular hurdle for those who do not speak English well or at all, as it means that each visit requires additional effort.

The NHS also does not meet expectations from Eastern European and Chinese communities about access to preventative tests and check-ups. In China there is a culture of having regular 'body checks' which are full health reviews and screening. Several Polish respondents also talked about being used to being able to pay to have blood and urine tests performed just to 'make sure things are ok'. Many from both these communities are getting health checks performed when they visit their home country as reassurance. This additional reassurance is sufficiently important to many people that they spend valuable time 'at home' on visiting the doctor.

> Tamara, from Latvia registered with three different GP surgeries before she found one she was happy with. It's been hard to adjust to seeing a different doctor – in Latvia your doctor knows you and your medical history inside out. She got pregnant soon after moving to England and was really shocked at how differently pregnancy is treated here. In Latvia you would be seen by a gynaecologist straight away and then throughout the pregnancy, not left to do a home test and then see a midwife.

Many communities have found it difficult to adjust to a system where they do not have access to specialists such as dermatologists, paediatricians or gynaecologists without referral from a GP. This is particularly the case for the Eastern European community. The fact that children are cared for by GPs in the UK rather than paediatricians is a cause for concern. One Hungarian parent feels

it would be '*safer if children were seen by paediatricians not GPs*' (Female, Hungarian, 25-64). A Bulgarian mother believes that in England, '*they don't take very good care of children*' (Female, Bulgarian, 25-64). There seems to be a lack of trust in the expertise of GPs with many people from Eastern Europe feeling GPs do not do much more beyond recommending paracetamol: '*They would just say: take paracetamol and you'll be fine tomorrow*' (Male, Polish, 25-64). Another states '*For every condition they prescribe paracetamol…maybe it's a magic pill*' (Female, Polish, 25-64). This perceived tendency to prescribe paracetamol as a default option is also reflected in other communities as well.

Some people related stories of conditions missed by GPs which were picked up by their home healthcare system. For example one Polish man had been told just to take paracetamol for his back pain when presenting to A&E. A series of scans in Poland revealed quite a serious problem which could have got much worse if left untreated. *'GPs should listen more carefully, not just prescribe painkillers for every problem'* (Male, Polish, 25-64). Stories like these contribute to a feeling among some ethnic groups that GPs do not have the time or resources needed to thoroughly investigate conditions.

Secondary care

Experiences of hospital care have been predominantly positive in terms of the treatment received. That said, there are cultural needs which are not being met (see later section) and language barriers can be even more acute as family members cannot be on hand continuously to provide interpreting services. Many women have given birth in the UK and this is an instance where quality and safety of care can be severely compromised if language is a problem, especially if 'technical terms' are not understood. Several reported that their partners had needed to interpret during labour and that this was very stressful for all parties. Some residents also raised the reduction of services at Crawley hospital as a particular issue. They are now required to travel further to East Surrey hospital in Redhill for outpatient care. This was flagged as a particular concern for older Asian women who do not drive and feel nervous using public transport, further increasing reliance on family members or friends.

Key findings: Experiences of primary and secondary health care

- Broadly people understand the roles of different primary and secondary care services but their expectations for these are often not met. Expectations of service are often formed on the basis of experiences in 'home' countries.
- The Eastern European and Chinese communities, particularly, feel that primary care does not deliver the same 'type' of service that they receive elsewhere. For example, patients describe being given fewer tests, fewer specialist referrals, less preventative care and fewer drug based interventions. This is not always seen as a negative but 'difference' can cause feelings of unease which escalate to stress and uncertainty in times of illness.
- There is widespread dissatisfaction with GP services. The appointment booking systems, not having a relationship with one particular doctor, the apparent lack of communication between doctors and the lack of access to specialists were all cited as major frustrations.
- Frustrations around appointment availability (out of hours services, waiting times, weekend services) and consistency of GP lead people to use alternatives. These are sometimes good options (using pharmacies or sexual health clinics etc.) but sometimes represent poorer choices for personal wellbeing (using google, going to A&E, using imported drugs etc.)

Social care

In terms of experiences of social care provision, fewer people have had experience of services. This is particularly the case among the Eastern European community which, on average, is younger and reports less need for social care services.
There seems to be an expectation particularly amongst Asian communities that families would take on caring responsibilities: '*it is a big no-no to get services involved, like carers*'. (Female, Indian, 25-64). This might contribute to a reluctance to take up support services available for carers. However there is also some indication that people feel communication about what is available is poor. One Indian woman had been able to access Carers Support Service but says this was only made known to her once she had reached 'crisis point' (Female, Indian, 25-64). She notes that she also told another friend about it who would not have otherwise come across the service.

However, there do seem to be some negative experiences of the system of means testing. For example, an Indian man who works in a care home feels there is a lack of communication and understanding about why different people are entitled to different levels of service (Male, Indian 25-64). Another described how her late husband had carers to help with washing and dressing for just five weeks but was then told she would have to pay to continue the service. He ended up having to go into hospital and

then a care home because she couldn't afford carers: '*I live on a pension and they said I did not qualify for care support nurses, so my husband had to go to a care home and now he is alone and so am I*' (Female, Indian, over 75).

There is also perception amongst some older residents that social care may not be provided fairly. There are reports of instances where for example an Asian individual has not received the same level of support as a white person in the same area. People are not sure if this is overt discrimination or whether there is something about the system which they do not understand, or if it is a result of language barriers meaning that needs have not been effectively communicated. The lack of understanding can have severe consequences including incentivising people not to seek care: *'I am scared to ask for too much. My leave to stay here is not permanent and if I ask for too much I am scared that they will tell me to leave. I am not sure if the amount of care I access affects my residency so I just don't risk it. My family take on the burden. Although they are all working and have young children of their own they have to take care of me too.'* (Male, Pakistani, 75+). At the very least this suggests a lack of clarity about the criteria being used to determine care needs and how best to access support.

Hardit is in her 60s, married, and is the main carer for her father-in-law who lives with them and their teenagers. For the last 2-3 years he has been provided with a care package which they feel is tailored for his needs. Nonetheless, Hardit finds being a carer hard but was only referred to a Carers Support Service when she "reached crisis point". Hardit now values the change to meet other carers, and share experiences.

In terms of social care day services and care homes, there is a perception that these are not particularly well tailored to cultural and religious needs (see section: Tailoring of services for cultural and religious needs), particularly for the Asian community. Language barriers also mean that even if older people are able to access a day centre, they may still feel very isolated there as they cannot communicate with other attendees. There is a desire to see more inclusive service provision in terms of the activities provided, language needs and cultural/ religious requirements.

Key findings: Social Care

- Younger communities (e.g. the Eastern European community) have significantly less experience of engaging with social care services, particularly with respect to older people. The findings therefore predominantly reflect the experiences of those from other communities.
- Asian communities report strong levels of family and community obligation to and support for older people. However as families move apart and there are generational changes in lifestyles and expectations, there is evidence that families are less able to maintain the same level of support for elders.
- Use of social care services requires that families realise and accept the need for help, that they understand how to go about accessing it, and that they do not feel ashamed to do so. Issues around acceptance seem particularly pronounced in the Asian community.

Dental care

On the subject of dental care perceptions are mixed, however a trend did emerge. Many residents reported returning to their home country in order to access dentist services. Trips are rarely made for this specific reason, but the opportunity to visit a dentist is usually taken during other visits. Reasons for accessing services elsewhere range from a lack of trust in UK dentistry, to price and experience. *I wait 'til I go to Uganda, it's much cheaper there. We do have alternatives [to the UK system]' (Female, Ugandan, 25-64)*

Eastern European residents in particular feel that you receive "VIP treatment" at home for the same price as basic care in the UK. Certain procedures are also far more available and affordable in Eastern Europe than the UK. The same is true to some extent among Asian communities but trips 'home' tend to be less frequent. Many spoke about the relationship they have with their family dentist from back home, with one Italian man stating that he returns home to Italy *'four times a year'* and twice a year goes to visit the same dentist who has taken care of his teeth since he was a child (Male, Italian, 25-64). Whilst the tendency to go abroad for dentistry is particularly pronounced in the Eastern European community it did present across communities.

Key findings: Dental Care

- The standard of British dental care is considered to be poor. It is not uncommon for people with experience of alternative systems to access services abroad that they believe to be better and/or cheaper.

Tailoring of services for cultural and religious needs

On the one hand, a common view from people across all ethnicities is that they do not see a need for *all* services to be tailored to meet their cultural and religious needs: '*They don't need to take into account my religion or culture. They don't ask and I don't tell them. They just need to treat me.*' (Male, Pakistani, 25-64). Another respondent believes '*public services are to provide a service equally for everyone, where does religion or culture come into it?*' (Male, Indian, 25-64). A Namibian respondent comments '*I am asked if I want to be seen by a woman upon examination but besides this tailoring I am not sure how else medical institutions could cater or should cater for people's cultural or religious needs'* (Female, Namibian, 25-64).

However, there are some important exceptions to this view and the belief that *some services* should be tailored to the needs of different groups. The main issues relate to the availability of gender-appropriate staffing, food choices, culturally and language inclusive services, and, in some situations, respect for religious needs.

Having staff of the same gender available in GP, hospital and care home settings is very important, particularly but not exclusively for older Asian women. A number of women reported that having a female doctor was important in order to meet their cultural/ religious needs and the majority reported that this was catered for by their GP surgery. However in one isolated example a patient was not obliged when making

this request and this had a negative impact on her perceptions of GP services: *"When I asked my GP if I can have a female examiner- as I am a female and I don't feel comfortable being examined by a man -I could not be given one. As a Muslim this is very important to me. So what was the point of asking me what religion I am if when it matters they don't care?"* (Female, Morocco, 25-64).

In hospitals and care home settings, however, there appears to be less certainty that personal care will be provided by a professional of the same gender. There is a feeling that when resources are stretched in such settings, people are expected to make do with whoever is on shift and available. This can be a source of significant distress to people who feel embarrassed and uncomfortable as a result. Although most often mentioned by women, one woman from Pakistan also told us of her brother-in-law's distress at having his nappy changed and private areas cleaned by a female nurse.

Food also presents significant issues. One Indian woman reports that there was no consideration of her religion, Jainism, which does not allow her to eat meat or garlic or onions. (Female, 25-64, Indian). Her daughter had to bring food in for her during her stay. Family providing food to patients in hospital is very common in the Asian community. Although in most instances it is recognised that a vegetarian option is available, there are concerns around the limited choice for vegetarians or halal meat-eaters. Families and the community tend to play an important role in caring for people in hospital, both to make sure that cultural/ religious needs are met, and because they are keen to ensure that loved ones are well cared for as they know that hospital staff are extremely stretched.

Issues around food also manifest themselves in day services and care homes. An Indian woman explains that her husband's care home does not cater for his vegetarianism and his food options are extremely limited. Another woman from Sri Lanka feels that there is not very good provision for very strict vegetarians - this can prevent them taking some medicines but the issue and its implications are not well understood. The Asian community also notes that in general local care homes in some areas do not cater that well for older Asian people, presenting families with a dilemma about whether to place relatives somewhere further away where there are more Asian residents, or to keep them close by where at least they can visit regularly.

> Rahela is 75 and lives outside Bognor Regis on her own – her husband is now in a care home as he has Parkinson's. She has been in England since she was 22 when she moved here with her husband. Rahela has never learnt to drive and travels by bus. She makes food to give to her husband in the care home because he's vegetarian and they don't provide the right kind of food for him. Her husband cannot move his hands so she feeds him herself as she does not trust the staff to heat it up.

Key findings: Tailoring of Services

- The majority of people feel that on the whole services do not have to be tailored to the specific needs of the community. Their expectation is simply that they should have access to the same quality of services as the majority community. This, in some circumstances might require overcoming the limitations faced by these communities (e.g. language issues)
- However, there are some specific religious/ cultural needs which some groups feel should be respected and accommodated. In particular, patients should be able to choose the gender of their doctor. This desire was evident across all communities but was particularly pronounced among Asian communities for whom modesty can be an important religious/cultural value.
- Similarly, cultural and religious food requirements need to be more appropriately catered for in the health and social care systems.

Tackling taboos

Mental health issues

Across different ethnic groups there seems to be consensus that much has been done in the UK in recent years to raise awareness and understanding of mental health issues, particularly in the media. There seems to be fairly good awareness of the importance of a GP as a first port of call to get help and of other initiatives like helplines and online support. People from most backgrounds tend to report that UK society seems more open to discussing and dealing with mental health problems than their own countries. Across Western Europe, experiences are much more mixed and dependent on personal experiences and circumstances with some reporting their own countries are better at responding while others feel the UK is tackling the issue more effectively.

However, experiences of mental health continue to be affected by the traditional attitudes most common in different ethnic groups. In the Indian, Pakistani and Sri Lankan communities, mental health issues often continue to be regarded as a source of shame, especially for the older generation. It is an issue which is '*very much stigmatised*' (Female, Indian, 25-64). The Asian community '*refuses to acknowledge mental health problems, partly because back in Sri Lanka, you don't admit things like my son or daughter has a mental health problem*' (Male, Sri Lankan, 25-64). While this attitude is usually identified with older respondents and there is some suggestion that younger people are more open minded and willing to discuss these issues, others question how different the next generation really is. One Indian woman stated that: '*New generations are not all aware of mental health*' and argued that there should be more coverage of mental health topics at school (Indian, Female, 25-64).

Ifrah is originally from Pakistan and has lived in Crawley for the last 20 years with her husband and children. For the past four years, she has been suffering from severe mental health problems which started when her mother passed away. She feels she was treated well by her GP who referred her to the right specialists. The GP even wrote to the Home Office to support her application for her sister to be allowed to visit her from Pakistan for three months. Now she has regular visits with a care support worker and a social worker who come to her house with translators.

Ifrah is reliant on her husband to drive her places but worries he might lose his job if he takes any more time off to look after her. Her daughter helps her with basics like bathing and dressing but Ifrah doesn't feel like this is fair on her because she's so young. She also has a neighbour who brings food but she's not sure how long she can ask her to keep doing this.

Opinions on the role of religious groups in dealing with mental health problems are very varied. At one extreme, a minority view expressed in the Sri Lankan community is that the temple offers a total solution: '*they tend to be cured and happy once they visit the temple'*. (Male, Sri Lankan, 75 and over). Others feel that while it may not be the entire solution that the Temple can provide a forum for people to be educated on such issues. One woman felt that the temple would be a good place to hold sessions on mental health which might help the community to better understand (Female, Indian, 25-64). Among some there is a recognition of the issue's complexity and the limitations of the temple: '*People go to the temple to find peace, however the root of the mental health problem cannot simply be fixed by the temple'* (Female, Sri Lankan, 65-74). Others feel strongly that religious communities were unlikely to play an important role in tackling mental health issues: '*I would never advise a person to go to the mosque for help or to the elders in our community – how can they help in a medical problem?*' (Female, Pakistani, 25-64). A Sri Lankan man comments '*unfortunately Hindu priests are not capable of informing people at the temple as they simply wouldn't care, their job is to carry out festivals etc., get paid pray and go... even in Sri Lanka they are not trained for this sort of guidance in the community'* (Male, Sri Lankan, 25-64).

Although religious and community leaders are not considered to be an appropriate source of help for treatment, there is a perception that they could do more to tackle some of the myths and stigma around mental health to encourage a greater level of openness and willingness to seek professional help. There is also recognition that language is likely to present a barrier to treatment for mental health issues. One Polish woman describes how she ended up paying for counselling at a Polish clinic because she could not get counselling in her own language via the GP: '*mental problems are difficult so I can't tell about it in English'* (Female, Polish, 25-64, MS05).

In the Black African community there is some concern about medication being the most likely treatment and a lack of access to talking therapies as an alternative. A Namibian woman related the experience of a friend where '*the GP will only refer her to telephone counselling and will not send her to see a counsellor saying it costs too much and*

the NHS cannot pay for it. So instead they just waste time and money because how long will they keep her medicated for?' (Female, Namibian 25-64). There was also a sense of mental illness as being taboo in some African cultures, one resident referred to suicide as being '*a curse on a family'* (Female, Ugandan, 25-64).

Key findings: Mental Health

- Across different ethnic groups there seems to be consensus that much has been done in the UK in recent years to raise awareness and understanding of mental health issues, particularly in the media. People from most backgrounds tend to report that UK society seems more open to discussing and dealing with mental health problems than their own countries.
- In many BAME communities people with mental health problems continue to face stigma. This appears to be particularly the case within Asian and African communities.
- Religious and cultural leaders are not generally considered to be a good potential source of support for mental health issues, although at times they may play a role in support and signposting. They are, however, seen as having the potential to play an important role in raising awareness and changing attitudes.

Domestic abuse

Across all ethnic groups, domestic abuse is seen as a source of shame and something sufferers would be likely to cover up, at least initially. This attitude seems to be understood as pretty universal: '*abuse is always hidden, I think that stays between four walls*' (Female, Belgian, 25-64). However, there are some subtle differences in attitudes to domestic abuse. In the Asian community, the main concern seems to be around how speaking out about domestic abuse would reflect on the family. There is a sense that sufferers should not '*put dirty laundry out for everyone to see*' (Female, Indian, 25-64) and that a wife '*would be ruining her husband's name in the community if it gets out'* (Female, Sri Lankan, 18-24). For non-European citizens in both the Asian and Black African communities the issue of right to remain in the UK is raised. Usually this is for the victim of domestic abuse whose visa is dependent on remaining with their spouse. This can be a particular worry for women who have British children but who do not personally have residency rights. A fear of social care taking children away was also expressed in the Pakistani community – there was a sense that social care do not understand immigration issues very well which might lead to problems. However, visa worries relating to the partner may also be a concern because of the knock-on implications, '*women think twice about who they turn to because their partners could be deported which would have financial consequences'* (Female, Zambian, 25-64). Even where deportation is not a fear, the financial implications can lead victims to remain silent.

In terms of how to tackle domestic abuse, a common view is that this can and should be tackled within the wider family network, particularly in the older Asian community: '*Domestic abuse is not that great a concern in the Tamil community, there are*

minor incidences that are pretty much sorted out by relations' (Male, 65-74, Sri Lankan). An older Indian woman feels it is not a good idea to go outside the family; rather the elders would deal with it, visiting the man and telling him to stop (Female, Indian, over 75). Although there is a sense that views might be changing in the younger generation, others worry that even if they have different attitudes, younger people would continue to be pressurised by elders not to seek help from outside (Male, Indian, 64-75). European respondents sometimes felt that this was such a sensitive issue, it might be better to try to solve it amongst friends and family: '*You feel more at ease talking about these problems with a friend because it's something very personal*' (Male, Spanish, 25-64).

In the Eastern European community, there is a sense that domestic abuse is taken more seriously in the UK than in home countries and people here are more likely to get authorities involved: '*Polish people ignore, English people do something with it. They call the police when they see something suspect'* (Male, Polish, 25-64, MS10); '*English people take it more seriously and call the police more often than Polish people'* (Male, Polish, 25-64).

There are differing views on how likely it is that the wider public would get involved if abuse is witnessed. A Spanish man gave an example of seeing someone intervene on the street when a man looked to be acting violently towards his partner (Male, Spanish, 25-64). However, some Black Africans feel the looser community bonds in the UK mean that domestic abuse could more easily go unchallenged: '*We are not part of the same sort of community or family setting now and so a lot of people still suffer in silence and alone and do not get help'* (Female, Namibian, 25-64).

For those that accept the need for external help, the police are thought to be the place to turn in cases of domestic abuse. One woman shared a negative experience of a friend who had gone to police but found them rude and unhelpful. She believes this might be why people often do not seek help: '*it can be a barrier, a hindrance rather than a help*'. (Female, Ghanaian, 25-64). However, this seems to be a minority view with most groups assuming the police would be helpful even if they do not have personal experience of this.

Elena is from Latvia and grew up in a household affected by alcoholism and domestic abuse. As a child, she feels the community ignored the problem occurring on their doorstep. Elena feels that in the Latvian community alcoholism is not typically considered a problem – but alcohol is a fuel for violence, and Elena thinks community attitudes to alcohol need to change. Her perception is that very few people would seek help for domestic abuse as they are ashamed and would not admit it. Elena feels that the younger generation is more likely to report abuse but there is still a lot to do to raise awareness.

Eastern European residents, however, did note that many people within their community have an embedded distrust of the police which hangs over from experiences in their home countries. They suggest that this may be a barrier to victims of domestic abuse reporting incidents to the police. One Czech man stated that among Czech people the lack of trust in the police is such that people would only go to the police over domestic abuse if it was so serious that they were hospitalised (Male, Czech, 25-64). Likewise a Latvian woman argued that the lack of trust in the police is

*"in their blood" (*Female, Latvian, 25-64). One woman argued that this is also a result of how the police in her home country deal with domestic abuse. She expressed the view that in Estonia the attitude among police is that: *'what happens in your family – it is your home problem.*' (Female, Estonia, 25-64). This distrust of police may present problems in ensuring that Eastern Europeans access support for domestic abuse.

Across all groups there is a fairly good awareness that resources such as helplines, shelters and so on are available, even if there would be reluctance to use them. One exception is the Sri Lankan community where there are concerns about whether sufferers would know about sources of help: *'in our society they [women] are usually staying at home as housewives so they would not really know about these services; they only know what is going on in their house and temple'* (Female, Sri Lankan, 18-24).

There is not much discussion of religious communities as a source of help and in some cases, there is ambivalence about whether it could play a role here: '*Maybe in five or six years the temple may be able to play a bigger role in helping out with services and teaching people about them but it doesn't seem likely any time soon*' (Female, Sri Lankan, 18-24,). In the Pakistani community, respondents feel that community leaders could do more to play an educational role, but it has been difficult to engage them in the past. In general though, it is felt that if religious and community leaders could be more effectively engaged, they could be influential in changing attitudes.

Key findings: Domestic Abuse

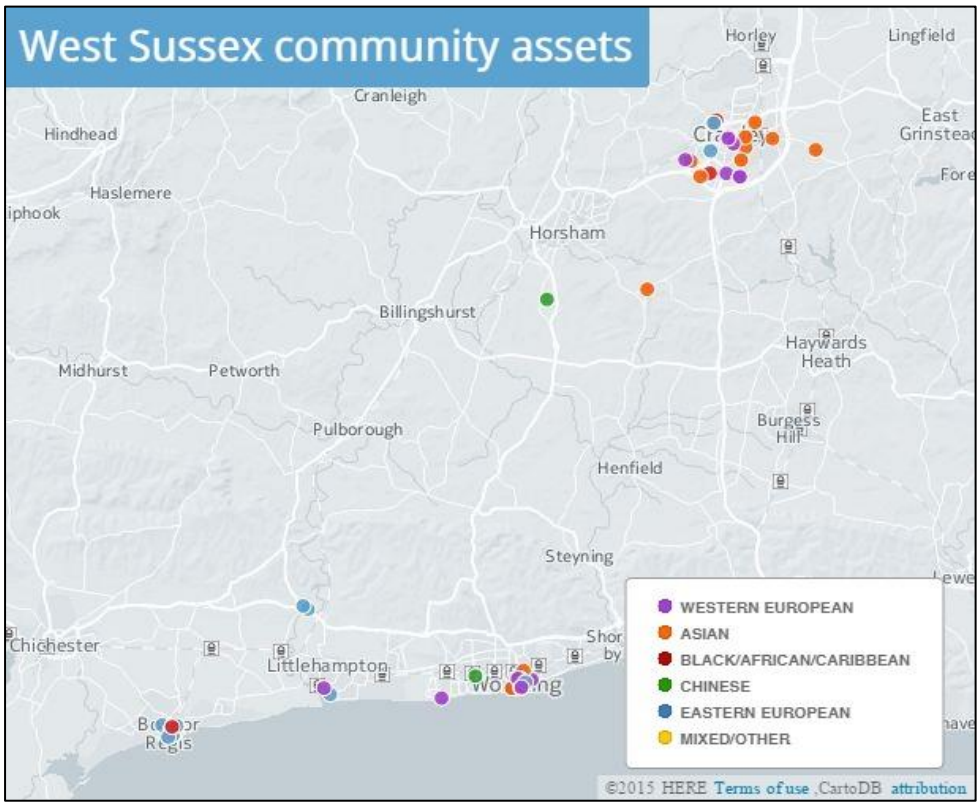
- Domestic Abuse, as in many UK communities, is often a source of shame and subject to high levels of secrecy. Reporting of domestic abuse is, among many communities, seen as a last resort. Among some women, who rely on men in order to remain in the country, there is a concern that reporting abuse may call their immigration status into question or have serious financial implications.
- It is often only dealt with in the family, or immediate community, if at all. Cultural and religious leaders are not typically encouraging discussion or reporting of domestic abuse.

COMMUNITY ASSETS

Community assets such as meeting places, local groups, community services and religious institutions provide opportunities for people to socialise, build community and social links and prevent feelings of isolation. They can be particularly important for BAME communities as they provide routes to maintaining cultural and religious links. Such community assets also offer forums for health and public services to engage with populations. Understanding where community assets are and how people use them is central to finding new ways to engage with potential service users.

In each of the three main localities where the research was conducted, many participants in the research were able to identify local places and resources which they value within in their community. Often people from the same national or ethnic background would identify the same assets but equally, time constraints mean that those identified here do not represent an exhaustive inventory of the assets in West Sussex.

The majority of the community assets identified were centred around Crawley, Worthing and Bognor Regis. However, there were examples of assets scattered around other areas of West Sussex, around Littlehampton, Horsham and Arundel.



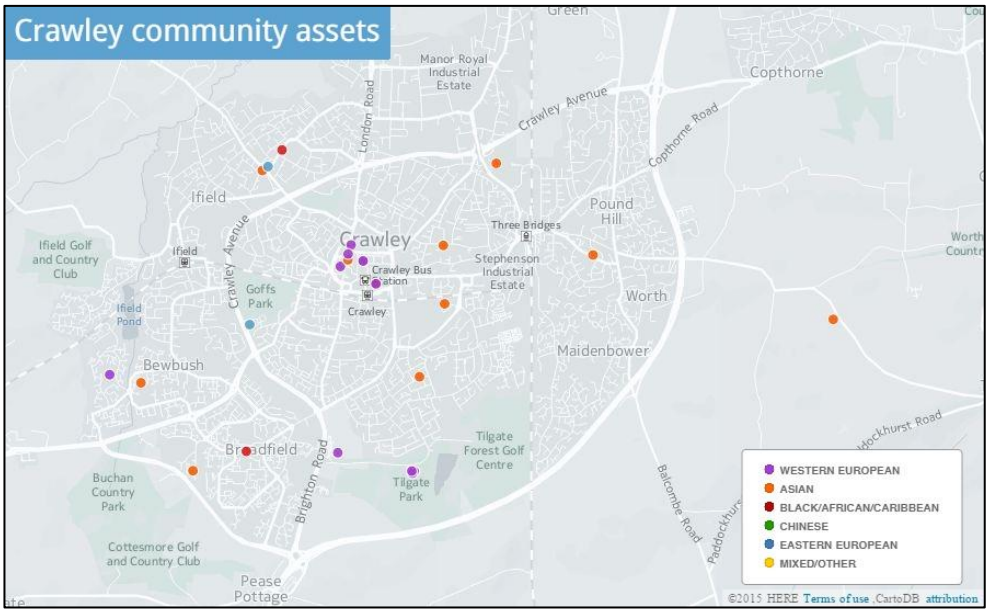
Whilst most of the assets identified are locations that are close by, some people did identify locations that were further afield. Arundel was a particular example of a place that people travelled to. It was given as an example of a location that people visited in

order to enjoy the history and architecture. The Cathedral in Arundel is also singled out as a place where many Lithuanians go for special religious occasions such as midnight mass. A Lithuanian man claimed that he was not religious and yet attended midnight mass at the Cathedral in part to be able to engage in a tradition with other Lithuanian people (Male, Lithuanian, 25-64).

In one case a Portuguese resident of Crawley identified a Portuguese café in Littlehampton as a location that they were happy to travel to in order to eat familiar food and socialise with other Portuguese people.

Crawley community assets

The community assets identified by the residents of Crawley mainly serve the Asian and Western European populations, although members of other communities did also identify places that they find important. While the assets named by the Western European population are often located in the city centre, the assets of other communities are more spread out.



The characteristics of these assets are also different according to ethnicity. Among the Asian community, religious and cultural institutions and groups are highly represented among the community assets that residents from these communities name as important. The Crawley Mosque, the Gujar Union Ltd Hindu Temple and the Tamil Language Lessons, provided at Hazelwick School, are among some of the most highly cited examples of assets among the Asian community. The Hazelwick School is also a location used by the Hindu Community for hosting weddings and large ceremonies and seems to be a particularly important asset to this population. However there are other, smaller examples of assets that were given by this community which could also provide routes into these communities. For example, one Pakistani woman names a local Pakistani shop as a community asset (Female, Pakistani, 25-64). In Crawley, many of the locations named by the Asian community are either public assets, such as the Civic Hall or Community Centres or they are places where the majority of people will also be Asian (e.g. religious or cultural meetings or groups).

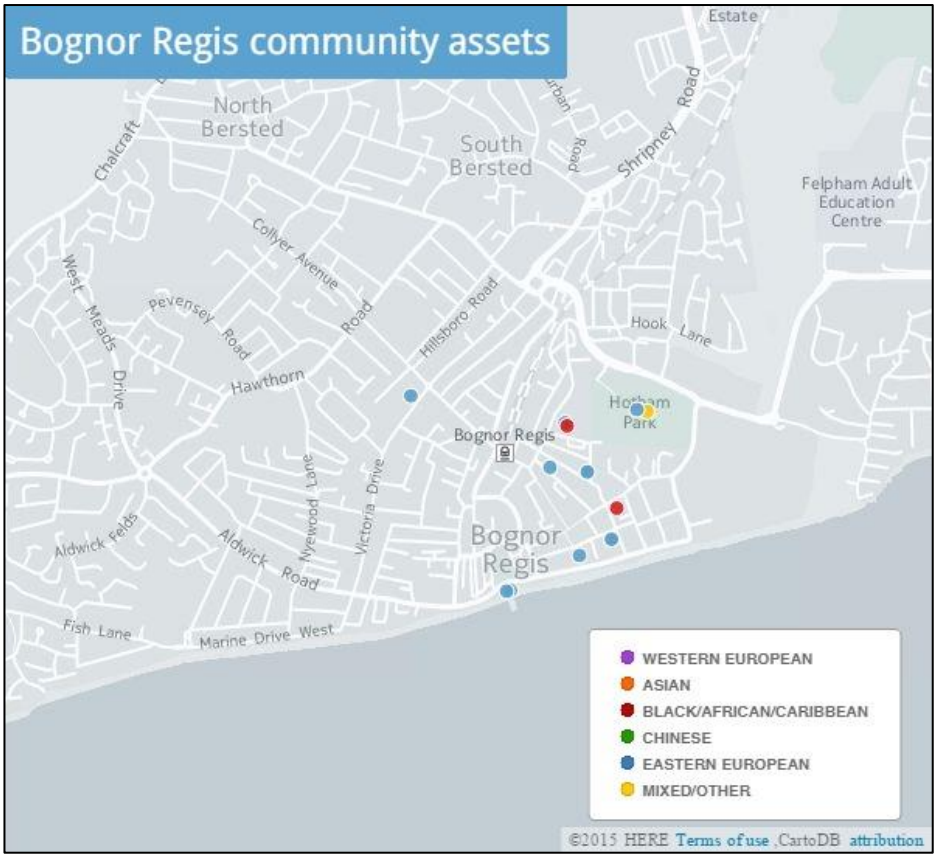
The Black and Eastern European communities, while identifying fewer assets in Crawley, also name religious and cultural institutions such as churches and, in the case of the Polish community a language school, as important spaces that contribute to their well-being and sense of community.

By comparison the assets named by the Western European community are quite different. Residents from this community do not often name religious institutions as community assets, though there is one exception to this. Instead, many members of this community name locations such as Tilgate Park, sports facilities like local gyms, a basketball court and high-street coffee chains as assets of value, which provide spaces for building and maintaining social relationships or for increasing well-being.

Among the Western European population, particularly, pubs and bars seem to be important community assets with such establishments often providing locations for people to meet with friends. One can observe from the asset map that most of the locations identified by Western Europeans appear located in the centre of town. This seems to reflect the fact that pubs, bars and restaurants are important community assets for people to meet and socialise with friends. In some cases such locations also provide spaces for members of particular communities to meet up. The Jubilee Oak Pub in Crawley is, for example, a place where the Spanish community choose to meet.

Bognor Regis community assets

The residents of Bognor Regis identify fewer community assets, on the whole, than the residents of Worthing and Crawley. That said, certain assets are mentioned by large numbers of people, demonstrating their integral role in community life.



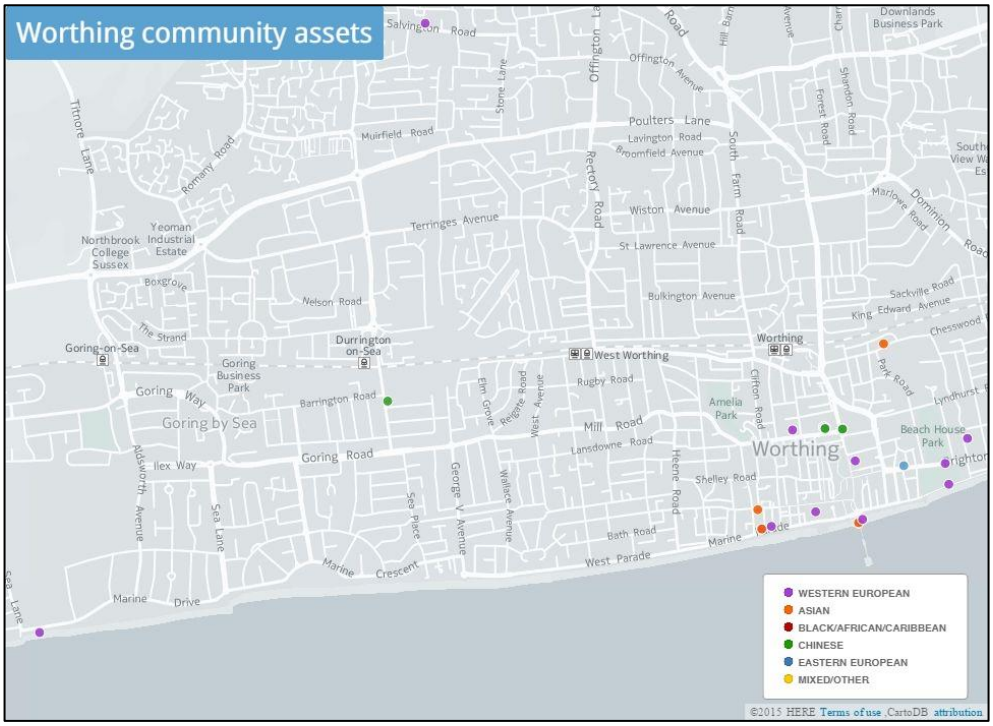
Residents from the Eastern European and Black communities identify churches, the local library and voluntary services like the Citizen's Advice Bureau and Voluntary Action for Arun and Chichester as important community assets. Many people from the Eastern European community identify Connecting Communities as an important source of assistance. Connecting Communities is a help service which provides support services to Russian, Polish and Lithuanian speaking groups. Eastern European language classes are also seen as important community assets.

The Eastern European community emphasise the importance of St. Marys Catholic Primary School, where Eastern European language schools (such as the Polish School and the Bulgarian School) are held. At these language schools the community can get together and families can help children to maintain a link to their culture. A Bulgarian Dance School, located at the Recital Hall in Sudley Road, was also identified as another important community hub. The Regis Pub is given as an example of a meeting place for the Eastern European community. It is also a place where regular English conversation classes are held and this is identified by residents as an important resource.

In addition, residents from across ethnicities talk about the importance of outdoor spaces such as Hotham Park and the sea front. One Czech man states that Czech people don't necessarily have community locations, as such, and that there are no particular pubs where the Czech community gathers but that Czech people might get together to have a BBQ on a beach (Male, Czech, 25-64).

Worthing community assets

More than any of the other population centres, the residents of Worthing cite the importance of their local library. Residents state that it is an important place to access things like information or WIFI and it also serves as a nice place to relax and spend time. Furthermore, the Worthing library is the West Sussex community asset that seemed to have the broadest appeal; residents from Western European, Eastern European and Asian communities cite its importance.



One resident also mentions her local family centre as having been an important asset for her after the birth of her child: *"The family centre was very much central in my life after I had my first child. And the breast-feeding consultant was absolutely amazing."* (Female, Belgian, 25-64).

People in Worthing, like in the rest of West Sussex, appreciate outdoor spaces such as Victoria Park and the sea front. Like in the other population centres Western Europeans, particularly, appreciate places that help them to keep fit. These include Splashpoint Leisure Centre and kite surfing at Baker Academy. These facilities were not used exclusively by Western Europeans, however, with members of other communities commenting on the importance of, for example, the local swimming pool.

The lighthouse retreat centre was mentioned by two members of the Worthing community, one Asian person and one Western European. It was mentioned that this is a good place to meditate and look after well-being. Bars were mentioned significantly less often in Worthing than they were in Crawley with only one Asian resident citing a pub as an important asset to them. However, places where one could socialise, such as the local street market and the bowling alley, were given as examples of locations which are important for wellbeing.

RECOMMENDATIONS

Life and wellbeing in West Sussex

It is important to ensure that people have opportunities to both integrate into wider West Sussex society and local communities, as well as to retain cultural and religious links, as desired.

In order to facilitate this, commissioners of public services, (such as local authorities, the police, NHS England and clinical commissioning groups) should:

- **Increase provision of and access to high quality, affordable English language and citizenship courses aimed at people coming to live in West Sussex, for whom English is not their first language.**
- **Enhance support (including physical space and service based support) for formal and informal community groups; for people to maintain connections to their cultural heritage and practice their religious beliefs.**
- **Embed a strategic approach in policy and services to target those in BAME groups who are most vulnerable and hard to reach. .**
- **Work with community groups and informal networks to disseminate key information about health and social care services to raise awareness and increase accessibility and uptake. .**
- **Commit further resources from Sussex police to focus on building and improving relationships with some BAME communities. Specifically, there should be a concentrated effort to tackle the increasing fear of crime present in the Asian community in Crawley.**
- **Work with head teachers and boards of governors to ensure robust and consistent policies and procedures exist to identify and tackle racially motivated bullying in schools.**

Health and social care service commissioning

Commissioners of health and social care services should;

- **Embed active anti-discrimination policies and training at the centre of procurement practices.**
- **Ensure that providers of residential care homes and home-care services are held accountable for discrimination in their services, (including that potentially by staff, residents and families) with appropriate monitoring and governance procedures to support this.**

- **Undertake, along with BAME community representatives, a review of culturally sensitive catering provision across commissioned health and social care services.**
- **Develop guidance for best practice at all points of contact with primary, secondary and social care services for those with language and communication barriers, specifically around, but not limited to, GP registration, hospital admission, and social care needs assessments.**
- **Consider how the 999 emergency service system can better enable people to communicate with them, where there are language barriers.**
- **Ensure that there are clear and robust safeguarding mechanisms for safeguarding those with particular vulnerabilities and cultural needs in BAME groups.**

Health and social care service delivery

Providers of health and social care, and voluntary services and the workforce should;

- **Raise awareness, as a priority, of existing interpreting services to anyone for whom English is not their first language, and have clear referral mechanisms.**
- **Review the provision of out-of-hours services and evaluate the consequences of the closure of the Crawley Walk-In Centre.**
- **Ensure that GP surgeries are required to mitigate the problems that could arise from accessing care, by ensuring appropriate and timely use of interpreting services.**
- **Ensure that services understand and take into account the proportion of the BAME population who might require English language support and ensure staff are trained appropriately to identify and facilitate this.**
- **Ensure that information leaflets in GP surgeries are available in a wide range of languages which reflect the needs of their local population.**
- **Work with BAME patients accessing care to manage expectations about the NHS and the care they will receive in local health systems; being clear about how the health system works, and encouraging appropriate use of services to ensure that they receive the right care, in the right place and the right time.**
- **Work with BAME social care service users to ensure that there is clarity and transparency in communicating what services people are entitled to, and the criteria applied to reach this decision.**
- **Increase visibility, availability and accessibility of talking therapies for mental health conditions for those for whom English is not their first language.**

Tackling taboos

Commissioners, providers, voluntary and community services and frontline staff should:

- **Continue efforts to engage cultural and religious community leaders in dialogue around their role in supporting their communities to deal compassionately, effectively and appropriately with sensitive issues.**
- **Work together to create local campaigns and awareness raising activities which involve and support people affected by these issues; giving them a voice.**
- **Increase support to the Voluntary Community Sector (VCS) in its work to proactively engage BAME communities.**
- **Co-ordinate local activity with existing national anti-stigma campaigns, such as Time to Change, and awareness raising activities such as #KnowHerName.**
- **Ensure that training on domestic abuse and how immigration/residency status may affect disclosure is embedded into the practice of social workers and immigration case workers.**
- **Provide local leaders with evidence based and evaluated tools and resources to enable them to use opportunistic approaches to introduce sensitive issues in an appropriate way, for example in citizenship classes, and cultural groups.**
- **Identify opportunities to approach and empower young people from BAME communities to champion change and raise awareness.**

Community assets

Commissioners and providers should:

- **Consider investing in further asset mapping which may reveal clearer trends in the types of community assets utilised and hence offer opportunities to better target outreach work to different communities at ground level.**
- • **Explore opportunities to capitalise on community assets as potential routes for health and public services to engage with specific groups.**

APPENDIX I

Discussion guide

Thank you for agreeing to take part in this interview.

My name is... I work for The Young Foundation. We are an independent organisation that carries out research across the UK and explores new ways to tackle inequality.

We are currently working with West Sussex County Council to try and better understand the experiences and needs of residents using health, social care and other services. In particular, we want to understand whether people feel that services meet any specific needs which people have because of their religion, ethnicity or language preferences.

We will use what you have told us to help us understand what you think about services. When we write our report, we may use some quotes or examples from you or other people. We will use general ways to identify who the quote comes from, such as age-range, ethnicity and gender. We will not identify you personally.

West Sussex County Council will not know the names of those who took part.

You can stop the interview at any time and you do not have to answer anything you are not comfortable with. This interview will take around an hour to an hour and a quarter.

I will leave you with contact details for The Young Foundation so if there is anything that you want to ask after the interview, or any more information you want to share, then you can get in touch.

I would also like to record our conversation. This is purely for my benefit so that I can focus on what you are saying instead of taking notes. Only I and my supervisor at The Young Foundation will have access to this recording and it will not be used for any purpose other than helping me to remember correctly everything you say. After the research has been finished, the recording will be destroyed. Is that ok?

If yes: switch on recorder

Do you have any questions before we start?

SECTION 1: 5 minutes	
Could you perhaps start by telling me a little bit about yourself? For example, where you live and who with. Prompt: Children? Employment?	
What do you think about living in West Sussex?	
What do you like or dislike?	Allow free response. Prompt with "anything else?" Use Show Card as prompt if necessary
Why is this? What makes most difference to your happiness?	**If necessary prompt by asking, e.g.** What makes you feel comfortable here?
IF THEY HAVE LIVED IN WEST SUSSEX LESS THAN 2 YEARS: **What has your experience of living here been like so far?**	
For example, how easy or difficult was it to find a place to live? Do you feel settled here? Do you feel part of the community?	
SECTION 2: 5 minutes	
IF A LANGUAGE OTHER THAN ENGLISH IS THE MAIN LANGUAGE: **Do you find that written or spoken language can be a barrier to communicating with people?**	
When? In what types of situations?	
What are the problems it causes you?	
Have you ever used a formal translation service in order to obtain advice or support?	
If yes, when? What difference did it make?	
Have you ever used a friend/relative to translate something/read something for you?	
If yes, when? What difference did it make?	
SECTION 3: 5 minutes	
If you had a general health concern, where would you normally go or who would you ask for information or advice? Prompt: A GP, dentist, walk in clinic, A&E, community leader, male or female family member, a close friend, charity, helpline, the internet, etc. If necessary, by health concern we mean: Coughs/colds, Ear infections or rashes, Back problems etc.	
Why would you go there? **If not British**: Is this different to how you would expect the healthcare system to operate? Do you feel you understand how this system works?	Prompt to get full understanding. E.g. if "convenient" ask why it is convenient – location, opening hours; speed of being seen etc.

Would this be different if you had a more immediate health problem? If necessary, by more immediate we mean things like: Pregnancy worries, an asthma attack, minor burns or heavy sprains, signs of a heart attack or stroke	
If yes: Where would you go in that case? Why? **If not British**: Is this different to how you would expect the healthcare system to operate? Do you feel you understand how this system works?	**Clarify what kind of incident they are thinking about**
SECTION 4: 5 minutes	
Are you currently registered with a GP? **If needed: Being registered with a GP means you have filled in a form, met with a GP or nurse, and they now have a copy of your medical records. You will then be able to book an appointment to see the GP when you wish.**	
If yes: Can you describe to me the experience of visiting your GP? How well would you say the service is tailored to your cultural, language or religious needs?	**Prompt:** What is good? What could be better?
If not: Why not? What would make it easier to register (or make you want to register)?	Probe to understand issues around: cultural, language or religious barriers; awareness of service; understanding of registration process; concerns about the service/ perceptions of GP care vs. other health services.
SECTION 5: 5 minutes	
Are you currently registered with a dentist?	
If yes: Can you describe to me the experience of visiting your dentist? How well would you say the service is tailored to your cultural, language or religious needs?	**Prompt:** What is good? What could be better?
If not: Why not? What would make it easier to register (or make you want to register)?	Probe to understand issues around: cultural, language or religious barriers; awareness of service; understanding of registration process; concerns about the service/ perceptions of dentist care vs. other health services.
SECTION 6: 10-15 minutes	
What other public services, if any, do you (and your family) use at the moment?" Prompt: By services we mean other health care services, social care services, carer support services, children's centres, schools, police, citizen's advice bureau, transport or community services, etc.	
RECORD ALL SERVICES USED	
If use multiple services: which services do you use most often? RECORD TOP 3 –	DO NOT INCLUDE GP OR DENTIST IN FOLLOW-UP
Can you please tell me about your experience of using service #1	**If necessary prompt:** - What makes a particularly positive experience

	- What makes a particularly negative experience
Can you please tell me about your experience of using service #2	**If necessary prompt:** - What makes a particularly positive experience What makes a particularly negative experience
Can you please tell me about your experience of using service #3	**If necessary prompt:** - What makes a particularly positive experience What makes a particularly negative experience
Thinking about all the public services you use, how well would you say they are tailored to your needs? Please think specifically about anything that is particularly relevant to your cultural, language or religious needs and preferences?	
If positive response: Can you give me 1 or 2 examples of a service which meets those needs really well and how they do that?	
If negative response: In what areas do services not meet your needs? Probe for specific examples What are the consequences of this?	
Could any of these services be improved to better meet your needs?	
Do you ever feel that you are treated differently because of your ethnicity or cultural/ linguistic background by staff providing public services?	
If yes: In what ways are you treated differently? Can you give me some examples?	
What are the consequences of this?	Probe specifically on how they feel it affects their interaction with the wider community and also with public services
SECTION 7: 5 minutes	
Do you know anyone within the community who has poor health or is in need of social support who is not accessing services? Prompt: By services we mean, health care, dental or social care, children's centres, police, schools, citizen's advice bureau, transport or community services, etc. – This could be children, adults or older people.	
Can you tell me a little bit about this person and what support you think they need?	E.g. Approximate age, gender, ethnicity etc. Health/ Social care need
Do you know if they have tried to get support?	
If yes: Why do you think they've not been able to access support? Or that the support has not been sufficient? **If not British**: Is this because the healthcare system to operates differently to how they would expect?	

If no: Why do you think they've not tried, or been able, to access support? **If not British**: Is this because the healthcare system to operates differently to how they would expect?	
Are there any cultural, language or religious barriers which mean this person cannot access the support they need? Or which mean that the support services available are not appropriate?	
SECTION 8: 5 minutes	
Do you ever feel that you are treated differently because of your ethnicity by the general public?" Prompt: By general public we mean, people on the streets, in shops or pubs/restaurants, sporting events, etc.	
If yes: "In what way?"	
How about other people you know or others in your family?	
If yes: "In what way?	
SECTION 9: 5 minutes	
How do you think mental health problems are perceived in your local community? **If necessary prompt:** Are they accepted, ignored, taken seriously or treated unsympathetically, do people hide their problems or are they perhaps concerned about being judged? Prompt: By 'mental health problem', we mean depression, anxiety, stress, insomnia, eating disorders, etc.	
If someone close to you had a mental health problem, who would they go to for advice or support? Prompt: A GP, walk in clinic, A&E, community leader, male or female family member, a close friend, charity, helpline, the internet, etc.	
Why would they go there?	Prompt to get full understanding. E.g. if "convenient" ask why it is convenient – location, opening hours; speed of being seen etc.
If not health or social care service: Why do you think they would they not seek help from a doctor or health service?	Probe particularly to understand issues around cultural, language or religious barriers
SECTION 10: 5 minutes	
How do you think domestic abuse is perceived in your local community? **If necessary prompt:** Is it accepted, ignored, taken seriously or treated unsympathetically, do people hide problems or are they perhaps concerned about being judged? Prompt: By 'domestic abuse', we mean the abuse of one partner within an intimate or family relationship. It is the repeated, random and habitual use of intimidation to control a partner. The	

abuse can be physical, emotional, psychological, financial or sexual. Anyone forced to alter their behaviour because they are frightened of their partner's reaction is being abused.. If necessary: We are talking about people over the age of 16, not children.	
If someone close to you was a victim of domestic abuse, who do you think they would they go to for advice or support? Prompt: Might they seek help / support from the police, a walk in clinic, A&E, WORTH services (an independent support service), community leader, male or female family member, a close friend, charity, helpline, the internet, etc.	
Why would they go there?	
If unlikely to seek help from professional service or charity etc.: Why do you think they would not seek help from a professional service?	Probe particularly to understand issues around cultural, language or religious barriers
SECTION 11: 5 minutes	
Do you feel able to influence how services are provided? Do you think that you have a voice?	
If yes: In what way?	
If no: Would you like to have more influence? What would help to give you a voice?	Prompt: Regular community/town meetings, opportunities to speak your mind, someone to speak on your behalf, attending political discussions or debates, regular public engagements, clear channels for feedback/complaints.
Do you think there are other important issues that we haven't discussed yet, with regards to the wellbeing of those in your community?	
If yes: Please explain	Probe particularly to understand cultural, language or religious issues
SECTION 12: 5 minutes	
USING A MAP AND POST-ITS, capture what people say and take a photograph of the map at the end of the session.	
What are the local places and resources that you find most useful in this area? Prompt: this could be a local community centre, church or other place of faith, a library, a café or business. Where do you meet people?	
Why would they go there?	**For help with… To…**
What is the best thing about this place/resource?	**Eg, the person who runs it, the people who go there, the activities etc.**

Thank the participant

Ensure you hand over the incentive – receipt signed

Hand over the information sheet

APPENDIX II

Demographic profile of BAME population in West Sussex

In conducting the analysis, certain groups were excluded, mainly Gypsy or Irish Traveller (included in a separate West Sussex Needs Assessment) and North American (small population; first language English). Those of Mixed Heritage background (e.g. White and Black, White and Asian) were excluded from the quota calculation but included as participants - they will be picked up through engagement with the other BAME groups (e.g. by speaking to Asian, European or Black communities).

The first significant point to note is that although Crawley has a much smaller population than Arun District in overall terms, it has by far the largest BAME population.

Table A1: Distribution of BAME population across three areas

	Arun District	Crawley Borough	Worthing Borough	Total
Total population	149518	106597	104640	360,755
BAME population	7,709	22,307	6,233	36,249
Proportion across 3 areas	21%	62%	17%	

The main BAME groups in each area vary: White Europeans are the main grouping in Arun, while Black and Asian groups are the majority in Crawley and Worthing.

Table A2: Breakdown of BAME population across the three areas (total numbers)

	Arun District	Crawley Borough	Worthing Borough	Total
Asian/Asian British: Bangladeshi	367	427	544	1338
Asian/Asian British: Indian	498	5530	783	6811
Asian/Asian British: Other Asian	732	2824	1400	4956
Asian/Asian British: Pakistani	107	4548	171	4826
Black/African/Caribbean/Black British	538	3469	869	4876
White: Baltic States	800	483	247	1530
White: European Mixed	1142	1102	489	2733
White: Italian	147	328	353	828
White: Other Eastern European	388	667	272	1327
White: Other Western European	891	1388	612	2891
White: Polish	2099	1541	493	4133
Total	7709	22307	6233	36249

Table A3: Breakdown of BAME population by area (% of BAME population)

	Arun District	Crawley Borough	Worthing Borough
Asian/Asian British: Bangladeshi	5%	2%	9%
Asian/Asian British: Indian	6%	25%	13%
Asian/Asian British: Other Asian	9%	13%	22%
Asian/Asian British: Pakistani	1%	20%	3%
Black/African/Caribbean/Black British	7%	16%	14%
White: Baltic States	10%	2%	4%
White: European Mixed	15%	5%	8%
White: Italian	2%	1%	6%
White: Other Eastern European	5%	3%	4%
White: Other Western European	12%	6%	10%
White: Polish	27%	7%	8%
Total	100%	100%	100%

For practical reasons, it is not advisable to sample at this detailed level as many groups are too small to realistically be identified and recruited. An aggregated approach is more appropriate.

Table A4: Aggregated breakdown of BAME population by area

	Arun District	Crawley Borough	Worthing Borough
Black African/Caribbean/Black British	7%	16%	15%
Asian	23%	61%	49%
Eastern European	16%	5%	9%
Polish	28%	7%	8%
Other European	27%	11%	19%
Total	100%	100%	100%

The role of language

Within these groups, and across West Sussex, there are a large number of languages represented. Of the 93 languages spoken in West Sussex, there are six with over 1,000 speakers.

Interestingly there appears to be a larger number of Polish speakers than those that identified themselves as Polish in the Census (4,738 compared to 4133). This is likely due to individuals identifying as White: Other Eastern European or another similar category in the census. It may suggest that the Polish population is under estimated in West Sussex.

Table A5: Most spoken languages in West Sussex

Main Language	West Sussex	Arun District	Crawley Borough	Worthing Borough
Polish	4,738	2,545	1,670	523
Portuguese	1,558	452	959	147
Gujarati	1,469	49	1,354	66
Urdu	1,321	35	1,229	57
Tamil	1,166	51	1,037	78
Lithuanian	1,163	527	416	220