

Black and Minority Ethnic Carers and their experiences of GP services in Croydon



December 2017

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Croydon BME Carer

CONTENTS

| | |
|---------------------------------|-----------|
| Executive Summary | 4 |
| PART A | |
| 1. Introduction | 6 |
| 2. The Policy Framework | 8 |
| 3. Methodology | 9 |
| 4. Findings and analysis | 10 |
| 5. Conclusions | 20 |
| 6. Recommendations | 22 |
| PART B | |
| 7. Research data | 24 |
| 8. References | 55 |

EXECUTIVE SUMMARY



This report focuses on how well GPs in Croydon have supported BME carers both in terms of their own health and wellbeing and in their caring role.

Our study raises both areas of concern and highlights good practice in terms of the support that GPs are offering BME carers in Croydon.

The most important issue to emerge are that GPs in Croydon are not sufficiently recognising the caring role or referring carers to the Carers Support Centre in Croydon and other support services, which is similar to what was reported in the Carers' Information Service report *Not Just a Patient* in 2017.

“Doctors made the assumption that because he (her father) had a good unit, a family, around him that we were all capable and will do the looking after him, for example cleaning my father when needed. (That) all individuals within the family will get involved, we will all become carers, especially within the Asian community.”

We also heard about some best practice examples, where BME carers enjoy a relaxed rapport with their GP and have been provided with recognition and referral to support services. These included two practices who have introduced care navigators who carers can use to find out about services and support. Our evidence found that when BME carers have this relationship with their GP practice, their feedback about

services they receive and their openness to referral and advice is immediately improved.

The varying quality in services given to BME carers indicates a need to implement better support across the board so that all BME carers in Croydon feel recognised and supported. There are already clear guidelines for best practice as well as NHS England's Commitment to Carers which lay out a clear pathway to improving support services for this group.

Our recommendations reflect the BME specific issues which came out in this report as well as some more generic carer issues which BME carers face along with all others.

Recommendations

The main recommendations of our report are as follows:

1. GP practices should review their Carers' policy to ensure that there is a specialist section focusing on BME issues and support.
2. GP practices should consider implementing training on an unconscious bias to unpick where assumptions about BME culture and lifestyles exist and positively address those in their practices.

3. A Carers lead should be created at all GP practices who will develop links with the Croydon Carers Support Centre and specific BME organisations to act as a conduit between BME carers, the GP surgery and appropriate sources of support.

4. All GP practices should have a Carers Register which should be reviewed regularly.

5. GP practices should develop close links with the Croydon Carers Support Centre working in partnership with them to develop best practice with reference to carer support and a carer awareness culture.

6. Healthwatch Croydon should continue its work with partner agencies in Croydon to develop a CCG carer champion network.

PART A

CONTEXT, FINDINGS, ANALYSIS AND CONCLUSIONS



1. INTRODUCTION

1.1 About Healthwatch Croydon

Healthwatch Croydon is the consumer champion for users of health and social care services. Our purpose is to listen to and understand the needs, experiences and concerns of people who use health and social care services in Croydon. We support patients, residents and service users to voice their views and opinions on services. Healthwatch Croydon works to get the best out of health and social care services by responding to the voice of local people.

1.2 About the borough of Croydon

Croydon is a diverse borough in South London. It has wealthy and deprived areas across its neighbourhoods, along with some of the biggest inequalities in the city. Its ethnic demography is mixed, with the census data from 2011 showing the population to be 55.2% White; 23.6% Black and 18.3% Asian¹

1.3 The population BME carers in Croydon

There are over 33,000 carers in the borough; just under 10% of the population (ONS 2011), so as we can see from the census data, over a near half of these are likely to be from a

Black Minority Ethnic background. This means there could be as many as 15,000 BME carers in Croydon.

Healthwatch Croydon began with a research project: *Carers and GPs - The Rationale for Additional Research*.

We were keen to ensure that the focus of this work needed to complement the work already carried out by the Carers' Information service around GP support for carers in Croydon and reflected the London Borough of Croydon's identification in their Carer Engagement report from 2017, that:

“Future engagements should seek responses from the Asian community to ensure a better representation”.

This work found that the voices of BME carers and their needs are largely unheard and generally unassisted by those outside their immediate family. This contrasts with the evidence of Carers Register (held by the Carers' Information Service) that shows that 58% of carers are White and 42% BME reflecting the London Borough of Croydon population, This shows the lack of knowledge by some carers about the support available.

A range of issues have shown to impact on traditional family organisation including strict immigration laws, a growing preference for living in nuclear families, occupational

¹ Calculated from Office of National Statistics 2011 Census data from <https://www.croydonobservatory.org/population/>

mobility and housing problems. Fragmentation of family networks impact on where carers are available and issues such as gender, class, employment status of the carer and their integration into such networks impact on the support they are receiving.

In addition, Carers UK² have noted that BME communities are more likely to suffer from long term illness or disability which restricts daily activity with over 25% of Pakistani and Bangladeshi communities most likely to be at risk. The organisation notes that some BME communities have a shorter life expectancy and the reasons for this are quoted as factors associated with ill health, poverty, poor employment and poor housing.

“BME carers provide more care proportionately than White British Carers putting them at greater risk of ill health, loss of paid employment and social exclusion.”³

In addition to this, there is an acknowledgement locally that carers neglect their own health and wellbeing and that BME carers in particular face additional difficulties with stereotyping and social exclusion.”⁴



² Carers UK (2011) Half A Million Voices: Improving support for BAME carers

³ Ibid

⁴ National Institute for Mental Health in England (2003) Inside Outside: Improving Mental Health Communities for Black Minority Ethnic Communities in England

2. THE POLICY FRAMEWORK

The following policies and legislation have been considered in the scoping and framing of this work.

Legislation:

Under the Care Act 2014, (introduced in April 2015), local authorities and health bodies in England must work together to identify carers.

Statutory Guidance to the Care Act emphasises the importance of GPs as a first point of contact with services, according to the Department of Health 2014.

Key developments include:

- **The NHS Constitution** (2013) commits the NHS to work in partnership with patients and carers and to ensure that care is co-ordinated around the needs, convenience and choice of patients, their carers and families.
- **Commitment to Carers** (April 2014) in which NHS England accepted that the NHS needed to become dramatically better at involving Carers and developed a series of priorities to achieve this.

- **Commissioning for Carers** (Dec 2014) - Principles and resources to support effective commissioning for adult and young carers, to help Clinical Commissioning Groups better identify and help carers to stay well.
- **The NHS Outcomes Framework** - a way of measuring quality in the NHS, has featured 'Enhancing quality of life for carers' as a key domain for a number of years
- **NHS Mandate 2016/17** (Dec 2015) -the government's objectives for the NHS each year: "*Carers should be routinely identified and given access to advice and information about the support available.*"
- **An integrated approach to identifying and assessing carers' health and wellbeing** (May 2016) - addresses changes to the way in which carer health and wellbeing need is identified, assessed, and supported, through the Care Act and Children and Families Act 2014.
- **Royal College of Practitioners (RCGP) Carers Guidance: Supporting Carers - An Action Guide for Practitioners and their Teams**
- **GP Patient Survey** -Ipsos Mori 2016
- **Carers UK: Missing Out - The Identification Challenge** 2016

3. METHODOLOGY

We wanted to focus on how well GPs in Croydon have supported BME carers, both in terms of their own health and wellbeing and in terms of their role as a carer. We felt it was important to get some quality data and to do this, we had some in depth conversations with local carers to try and understand their needs and the issues they deal with. We therefore decided to use focus groups and one-to-one interviews as well as distributing a survey as our data gathering methods.

In our study, carers were asked about:

- whether their GP had facilitated access to a range of services including information, (useful to their caring role and about the condition of the person they are caring for).
- flexible appointments.
- health checks and flu jabs.

In order to promote the project and make contact with BME carers locally, Healthwatch Croydon worked collaboratively with a number of partner organisations including:

- [Croydon BME Forum](#)
- [Asian Resource Centre Croydon](#)
- [ASKI \(Advice, Support, Knowledge, Information\)](#)
- [Carers' Information Service - Carers Support Centre](#)
- [Help for Carers](#)
- [Croydon Voluntary Action](#)
- [Partnership with Parents](#)
- [Mencap](#)
- [Age UK](#)

We thank all these organisations for the partnership and support.

We are immensely grateful to the BME carers themselves that assisted us with our work without which our work would not have the authenticity and directness that they have provided.

4. FINDINGS AND ANALYSIS

4.1 Context

This report provides an analysis of data gathered from a series of six focus groups and six interviews totalling 33 BME carers as well as a survey of 29 BME carers. We have focused our attention on how well GPs in Croydon have supported BME carers both in terms of their own health and well-being and in their caring role. Inevitably, many of the issues identified will also be applicable to non-BME carers, but this does not make them less important to acknowledge and address. The main themes we identified were as follows:

- **Recognition of the caring role**
- **Carer's health and the impact of caring on health**
- **Cultural issues**
- **Access to and confidence in their GP**
- **Lack of signposting to services**

This part of the report breaks down those themes into sections and details our findings and an analysis of those as well as giving a flavour of the experiences of the BME carers we spoke to.

4.2 Recognition of the Caring Role

“The longer it takes to identify as a carer the more likely it is that carers will struggle without the support and advice they need. Frontline professionals, such as GPs, social workers and pharmacists play a central role in ensuring carers are identified and then guided to support as early as possible in their caring journey”.⁵

Carers UK report that:

- Over half of carers (54%) took over a year to recognise their caring role.
- Almost one in four carers (24%) took over 5 years to identify as a carer, and nearly one in ten (9%) took over 10 years.

When GPs recognise an individual's caring role, it enables signposting to support and services and promoting a focused discussion about their health and wellbeing. There has been a wealth of best practice regarding how GPs can fully support carers and a clear policy framework within which GPs are directed to work in this arena. A key document is NHS England's *Integrated approach to identifying and*

⁵ Carers UK (November 2016) – Missing Out: The Identification Challenge

assessing carer's health and wellbeing (May 2016)⁶. Principle 1 in this document supports the identification, recognition and registration of carers in primary care so that their needs can be identified more quickly and before their health and wellbeing deteriorates.

Only a few of the BME carers we spoke to felt that their GP recognised their caring role. National research makes clear that, by not receiving support at an early stage, the negative impacts of caring are intensified. Many carers will miss out on benefits and entitlements and other carers forced to give up work altogether.

“I would like to be recognised as a carer, to be acknowledged. I would like to be asked how I am doing, how are you coping? Why do I have to keep repeating information? With respect to my expectations of my GP well, it is about acknowledgement, which is the most important thing. I felt so isolated and lost, if there had been some support from the GP, I would not have been in such a difficult position. If only someone had helped. You feel let down by the whole system, am I the only carer in the world, I don't think so, why wasn't there recognition and support?”

⁶ NHS England (2016) An integrated approach to identifying and assessing carer health and wellbeing

Our research backed up this national data. Locally, a key priority for carers was that their caring role should be recognised by GPs and other health professionals. This would bring acknowledgement of their input in the day to day care of the person receiving their support and access to services and support in their own right. For some carers, they reported that recognition could lead to a reduction of their own isolation.

“If the GP had recognised my caring role, he could have shared information about my father more easily. In terms of specific support for my mother who is also a carer, there has been no offer of a flu jab, health checks or flexible appointments. I have not been recognised as an expert by experience. The lack of recognition has been difficult for all concerned”.

NHS England (Carers' Toolkit) strongly recommends that GPs work collaboratively with other partner agencies in identifying, assessing and supporting the wellbeing of carers. This is also in line with statutory guidance to the Care Act 2014 which emphasises the importance of GPs as a first point of contact with services (Department of Health, 2014). The Royal College of General Practitioners (RCGP) *Supporting Carers guidance*⁷ similarly stresses the key role played by

⁷ RCGP (2013) Summary Report on GP Practice Journeys Towards Improved Carers Identification and Support

GPs in supporting carer health and suggests the following as best practice:

- Developing a practice policy for carers and appointing a carer lead(s).
- Involving carers and the patient participation group in the development of the carer strategy.
- Ensuring that the whole practice team, clinical and non-clinical, are involved.
- Using a variety of methods to identify carers, including encouraging self-identification.
- Developing and maintaining a carer register which needs to be regularly updated to remain accurate.
- Supporting carers by providing information using a variety of different media.
- Offering enhanced access and flexibility of appointments for carers to make it easier for them to access healthcare.
- Offering carer health checks to monitor physical and mental health and annual influenza immunisation.

- Signposting carers to where they can get more information and support.
- Developing close links with local carer organisations, social services and the voluntary sector.
- Participating in a CCG carer champion network where available

4.3 Carers' Health and the impact of caring on health

"I have a caring role for my son who has autism. I have had depression and migraine and at times I have felt suicidal and I have sometimes found it difficult to get out of bed. I feel that my difficulties have been compounded by loneliness and isolation and years spent having to fight for support because everything is a battle. It is hard getting professionals to listen and to take notice. I am always feeling down and my health suffers, I want professionals to understand how caring affects me and to really listen."

A high proportion of carers that we spoke to have long term health conditions in their own right and the majority felt that caring impacts on their health in some way. In our survey concerning BME carers we found that a significant proportion of carers (65.51%) overall commented that they

have a long term health condition. Significantly, when asked as part of our survey if their GP had offered them a health check, (72.41%) of our sample replied “no”. This is despite moves locally to make NHS Health checks easier for carers to access by providing them at the Carers Support Centre. These health checks are critical for picking up risk factors which can be linked to common long term health problems such as heart disease, type 2 diabetes and stroke.

Croydon still has one of the lowest NHS Health Check take up rates of all the London boroughs, with 5.4% of the eligible population being offered an NHS Health Check in 2016. In the report “*Not Just a Patient - GP Support Services in Croydon*”⁸ it is noted that:

“Offering the NHS health check has been shown to have a measurable impact on carers’ ability to take informed self-care of their own health.”

We know from inquiring about the BME carers health status that there were frequent references to high blood pressure, diabetes, arthritis and anxiety and depression. This also aligns with data about BME carers and health in London where Carers UK⁹ reported that 35% of all carers surveyed are BME carers in poor health:

⁸ Carers’ Information Service (May 2017) *Not Just a Patient – GP Support Services in Croydon*

“From surveys gathering their experiences, they put the reason down to stress, isolation, struggling to make ends meet, insufficient assistance, inability to attend to their own health needs because they are caring and, finally, insufficient training often leading to physical injuries whilst caring.”

Some of the carers we spoke to commented that GPs were not sympathetic to the physical pain that often accompanied their long term conditions.

“I have arthritis, and I have been prescribed pain killers, I have severe lower back pain in particular but I have been told by health professionals, it is mind over matter, if you don’t think about the pain you don’t have it.”

“I had to go and see the GP and I had to go upstairs for my appointment and I don’t do stairs. The surgery used to have a lift and they took it out. It should be on my notes that my knees are bad and my back and I cough a lot. They should test my breathing and I shouldn’t have appointments in rooms that are inaccessible to me.”

⁹ Carers UK (2011) – *Half a Million Voices: Improving Support for BME Carers*

Other carers have discussed the overwhelming impact of stress in their lives and how this can have a debilitating effect and lead to further anxiety for them. Carers frequently talked about the stresses inherent in caring.

“Sometimes the stress has been overwhelming and because you feel unwell, you suffer from anxiety and you don’t sleep, you get every cold going and you feel run down.”

“The mental aspect of caring is very hard. I have to get used to not being spontaneous too and I feel that my life has become restricted by caring. I am not able to get out and do exercise and make time for my health. I am not able to eat healthier food too as that is expensive.”

“I have suffered with anxiety for about 10 years and I feel that this has been aggravated by caring. My GP treated me with anti-depressants but these have not been very effective. I feel that my GP ... should have investigated the greater context of my life and provided me with the relevant information I needed and given me access to the right therapies”.

Challenges facing the carers crossed a wide range of issues from restrictions on personal freedom, lack of understanding about what the caring role can entail, assumptions about caring, and a lack of information about services and support. There were other challenges too for carers including a lack

of understanding by professionals and the often mentioned observation that GPs concentrate only on the medical aspects of a carer’s life. This was seen as ignoring the social dimension of caring and led to further barriers in terms of accessing services.

4.4 Cultural Issues

People that we spoke to revealed that there were assumptions that members of the BME community would take on a caring role as it was ‘what this community does’. and therefore less resources and support were offered to support the caring role.

“Doctors made the assumption that because he (her father) had a good unit, a family, around him that we were all capable and will do the looking after him, for example cleaning my father when needed. (That) all individuals within the family will get involved, we will all become carers, especially within the Asian community.”

This assumption of an automatic care role could be the reason why less resources and support were offered to these families. This lack of support can clearly impact on the carer’s health through carers lacking information for example about assessments or break services. In order for services to be appropriate for BME carers and their cultural

needs, several things would need to be taken into consideration: language, food that is appropriate to their needs and tastes, opportunities to take part in their own religious observances etc. Services that did not allow participants to take part in culturally appropriate activities could in turn prevent BME families from taking up services.

An additional key issue arising in the focus groups were the difficulties some BME carers had in advocating for first generation family members. Cultural taboos around caring and disability was also discussed in the focus groups. For example one Asian carer commented:

“In the Asian community we have a lot of respect in friends’ families especially when we speak about taking care of Dad’s personal care. We do feel that people come round less though and maybe this is because of Dad’s set up in the living room which can be uncomfortable for some”.

Carers commented too on the wider community’s assumptions and examples of stereotyping from some members of the community concerning their family and health issues. For example, around issues on language advocacy where, ironically, some GPs assumed that older members of the family would not be able to understand English, whilst others had no provision for providing information in a different language.

One BME carer we spoke to said that GPs made the assumption that she had accompanied her father to GP appointments because her father couldn’t speak English when in fact the key issue was her fathers’ confusion. Whilst another said:

“My mother is a first generation Asian, she can’t advocate for herself so we have to stand and be the voice of the patient, you need the language to talk. It is a struggle when your parents are first generation and they need advocacy. This is because their literacy levels are low, they are not able to access information and they are unable to engage with the information provided to them.”

Other cultural stereotyping issues were also encountered:

“I have to state that my GP is very good but when my son was sick we were faced with, your son is lying about his symptoms. You Asians like to push your kids.”

4.5 Access to and confidence in their GP

This topic brought up a wide range of issues, such as:

- The ability to contact the surgery by phone at peak times -this was considered difficult to do at 8.00am. Carers frequently mentioned that the phone lines were constantly engaged and when contact was made with the surgery some carers felt that additional barriers were placed by receptionists.
- Long waiting times to see a GP (a week or more) was also cited by some as causing difficulties for them and also the problems associated with getting a home visit was also a shared concern.
- Difficulties in getting 'flexible appointments' ie. double appointments or appointments at more convenient times (evenings and weekends); when asked about this further, the carers either stated that they did not know that this was an option or that the opportunity was not made available.

“Sometimes the waiting time to see a GP once you are in the surgery is too long. I am sitting up to an hour with my child who has special needs and that can be very difficult.”

“You can often wait for days/weeks to see your GP, so a lot of issues that I have, I wouldn't necessarily go and see my GP and there is no point in phoning as I might not get an appointment straight away.” “The receptionists act as a blocking influence. Can you help me, are you a GP?”

“I would prefer an email booking system for booking so that I can bypass the receptionist. I believe she needs training and has an unsympathetic attitude and that makes me angry.”

What carers seem to value most in their GP was a kind and understanding attitude as well as prompt access to the surgery and subsequent treatment for their needs. Where praise was given to GPs it is when they give the carer time, recognise their caring role and have an understanding of the potential impacts of caring on their health.

Where carers related concerns, it was partly that they felt GPs were concentrating on the medical model and not enough time and attention was given to the social aspects or wider context of a person's life. Our data showed that just over half of the BME carers had confidence in their GP

“Caring was a completely new thing for me. It was a caring job that I had done for my mother but I never expected that I would have to care for my sister too. That fell on my shoulders. I was so stressed, I could not sleep very well, in the middle of the night you wake up and early in the morning. So many thoughts are running through your mind but I had the support of my husband and the support from organisations. I had to go to counselling, I didn’t know which way to go at first. If you ask me about my doctor, I am very happy with my doctor, she looks after me and is very understanding as well. I thank God that I had good people around me to help because I had a lot to deal with.”

4.6 Lack of signposting to services

NHS England has a number of responsibilities towards carers that have been outlined in a wide ranging policy framework (see section 2). Their Commitment to Carers engagement process highlighted a number of themes that carers have said are important to them, and signposting information for carers is an important priority. That GPs routinely refer carers to the significant support agencies such as the Carers Support Centre in Croydon is hugely important in so many ways as the organisation provides information and advice, training, ongoing support and respite through their support groups, social outings and health and well-being activities. They support carers of all ages offering advice and guidance in complete confidentiality. Similarly referral to an

appropriate BME support organisation would also be beneficial.

Many general organisations including the Royal College of General Practitioners, Carers Trust, Carers UK and local commissioners have described initiatives that practices can use to improve the care they give to carers. While these are not BME-specific they show that good and outstanding care for carers can be identified through a range of services and support. The Croydon Carers’ Information Service report, *Not Just a Patient* of 2017 also raised some of these issues and to compare where themes were similar, these are shown in bold, in the following:

- **Directing carers to local carer and patient support services.**
- **Working collaboratively with carers on patient care.**
- GPs being aware of mental health issues for carers and screening them annually for depression.
- **Providing access to flexible appointments to fit in with caring responsibilities.**
- **Ensuring carers’ overall health is properly monitored, for example by issuing reminders to carers to have an NHS health check and a flu jab.**

- Organising carer support groups or advice surgeries.
- Organising surveys to gather carers' feedback about services and their satisfaction with them.
- **Referrals to carers services for more specialised information, advice and support (including carers assessments and support for young carers).**
- Helping to ensure carers have emergency plans in place.
- **Providing an understanding and compassionate approach.**

This list serves to remind us to pause and then reflect on what the carers in our study have told us about the services and support that they have received in Croydon.

When we asked BME carers what would most support their health and wellbeing, the most frequent response was access to information to support and manage their health condition. Those who had had input from elsewhere to support them in their role had found this invaluable.

“I have had 12 weeks counselling and Go Active has also been helpful. My GP could have told me about that. Voluntary groups have been very helpful to me, more support would follow recognition of the caring role.”

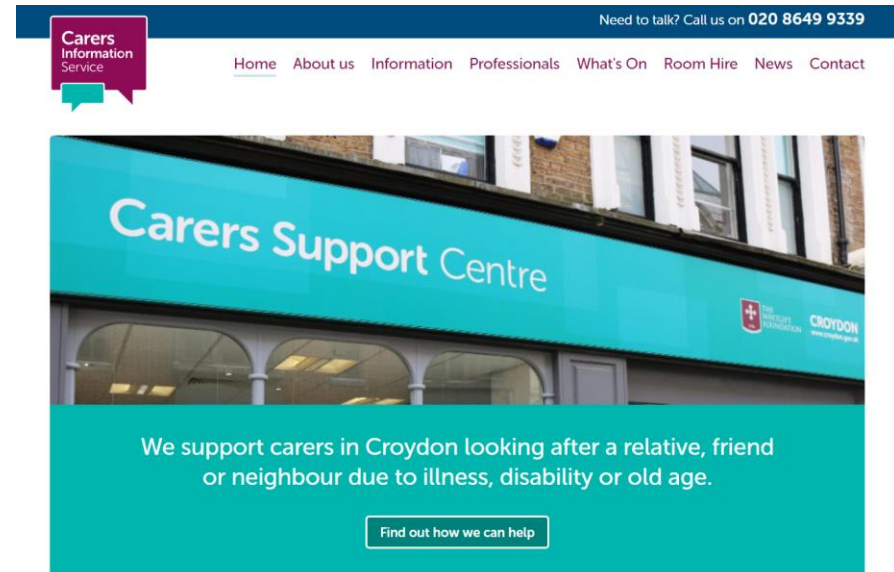
Unfortunately, a recurrent theme in the focus groups and individual interviews was that carers feel that they lack knowledge about services and support and that their GP should assist them in referring them to services or signposting them to where that support exists. They felt this would greatly assist them in terms of their health and their caring role. Respondents felt that the willingness of their GP to do this was related to their recognition from the outset that their patient may also be a carer.

“I should have been given the right information at the onset of caring. The doctors should be responsive to your needs and they should tell you about the services that can help you. I wasn't in the frame of mind to do my own research and the GP should help you. Double appointments would be helpful and to signpost you to services. It needs proactive support or it might be too late.”

“Not knowing about support is a real barrier, you are just working in darkness.”

“It is like a big secret and you are not in the know and yet there are services out there that can help you.”

“Doctors need to just to tell you about a carers’ group and if you are stressed, send you to somewhere in the community to help. Doctors need to be skilled and educated and be aware of our presence, be aware of illnesses, our caring role and signpost us. Open the door and tell us about support, information and services.”



Carers Information Service website - www.carersinfo.org.uk

5 CONCLUSIONS

We have concentrated throughout this report on the “lived experiences” of BME carers in relation to GP services in Croydon. The qualitative data provided by the carers has shaped our recommendations alongside a consideration of the policy framework which underpins this work.

The most important issues to emerge in our study are that GPs in Croydon are not sufficiently recognising the caring role or referring carers to the Carers Support Centre in Croydon and other support services. This leads to a situation where carers themselves lack awareness about their own carer status and the wider support available to enhance their caring role. Without appropriate support BME carers feel they are grappling in the dark having to navigate the health and social care system. When BME carers have had swift referrals for treatment and support (health and wellbeing) as well as where GPs have provided access to appropriate services, they have spoken really positively about this. Access to appropriate information is highly valued by BME carers and top priority is accorded to access to pampering services and to support physical and mental wellbeing. Access to back care services, employment support and counselling are also priorities.

Carers UK had noted that BME communities are more likely to suffer from long term illness or disability which restricts daily activity. The 2011 Census informed us that if carers care over 50 hours per week they are twice as likely to report being in poor health as the non -carer population. A number of the carers we spoke to had caring commitments in excess of 50 hours and accompanying long term health issues. It is therefore critical that access to appointments are flexible at a time which is more convenient to the carer and their family.

The *NHS Commitment to Carers: Principle 3 Right Care, Right Time, Right Place*¹⁰ recommends that:

“By offering flexibility with appointments for example outside normal clinic times and offering a home visit for those carers who cannot leave the person for whom they care in order to attend a surgery appointment improves access”.

BME carers have been positive about experiences when they have been provided with some flexibility with regard to their appointments particularly home visits.

Where there have been very positive comments about GPs in our study this has related to having access to a warm and understanding doctor. Where the GP has given the carer time, listened to them sympathetically and where there was a good rapport, BME carers have felt valued and acknowledged.

¹⁰ NHS England (2017) see <https://www.england.nhs.uk/commissioning/comm-carers/principles/principle-3/>

Where GPs are prepared to work in partnership with the carer recognising them as an expert by experience is particularly valued. 55.17% of carers in our survey expressed confidence in their GP.

BME carers have provided us with some clarity in this study about what matters to them most. There is a great deal of information in literature, wider research, nationally and at local level about what BME carers say is important to their support in caring and wider health. A large proportion of the issues in this report also reflect those of non-BME carers, but it is important to take notice of the specific set of issues around language, culture and assumptions about those which can greatly affect this group.

The RCGP makes clear that supporting carers will benefit practices as it will help prevent unnecessary hospital admissions and save them work in the longer term. We have provided some analysis of the support that BME carers state that they have received and recommendations accompany this report.

We want this report to be a first step to help influence and improve the support that GPs provide BME carers of all ages and backgrounds. We hope that our research can help to shape what works and in sharing that information we can help to make every contact count.



6 RECOMMENDATIONS

This report makes the following recommendations

1. GP practices should review their Carers' policy to ensure that there is a specialist section focussing on BME issues and support.
2. GP practices should consider implementing training on an unconscious bias to unpick where assumptions about BME culture and lifestyles exist and positively address those in their practices.
3. A Carers Lead should be created at all GP practices who will develop links with the Croydon Carers Support Centre and specific BME organisations to act as a conduit between BME carers, the GP surgery and appropriate sources of support.
4. All GP practices should have a Carers Register which should be reviewed regularly
5. GP practices should develop close links with the Croydon Carers Support Centre working in partnership with them to develop best practice with reference to carer support and a carer awareness culture.

6. Healthwatch Croydon should continue its work with partner agencies in Croydon to develop a CCG carer champion network.

7. Action against recommendations should be reviewed by a multi-agency group including BME carers within 6 months of the publication of the report.



PART B

RESEARCH DATA



Croydon BME carers taking the survey

7. RESEARCH DATA

7.1 Service users

Focus Groups: Dates and Venues:

- 27 June Focus Group at the Croydon BME Forum - 3 carers attended
- 28 June Focus Group - contact with 9 carers at their Carers Group
- 4 July Focus Group - an evening meeting for working carers - 2 carers attended plus a carer scribe
- 5 July: Focus Group at the Carers Centre, 2 carers attended - 1 carer scribe
- July: Focus Group at ASKI, 6 carers attended
- 11 July Focus Group at the Asian Resource Centre Croydon - 5 carers attended
- 12 July 1 carer attended and this was a one-to-one interview

Also on 12 July we attended the Eid party and interviewed 3 carers through a one-to-one scenario for the purposes of inputting into our survey

Total no of Carers contacted through focus groups and one-to-one interviews for case studies only (not survey): 28

One-to-one Interviews in person or over the telephone for case studies:

- Carer 1 Interview - Black British Female (age range 51-60)
- Carer 2 Interview - Black African Female (age range 41-50)
- Carer 3 Interview with Asian Female - (age range 30-40)
- Carer 4 Interview - Black British Female (age range 51-60)
- Carer 5 Interview - Asian Female (age range 41-50)

Total no of carers contacted in person or over the telephone: 5

Survey - total no of carers inputting 29.

Total no of carers inputting into our project: 62

7.2 Focus Group Questions:

Questions arising in the focus group work concerned carers' health status, whether they believed caring had an impact on their health and whether their GP had recognised their caring role. There was a focus on the carers' experiences of the GP services, their expectations, barriers and opportunities and priorities for the future.

7.3. Survey:

The survey comprised of 29 questions and it was anticipated that the survey would take 10 mins to complete. The survey comprised the above areas described in the focus group questions but also covered areas concerning ease of access to their GP, access to a preferred GP, confidence in their GP and whether their GP had

supplied best practice in relation to their own health and caring role.

About the survey respondents

29 BME carers took the time to complete our survey and to tell us their views and experiences of using their GP services in Croydon.

Ethnicity, Gender and Age Range profiles:

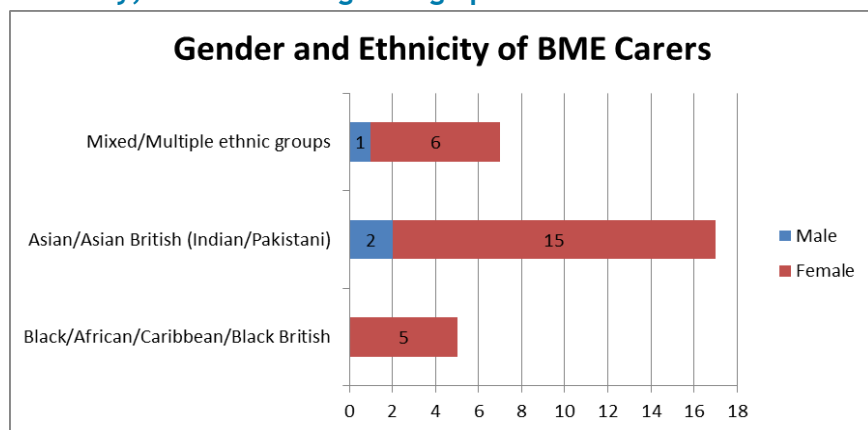


Figure 1 Gender and Ethnicity of BME carers

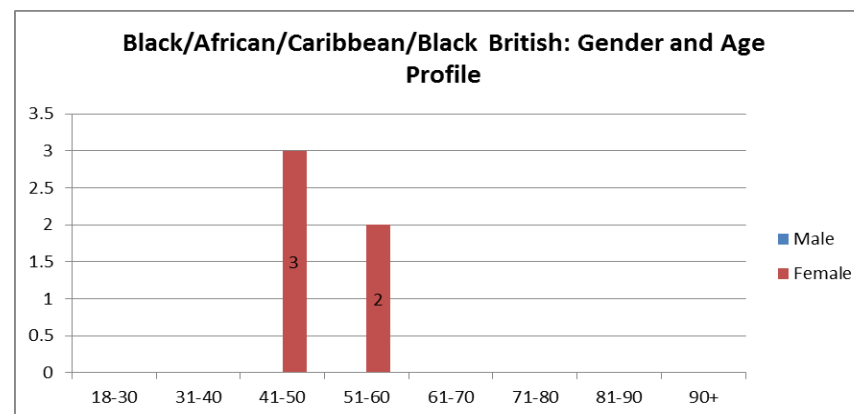


Figure 2 Black/African/Caribbean/Black British: Gender and Age Profiles:

Here the carers represented in Figure 2 are female only. This cohort represents 17.24% of the overall BME carer sample. Caring activity is clustered in the age range of 41-60 and this age range represents 100% of the Black African/Caribbean/Black British cohort. It provides an interesting comparison to the national picture for generic carers respectively where one in five people aged 50-64 are carers.

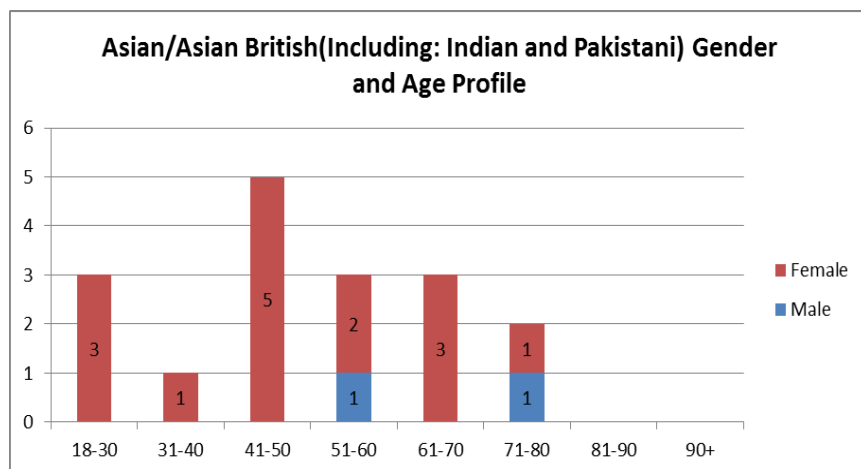


Figure 3 Asian/Asian British (including: Indian and Pakistani) Gender and Age Profiles:

The Asian/Asian British carers represent 58.62% of the BME carer cohort overall. The carers represented in Figure 3 indicate that the majority of carers are female with 88.23% of the Asian/Asian British cohort) with male carers representing 11.76% of this sample. The majority of carers are seen in the 41-50 age bracket, (29.41%) and (17.64%) of carers are young adults and this proportion is also caring in the age range 61-70.

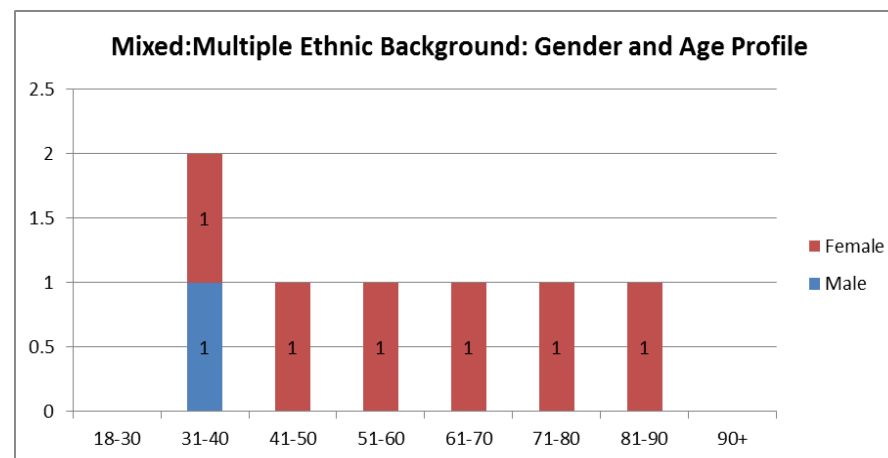


Figure 4 Mixed: Multiple Ethnic Background: Gender and Age Profiles :

The Mixed Multiple Ethnic carers represent 24.13% of the BME carer cohort overall. The carers represented in Figure 4 indicated that the majority of carers are female (85.71% of the available sample) as compared to 14.28% of the sample being male carers. Here 28.57% of the Mixed Multiple ethnic carers cohort are caring in the age range 31-40, however caring activity is on the whole reflected across the age ranges other than the onset of young adulthood and the older age range.

Health of the Carer

Long term health conditions:

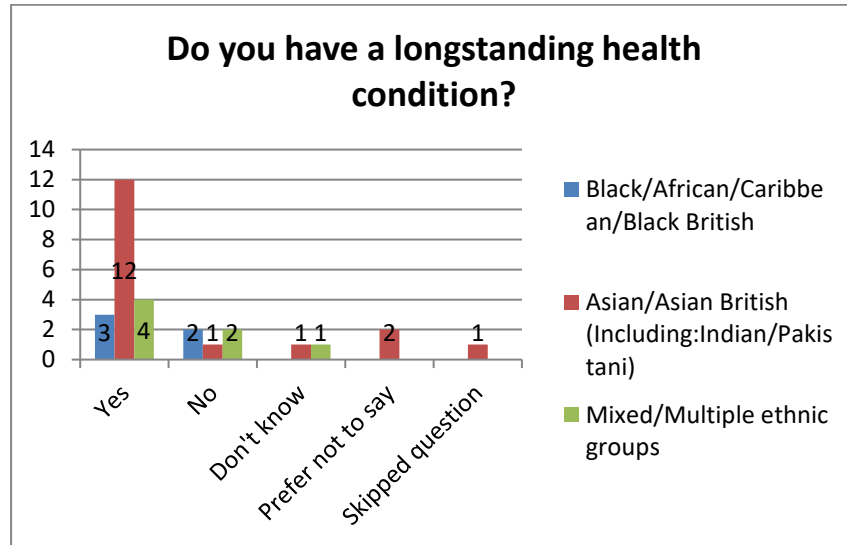


Figure 5: Do you have a long term health condition?

- A significant proportion of carers (65.51%) of the BME carer cohort overall commented that they have a long term health condition, while 17.24% of the carers surveyed stated that they did not have a long term health condition. A significant proportion of Asian/Asian British cohort have longstanding health conditions (70.58%) as compared to (60%) of the Black/African/Caribbean/Black British carer community and 57.14% of the Mixed/Multiple ethnic group.

- BME communities are more likely to suffer from long term illness or disability which restricts daily activity with over 25% of Pakistani and Bangladeshi communities most likely to be at risk.
- Significantly, our sample also provides an interesting comparison with a generic carers survey in “The GP Patient Survey in 2015” which highlighted the impact of generic caring on carer health - whilst 51% of non-carers had a long-standing health condition this rose to 63% of all carers and 70% of carers caring for more than 50 hours per week.

Long Term Health conditions: By Ethnicity

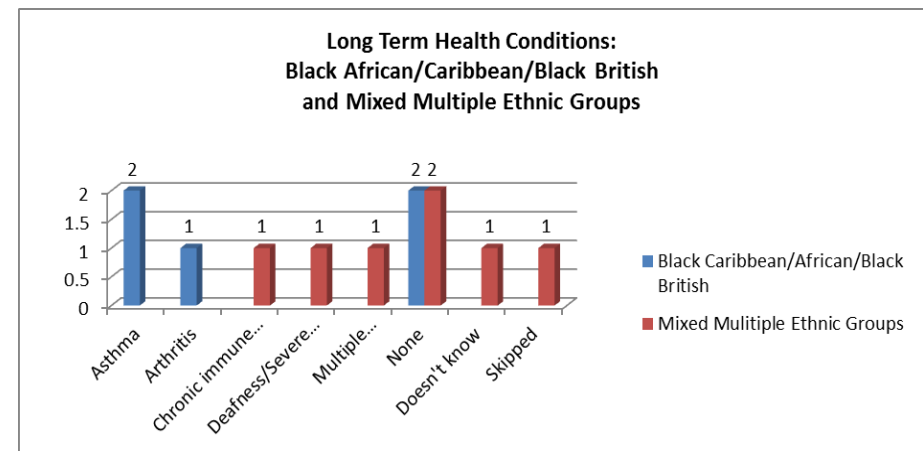


Figure 6: Long term health conditions (Black Caribbean/African/Black British and Mixed Multiple Ethnic Groups)

Mutple conditions refer to: Arthritis, visual impairment, mental health in one carer.

Asian/Asian British (including Indian and Pakistani)

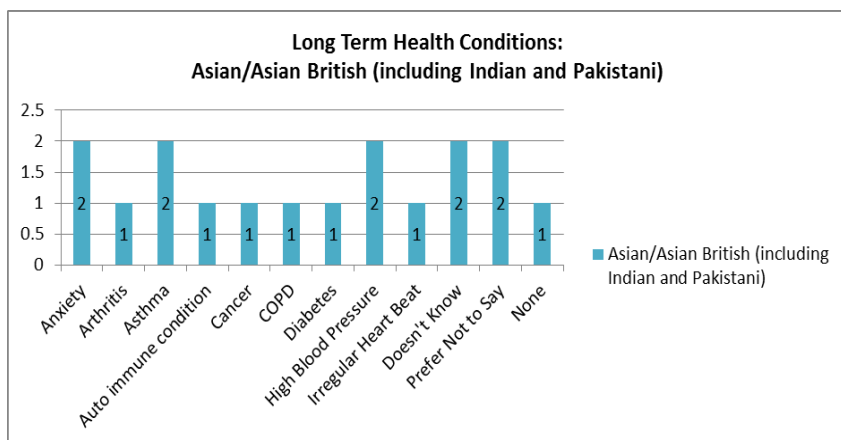


Figure 7: Long term health conditions Asian/Asian British (including Indian and Pakisani)

Common conditions reported in the focus groups and one-to-one interviews have included: asthma, arthritis, high blood pressure diabetes and anxiety. These conditions are also seen here (Figures 6 and 7) in the responses to the survey. In terms of the national picture Carers UK provide an interesting comparison with generic carers, relating that in the GP Patient Survey 2015 carers also reported higher levels of arthritis, high blood pressure, long-term back problems, diabetes, mobility problems, anxiety and depression.

The Health condition of the person requiring care.

| What is the Health Condition of the person you are caring for? | | |
|----------------------------------------------------------------|------------------------------------------------------|-----------------------------------------|
| Ethnicity of Carer | Health condition of service user | Caring role(s) |
| Black/African/Caribbean/Black British | | |
| Carer 1 | Carer skipped question | Cares for 1 child |
| Carer 2 | Learning disability | 1 Caring role for an adult |
| Carer 3 | Dementia, elderly, frail and arthritis | 1 caring role for an adult |
| Carer 4 | Child with autism, 1 child with asthma and allergies | 1 carer has caring roles for 2 children |
| Carer 5 | Child with autism | 1 caring role for 1 child with autism |

Figure 7 (1) : What is the health condition of the person you are caring for?

| What is the Health Condition of the person you are caring for? | | |
|----------------------------------------------------------------|----------------------------------------------------------------------------|--------------------|
| Ethnicity of Carer | Health condition of service user | Caring role(s) |
| Asian/Asian British (including Indian and Pakistani) | | |
| Carer 1 | Skipped the question | Cares for 1 adult |
| Carer 2 | Elderly/Frail | Carers for 1 adult |
| Carer 3 | Elderly/Frail: Diabetes, glaucoma, thyroid, high blood pressure and asthma | Cares for 2 adults |
| Carer 4 | ADHD, Autism, learning disability | Cares for 1 child |
| Carer 5 | Hearing impairment | Cares for 1 adult |
| Carer 6 | Skipped the question | Cares for 1 child |
| Carer 7 | Frail/elderly | Cares for 1 adult |
| Carer 8 | Heart problems | Cares for 1 adult |
| Carer 9 | Dementia/frail elderly | Cares for 2 adult |

| | | |
|----------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------|
| Carer 10 | Dementia/Elderly/frail | Cares for 1 adult |
| Carer 11 | Dementia/Elderly frail /hearing impairment | Cares for 1 adult |
| Carer 12 | Hemiplegia and mental health | Cares for 1 adult |
| Carer 13 | Life limiting illness | Cares for 2 children |
| Carer 14 | <ol style="list-style-type: none"> 1. Stroke and Parkinsons 2. Suspected dementia and stroke: Elderly/frail/life limiting illness Elderly/hypothyroidism, spinal spondylosis, osteoporosis | Two caring roles, caring for adults (parents) |
| Carer 15 | Older age related | Cares for 1 adult |
| Carer 16 | Elderly frail | Cares for 1 adult |
| Carer 17 | Stroke/Life limiting illness | Cares for 2 adults |

Figure7(ii): What is the health condition of the person you are caring for?

| What is the Health Condition of the person you are caring for? | | |
|----------------------------------------------------------------|----------------------------------------------------------------------------------------------------|-------------------------------|
| Ethnicity of Carer | Health condition of service user | Caring role(s) |
| Mixed Ethnic Groups | | |
| Carer 8 | Autism | Cares for 1 adult |
| Carer 9 | Dementia | Carers for 1 adult |
| Carer 10 | Multiple (depression, dyspraxia, dyslexia) | Cares for 1 adult |
| Carer 16 | Severe autism, learning disabilities, epilepsy | Cares for 1 child |
| Carer 21 | (i) Elderly parent with heart condition (ii) adult son with visual impairment and mental health | 2 caring roles for two adults |
| Carer 22 | Rheumatoid arthritis and Alzheimers | 1 adult |
| Carer 28 | (i) Cancer (ii) registered blind | 2 adults |

Figure 7(iii) : What is the health condition of the person you are caring for?

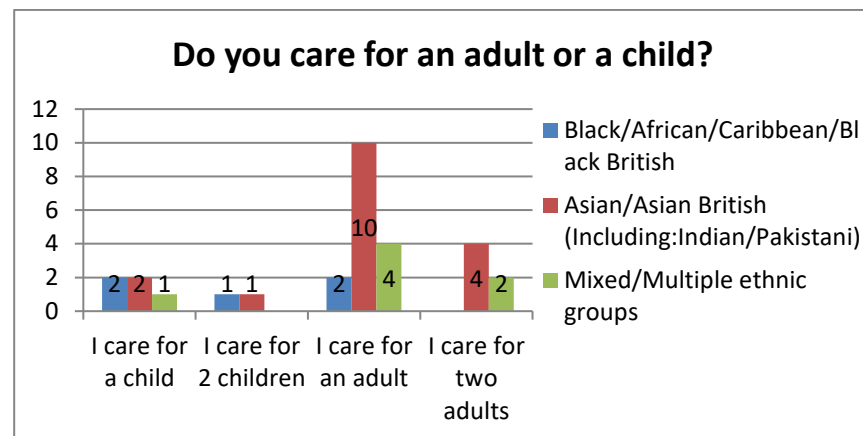


Figure 8: Do you care for an adult or a child?

75.86% of BME carers in our sample are caring for an adult and 24.13% are caring for a child.

The caring role: How many are you caring for?

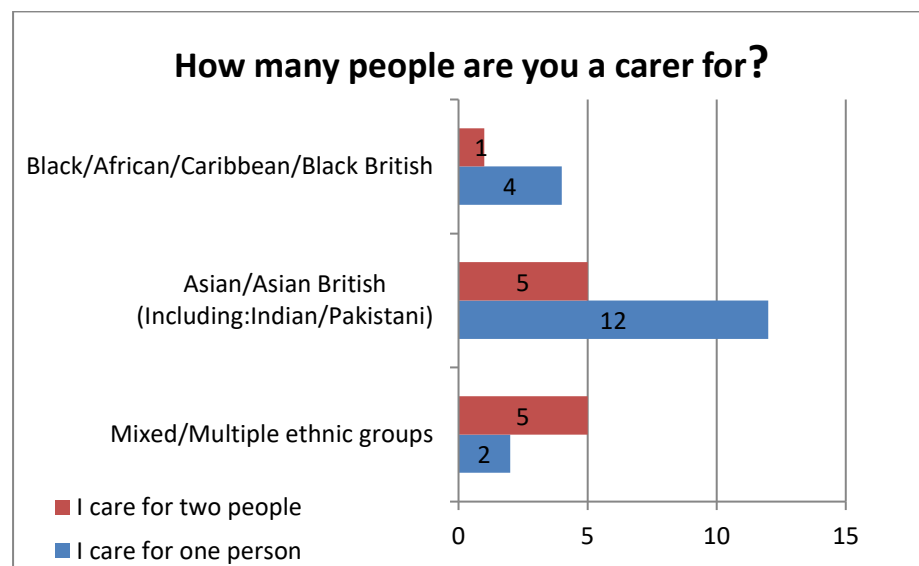


Figure 9: How many people are you a carer for?

The caring role: Hours spent caring

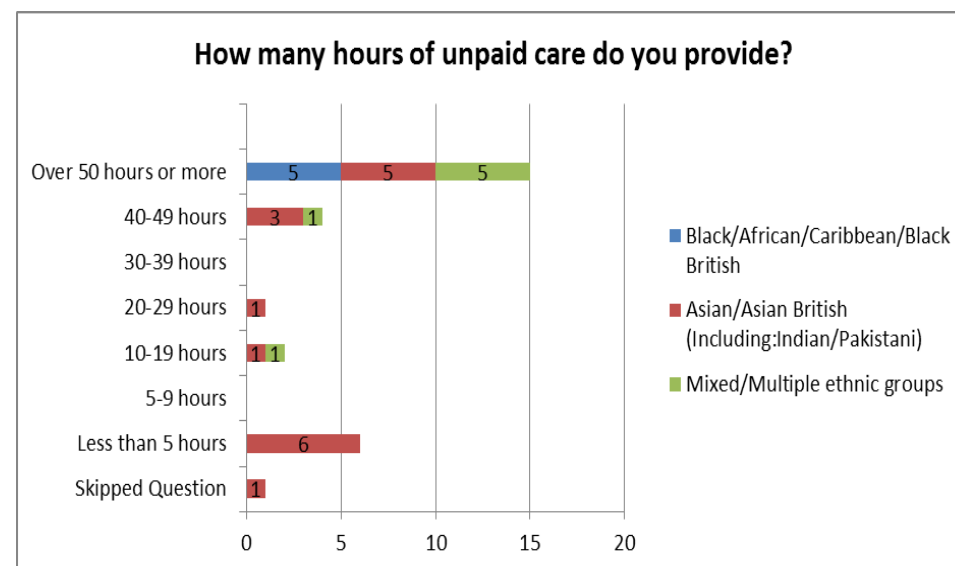


Figure 10: How many hours of unpaid care do you provide?

Just over half (51.72%) of our sample of BME carers overall are caring for over 50 hours or more a week.

- The 2011 Census reported that Carers providing round the clock care are more than twice as likely to be in bad health as non-carers.
- 100% of the Black/African/Caribbean Black British cohort are caring for over 50 hours or more per week. This compares with 29.41% of the Asian/Asian British group and 71.42% of the mixed multiple ethnic groups.

Impact on Health

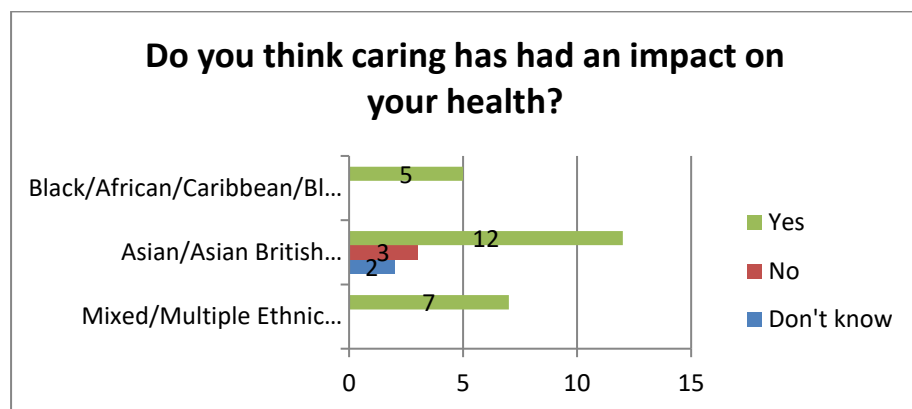


Figure 11: Do you think caring has had an impact on your health?

The clear majority of BME carers responding to our survey (82.75%) believe that caring has had an impact on their health.

- 100% of the Black/African/Caribbean/Black British cohort believe that caring has had an impact on their health and this is also true of the Mixed/Multiple Ethnic groups.
- 70.58% of the Asian/Asian British group believe that caring has had an impact on their health.
- 100% of the Mixed Multiple Ethnic carers group believe that caring has had an impact on their health.
- Analysis of the 17.64% within the Asian/Asian British group that reported that caring had not had an effect on their health, 2 are male and 1 is female.

How easy is it to see your GP?

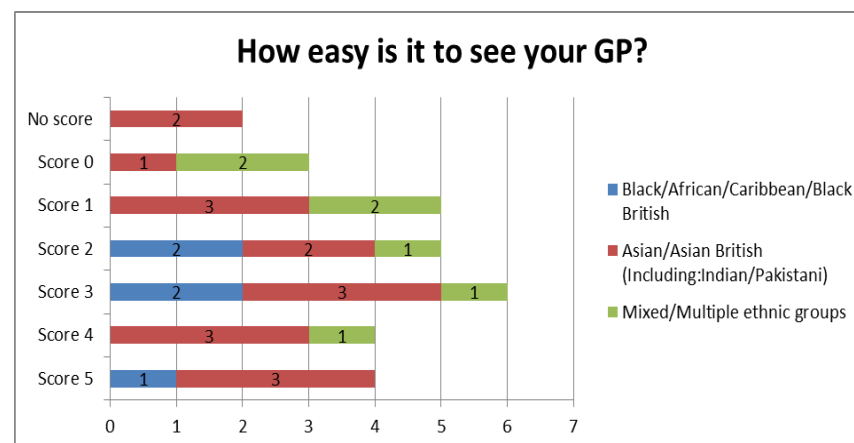


Figure 12: How easy is it to see your GP?

Carers were asked how easy it has been to see their GP. The scale was as follows: 5 being very easy and 0 not easy at all.

BME carers most frequently provided a score of 3 in terms of the ease in which they can see their GP. This represents 20.69% of the sample overall.

The group that found it easiest to access their GP were the Asian/Asian British cohort with 20.68% of the BME sample providing the top scoring of 4 and 5 with respect to ease of access in terms of seeing their GP.

The group that found it the most difficult to see their GP was the mixed/Multiple ethnic group with 17.24% of the overall sample of BME carers reporting a scoring range from 0-2.

Difficulties in getting through to the surgery at 8.00 am and when the phone is engaged is a common refrain from BME carers.

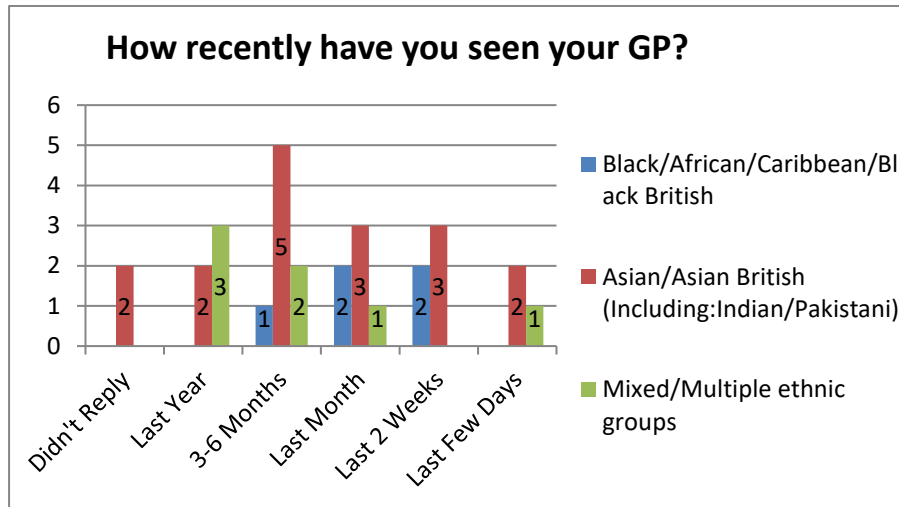


Figure 13: How recently have you seen your GP?

27.59% of the available BME carer sample have seen their GP in the last 3-6 months

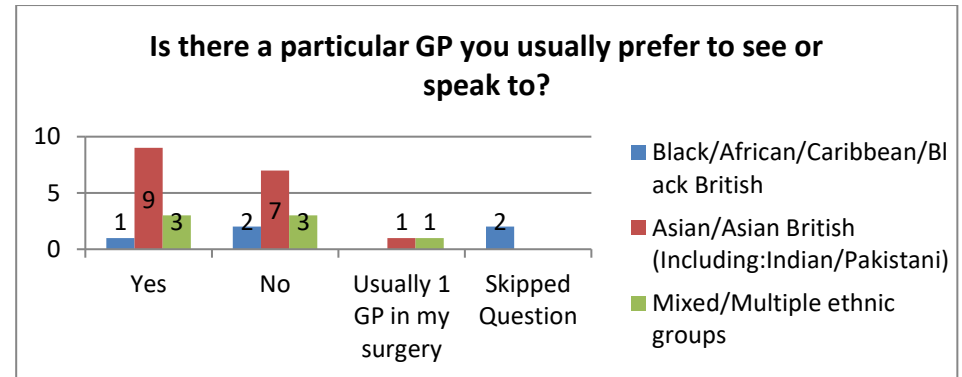


Figure 14: Is there a particular GP you usually prefer to see or speak to?

- Of the BME sample that elected to answer the question and had a choice in their GP, 52% of this sample stated that there is a GP that they usually prefer to see or speak to.

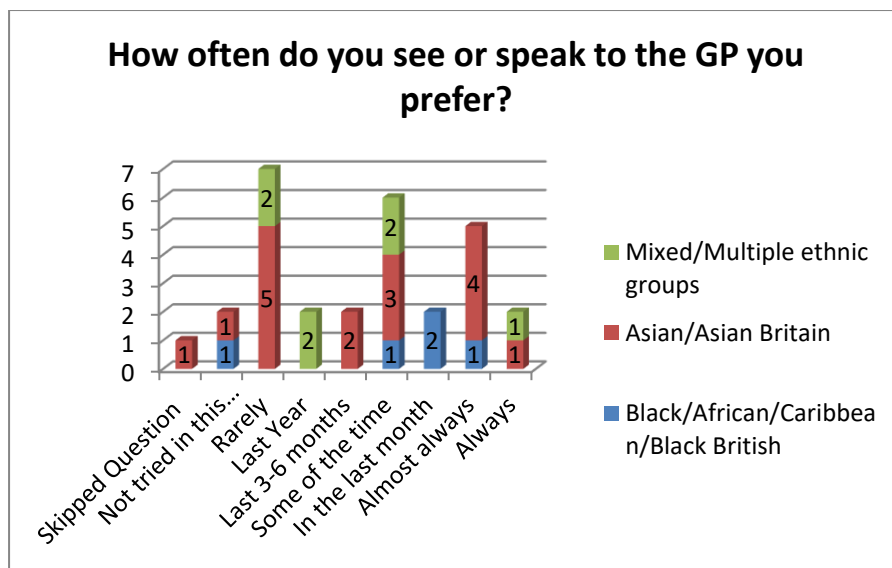


Figure 15: How often do you see or speak to the GP you prefer?

24.13% of the available BME carer sampled rarely see or speak to the GP that they prefer.

Analysis of the GP Patient Survey (2017) provides us with an interesting comparison. The analysis informs us that carers have a greater need for personalised care and are more likely to say they have a preferred GP. In spite of their greater preference for seeing a particular GP, carers in the aforementioned survey were slightly less likely to be able to see their preferred GP almost always or a lot of the time, 57% compared with 59% of non carers.

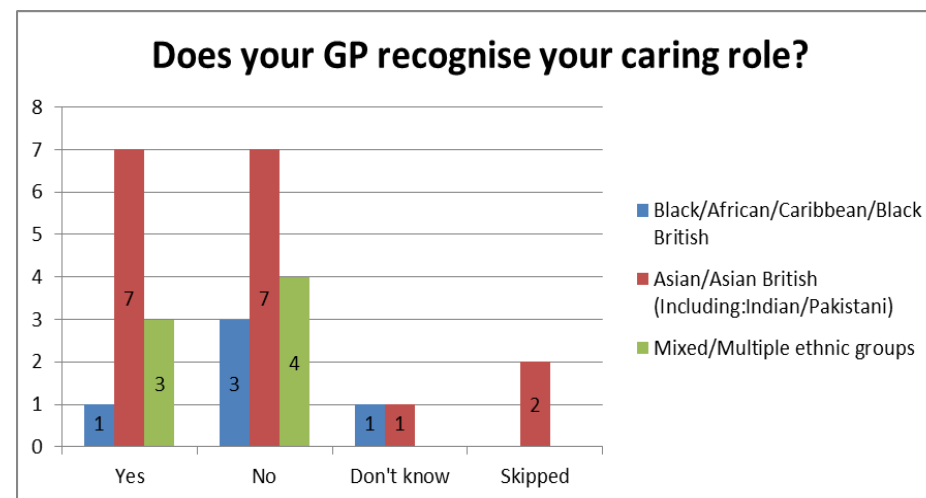


Figure 16: Does your GP recognise your caring role?

Only 37.93% of BME carers in our survey reported that GPs recognised their caring role. In terms of the specific ethnicity of the carers responding to the question about recognition we can note the following:

- 20% of Black/African/Caribbean/Black British carers responded that their GP recognised them as carers.
- 41.17% of Asian/Asian British carers commented that their GP recognised them as carers.
- 42.85% of the carers from the Mixed/Multiple ethnic groups commented that their GPs recognised them as carers.

From this small scale exploratory study we can see clear evidence that more needs to be done by GPs to support carers in recognising their caring role and signposting them to support.

By not receiving support at an early stage, it has been recognised that the negative impacts of caring can be intensified with many carers missing out on vital support. National research¹¹ has shown that a lack of support can have a huge impact on health and well-being from long term physical health effects to mental ill health and social isolation.

Front line professionals such as GPs can play a central role in ensuring carers are identified and then guided to support as early as possible in their caring journey. GPs in Croydon are not sufficiently recognising carers and signposting them to support.

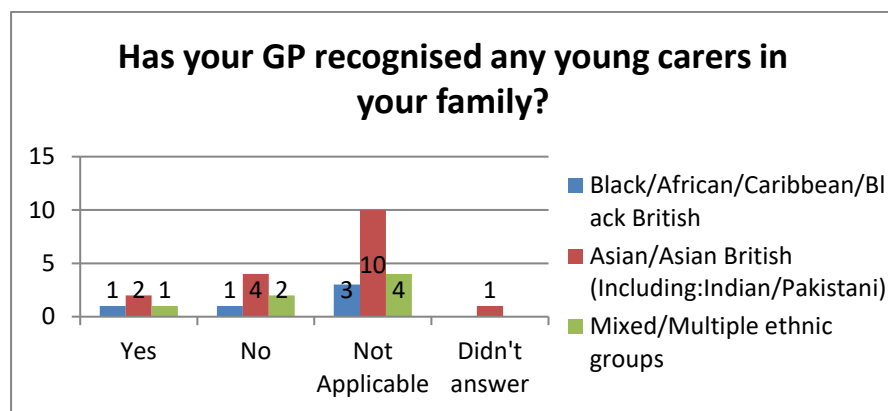


Figure 17: Has your GP recognised any young carers in your family?

In terms of the BME sample overall, when the “non-applicable” and “didn’t answer” categories are taken account of 36.36% of young carers have been recognised by the GP. 63.63% of the sample have not been recognised.

- 50% of the Black African/Caribbean Black British cohort has had young carers recognised in their families. 50% have not had recognition.
- 33.33% of the Asian/Asian British cohort has had young carers recognised in their families, 66.66% have not.
- 33.33% of the Other Mixed Ethnic Group has had young carers recognised in their families, 66.66% have not.

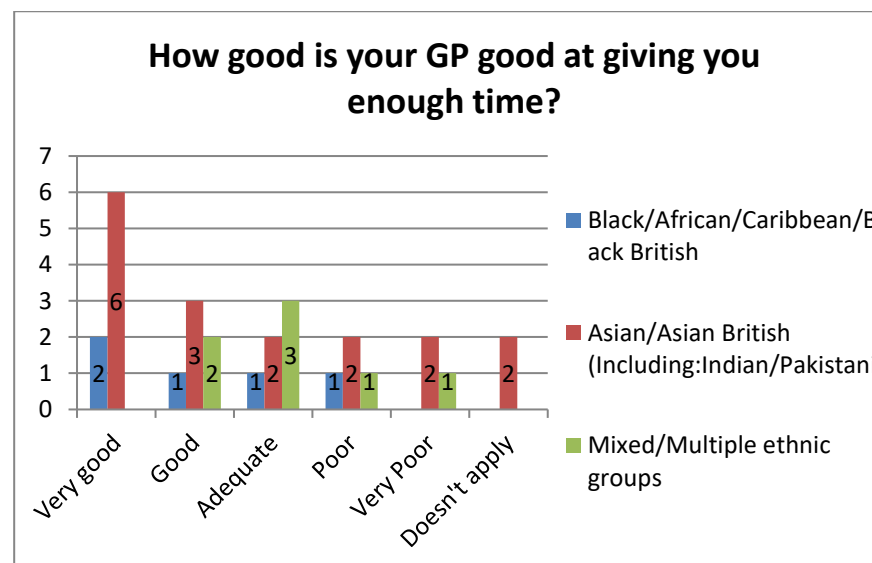


Figure 18: Is your GP good at giving you enough time?

¹¹ Carers UK – Missing Out: The Recognition Challenge (Nov 2016)

- 27.58% of the sample of BME carers thought that that their GP is very good at giving them enough time while 10.34% of the sample thought that their GP is very poor at giving them enough time

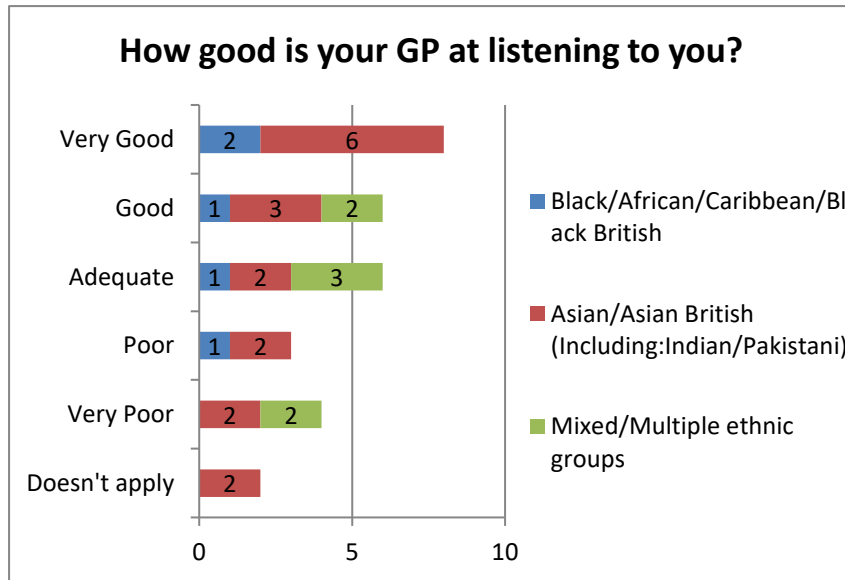


Figure 19: Is your GP good at listening to you?

- 27.58% of the sample of BME carers thought that their GP is very good at listening to them while 13.79% of the sample thought that their GP is very poor at listening to them.

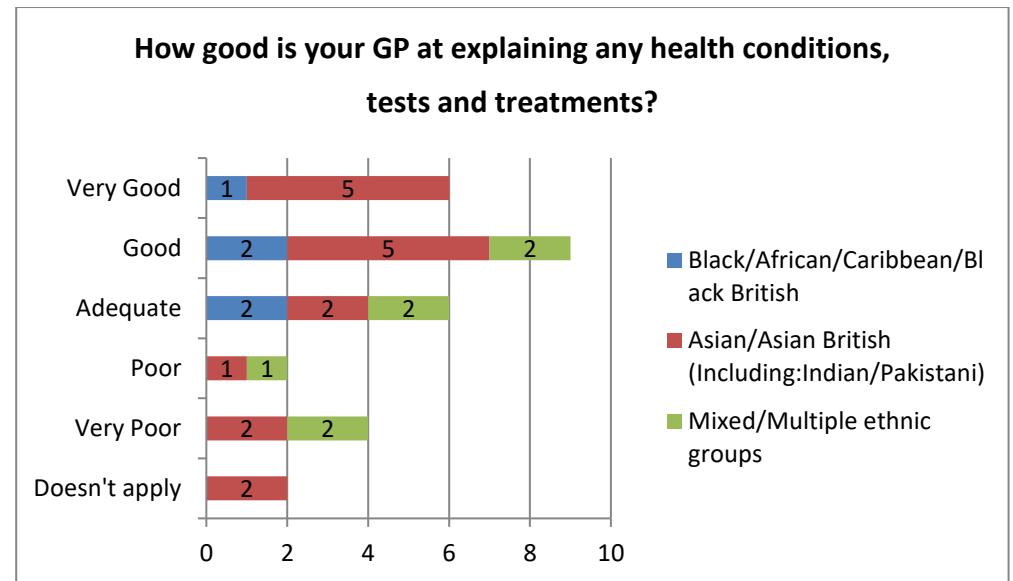


Figure 20: How good is your GP good at explaining any health conditions, tests and treatments?

- 20.69% of BME carers thought that their GP is very good at explaining health conditions, tests and treatments.
- 13.79% of BME carers thought that their GP is very poor at explaining health conditions, tests and treatments.

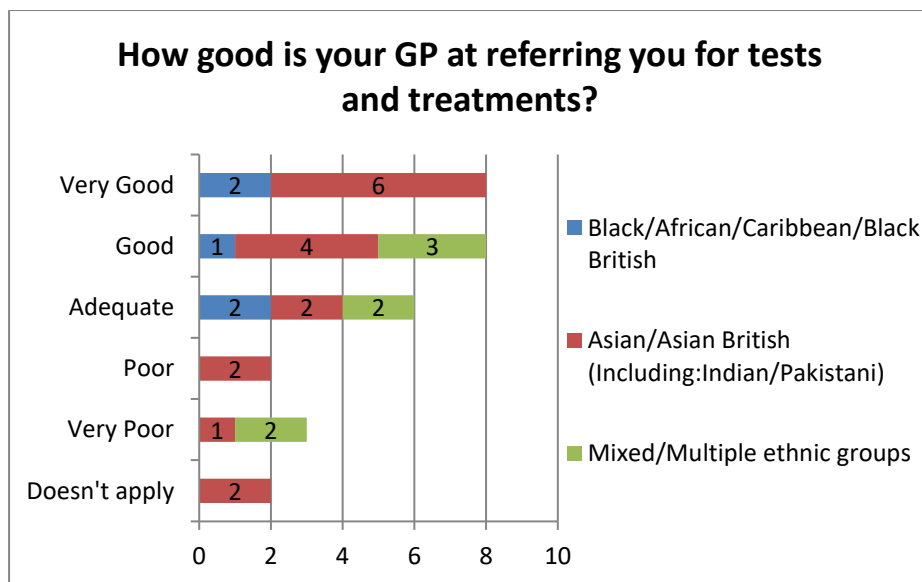


Figure 21: How good is your GP at referring you for tests and treatments?

- 27.58% of BME carers thought that their GP is very good at referring them for tests and treatments.
- 10.34% of BME carers thought that their GP is very poor at referring them for tests and treatments.

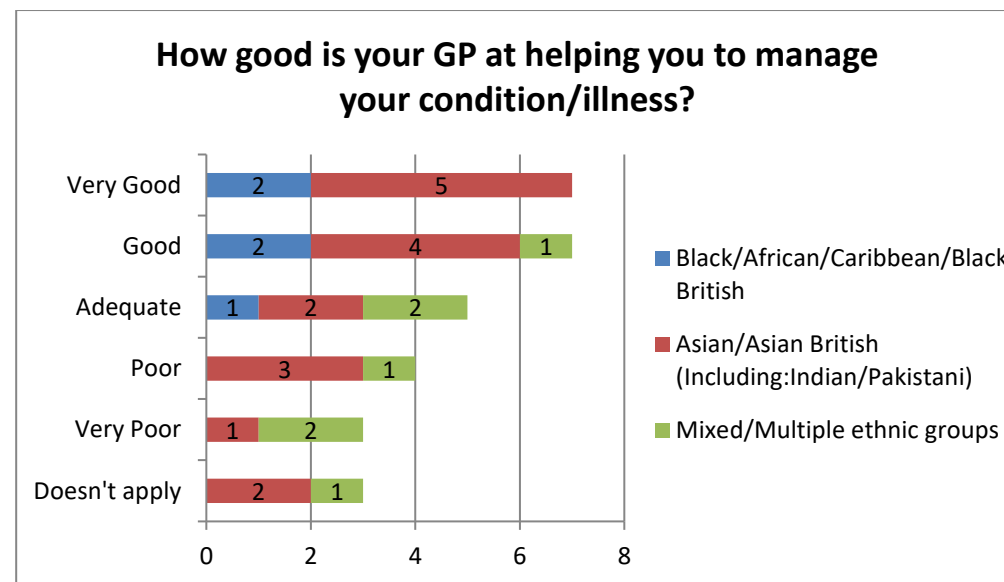


Figure 22: How good is your GP at helping you to manage your condition/illness?

- 24.13% of BME carers thought that their GP is very good at helping them to manage their condition.
- 10.34% of BME carers thought that their GP is very poor at helping them to manage their condition.

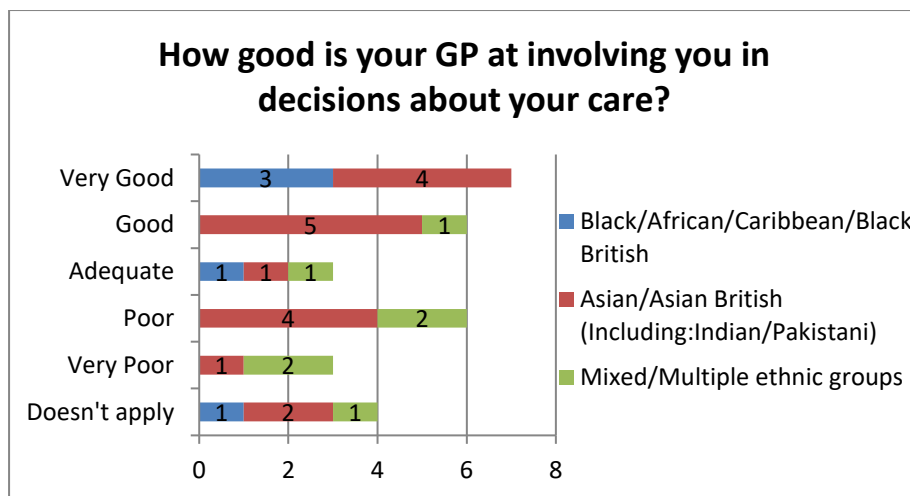


Figure 23: How good is your GP at involving you in decisions about your care?

- 24.13% of BME carers thought that their GP is very good at involving them in decisions about their care.
- 10.34% of BME carers thought that their GP is very poor at involving them in decisions about their care.

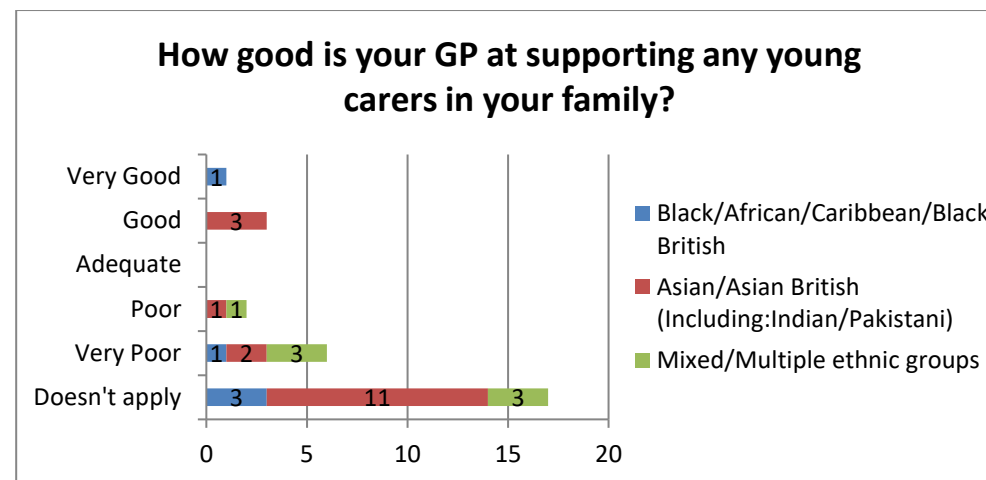


Figure 24: How good is your GP at supporting any young carers in your family?

- For those where the question applied, 8.33% of BME carers thought that their GP is good at supporting young carers in their family.
- 50% of the available sample thought that their GP is very poor at supporting young carers in their family.

Does your GP provide you with the following support?

Section A

| Ethnicity of Carer: Black African/Caribbean/Black British | Yes | No | Doesn't apply | Skipped Question |
|---------------------------------------------------------------------|-----|----|---------------|------------------|
| Information in relation to your caring role | 1 | 3 | | 1 |
| Information about the disability/illness of the person you care for | 1 | 3 | | 1 |
| A referral to the Carers Centre | | 4 | | 1 |
| A referral to a BME organisation | | 4 | | 1 |
| Flexible appointments | 2 | 2 | | 1 |
| Appointments at more convenient times | 1 | 3 | | 1 |
| Longer appointments | | 4 | | 1 |
| Interpreters if necessary | | | 4 | 1 |
| Support to young carers | 1 | | 3 | 1 |

Figure 25: Does your GP provide you with the following support? (Black African/Caribbean/Black British)

| Ethnicity of Carer: Asian/Asian British | Yes | No | Doesn't apply* | Skipped Question |
|---------------------------------------------------------------------|-----|----|----------------|------------------|
| Information in relation to your caring role | 3 | 13 | 1 | |
| Information about the disability/illness of the person you care for | 3 | 13 | 1 | |
| A referral to the Carers Centre | | 16 | 1 | |
| A referral to a BME organisation | | 16 | 1 | |
| Flexible appointments | 3 | 13 | 1 | |
| Appointments at more convenient times | 1 | 15 | 1 | |
| Longer appointments | 6 | 10 | 1 | |
| Interpreters if necessary | | | 17 | |
| Support to young carers | 1 | 5 | 11 | |

Figure 26: Does your GP provide you with the following support? (Black African/Caribbean/Black British)

*An Asian (Indian) carer indicated that she was not registered with a GP in Croydon

| Ethnicity of Carer: Mixed: Other ethnic groups | Yes | No | Doesn't apply | Skipped Question |
|---------------------------------------------------------------------|-----|----|---------------|------------------|
| Information in relation to your caring role | 1 | 6 | | |
| Information about the disability/illness of the person you care for | 1 | 6 | | |
| A referral to the Carers Centre | | 7 | | |
| A referral to a BME organisation | | 7 | | |
| Flexible appointments | 1 | 6 | | |
| Appointments at more convenient times | 5 | 2 | | |
| Longer appointments | 0 | 7 | | |
| Interpreters if necessary | | | 7 | |
| Support to young carers | | 4 | 3 | |

Figure 27: Does your GP provide you with the following support?
(Mixed: Other Ethnic Groups)

Overview:

In terms of support provided to the BME carers overall, (Section A) GPs are performing better in areas concerned with the offer of longer appointments to the Asian/Asian British cohort, (a slightly reduced sample in this section, as 1 carer reported as not being registered with her GP). Here, the offer was extended to (37.50%) This compares to (62.50%) of carers who were not.

One positive area is shown in the responses from the other mixed ethnic groups. Here (71.42%) of carers report appointments at more convenient times compared to (28.57%) of carers in this sample who are not.

With respect to the Black African/ Caribbean/Black British group, here (a slightly reduced sample, as one carer skipped the question) the area that performs the best overall is the offer of more flexible appointments but this still only represents 50% of the sample overall.

Otherwise a scrutiny of this section of the survey throws up many areas of concern in terms of the potential support that could be offered to the BME cohort. The worst performing areas are as follows:

Black African/Caribbean/Black British:

Referral to the Carers Centre - 100% not achieved.
Referral to a BME organisation - 100% not achieved.
Longer appointments - 100% not achieved.

Asian/Asian British:

Referral to the Carers Centre - 100% not achieved.
 Referral to a BME organisations - 100% not achieved.
 Appointments at more convenient times - 93.75% not achieved.

Mixed: Other ethnic groups

Referral to the Carers Centre - 100% not achieved.
 Referral to BME organisations - 100% not achieved.
 Longer appointments - 100% not achieved.

Does your GP provide you with the following support?

Section B

| Ethnicity of Carer: Black African/Caribbean/ Black British | Yes | No | Doesn't apply | Skipped Question |
|------------------------------------------------------------|-----|----|---------------|------------------|
| General Health Check (if eligible) | | 1 | | 1 |
| Not eligible for General Health Check | 3 | | | |
| Flu Jab | 1 | 2 | | 1 |
| Yes I had the flu jab at the surgery or elsewhere | 1 | | | |

| | | | | |
|---------------------------------------------|---|--|--|--|
| Yes but I chose not to have the flu jab | | | | |
| I am not currently eligible for the flu jab | 1 | | | |

Figure 28: Does your GP provide you with the following support? (Health Checks and Flu Jabs - Black African/Caribbean Black British)

| Ethnicity of Carer: Asian/Asian British | Yes | No | Doesn't apply | Skipped Question |
|---------------------------------------------------|-----|----|---------------|------------------|
| General Health Check (if eligible) | 3 | 13 | 1 | |
| Not eligible for General Health Check | | | | |
| Flu Jab | 6 | 10 | 1 | |
| Yes I had the flu jab at the surgery or elsewhere | 6 | | 1 | |
| Yes but I chose not to have the flu jab | | | | |
| I am not currently eligible for the flu jab | | | | |

Figure 29: Does your GP provide you with the following support?
(Health Checks and Flu Jabs - Asian/Asian British)

| Ethnicity of Carer: Mixed other ethnic groups | Yes | No | Doesn't apply | Skipped Question |
|---------------------------------------------------|-----|----|---------------|------------------|
| General Health Check (if eligible) | | 7 | | |
| Not eligible for General Health Check | | | | |
| Flu Jab | 2 | 2 | | |
| Yes I had the flu jab at the surgery or elsewhere | 2 | | | |
| Yes but I chose not to have the flu jab | 3 | | | |
| I am not currently eligible for the flu jab | | | | |

Figure 30: Does your GP provide you with the following support?
(Health Checks and Flu Jabs - Mixed Other Ethnic Groups)

Overview:

The standout statistics in Section B : Does your GP offer you the following support, the areas for concern are illustrated across the following areas:

Asian/Asian British carers, 81.25% of the available sample are not offered health checks and 62.50% have not been offered a flu jab.

Mixed Other Ethnic Groups. 100% of the cohort have not been offered a health check.

A more positive trend is shown in the offer of a flu jab for the Mixed Other Ethnic Groups which shows that 71.42% of the group given the offer but only 28.57% taking up the flu jab option.

With respect we are considering a slightly smaller sample as one carer skipped the question. 75% of this sample is not eligible for the health check. With respect to the flu jab we have an even more reduced sample as one carer skipped the question; one carer stated she was not eligible for the flu jab. This leaves 66.66% of the available sample and eligible for the flu jab not receiving the offer, with 33.33% of the sample received the offer of the flu jab.

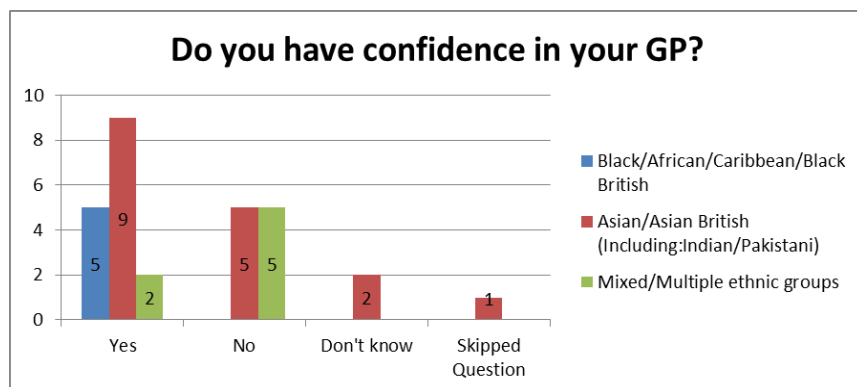


Figure 31: Do you have confidence in your GP?

Just over half (55.17%) of the BME carers surveyed overall had confidence in their GP.

- (100%) of the Black/African/Caribbean/Black British carers sample expressed confidence in their GP.
- (52.94%) of Asian/Asian British of the carers sample reported confidence in their GP.
- Only (28.57%) of the Mixed/Multiple ethnic group carers sample stated that they had confidence in their GP.

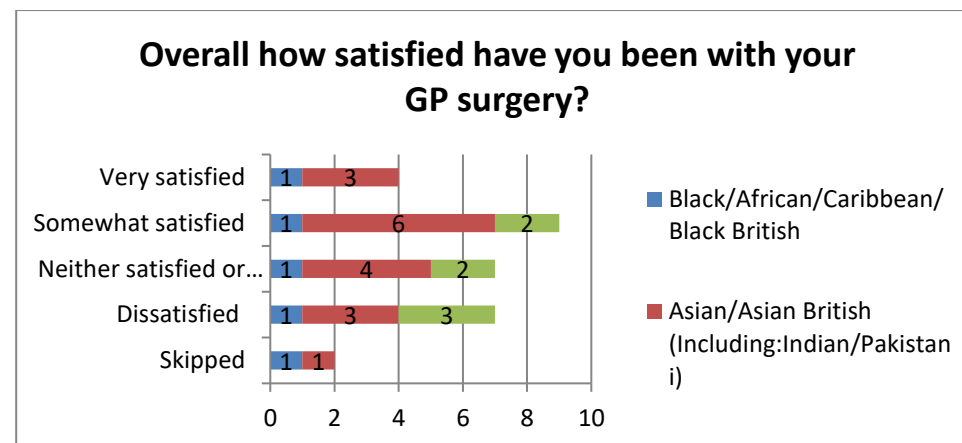


Figure 32: Overall how satisfied have you been with your GP surgery?

- 31.03% of the BME sample of carers were somewhat satisfied with their GP surgery.

This particular piece of data shows a relatively low satisfaction with their GP surgery. Whilst just over half of carers 55.17% had expressed confidence in their GP, carers have expressed dissatisfaction with aspects of the service provided by the surgery overall including access (including frequent negative comments about receptionists) access to information, signposting and referral to support.

Questions requiring more than one option:

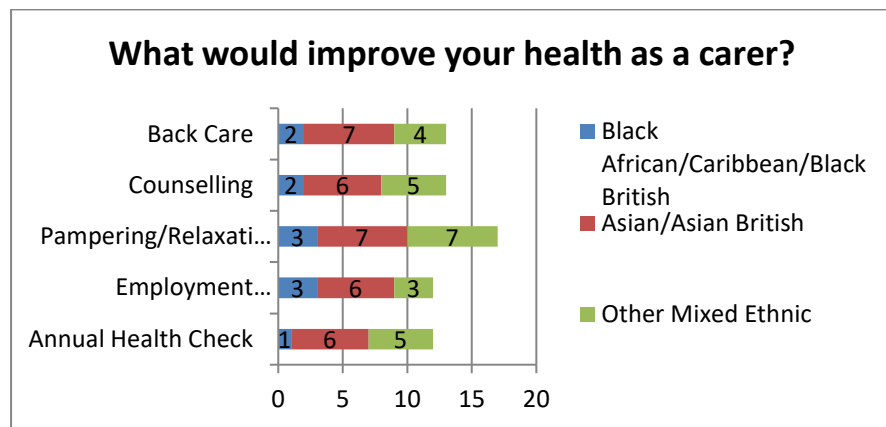


Figure 33: What would improve your health as a carer?

BME carers were asked what would improve their health as a carer and a range of options were selected. The most frequently cited services are shown here. Four carers did not to answer the question so the sample size is 25. Pampering/Relaxation days were the most frequently cited service that would improve health by 68% of the BME carers.

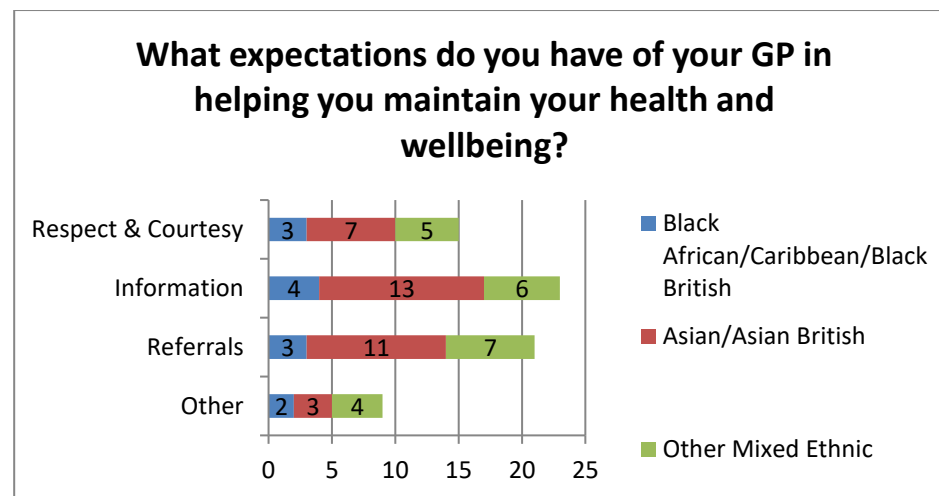


Figure 34: What expectations do you have of your GP in helping you maintain your health and wellbeing?

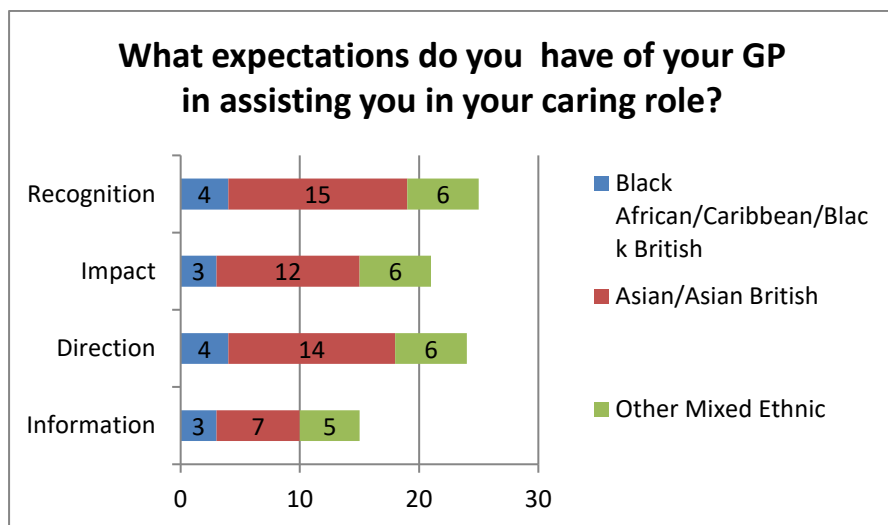
BME carers were asked what expectation they had of their GP in helping them to maintain their health and wellbeing. Two carers did not to answer the question so the sample size is 27. Access to information to support and manage their health condition was cited the most frequently by BME carers. This represents 85.18% of the cohort and 55.55% of the BME cohort cited respect and courtesy as an important expectation of the GP in helping to maintain health and wellbeing. 77.77% BME carers cited the importance of swift referral to specialist treatment and support as an expectation of their GP in helping to maintain health and well-being.

The “other” category cited in the graph mentioned by 9 BME carers as an important expectation of their GP included as follows:

1. Access to breaks.
2. An understanding attitude of the GP.
- 3 Priority treatment for carers.
4. The GP to be available to the carer.
5. More support with elderly care.
6. To have a professional manner and to offer sympathy and to listen to you well and go the extra mile for you.
- 7 Recognition of the caring role and impact on your health.#
8. More immunisations for carers
- 9 The impact of caring on health and the symptoms that may be stress related and hence provide lifestyle management.

Figure 35: What expectations do you have of your GP in assisting you in your caring role?

BME carers were asked what expectations they had of their GP in assisting them in their caring role. Two carers did not to answer the question so the sample size is 27. Recognition by their GP of their caring role was considered by BME carers as the most important expectation in assisting them in their caring role. This was cited by 92.59% of carers. This was closely followed by 88.88% of carers citing understanding that their GP knew where to direct them for help and support in caring as an important expectation. 77.78% of carers responded that knowing that their GP understood the impact of caring on health as an important expectation. 55.55% of carers thought that that having a GP that could provide information about the disability/condition of the person that they care for (and their care plan) is an important expectation.



8 Qualitative Data

The survey has provided BME carers with an opportunity to respond to some open ended questions so that they can respond in some depth if they wish choosing their own words. The information supplied is non numerical in nature and analyses the overarching themes that have arisen.

BME carers were asked:

If you had any difficulties in trying to get help and support you need to maintain your health as well as your caring role, please tell us

The main themes to arise in response to this question concerned access and in particular difficulties posed by Reception staff and the need to get solutions to practical concerns such as housing and finding that support is not forthcoming. A lack of recognition of the caring role is also raised:

“Communication issues (to and from patients and carers). Reception staff don’t listen properly.” (Other Mixed Ethnic group carer)

“Making appointments is a key issue. The receptionist has been a barrier. I would prefer an email system for booking so that I can bypass the receptionist. I believe that she needs training and has an unsympathetic attitude and that makes me angry.” (Asian carer)

“Trying to get appointments in times of distress, I have had difficulty in passing through the receptionist and explaining all

your health conditions means there is no privacy or confidentiality.” (Asian carer)

“Difficulties are compounded by being a working carer, having to go to work when in pain. Employers should give priority to supporting working carers. Access to a GP is more difficult when working full time.” (Other Mixed Ethnic Group carer)

With respect to housing issues, one Black African/Caribbean/Black British carer emphasised the importance of getting help with accommodation issues when temporarily immobilised and the GP and other agencies being lacking in support. Another carer from this cohort expressed the difficulties she is having with housing issues which has caused sleeplessness, worry and anxiety and the person for whom she cares. She commented that the GP had not been supportive.

Other themes to emerge included difficulties that arise through GPs not recognising their caring role:

“The GP deals with the medical aspects of care, but not the caring side.” (Asian carer)

“No help or support or understanding of the stress of the carer.” (Asian carer)

BME carers were asked a question that sought positive comments about their GP’s performance in relation to their health and their caring role.”

If you feel that your GP has done well in supporting your health and helping you in caring please tell us.

Positive comments were quite sparse but where BME carers had positive experiences to relate they concentrated in the main on the GPs having a helpful and sympathetic attitude.

“My GP listened and supported me to keep healthy whilst caring for my husband.” (Asian carer)

“My GP has a listening and sympathetic attitude.” (Asian carer)

Other carers commented positively on their GPs willingness to make a referral, e.g. to a specialist in relation to arthritis (Mixed other ethnic group carer) or instigating a review in asthma and writing to the carer about this. The carer reported this as good support. (Black African/Caribbean/Black British carer).”

One Asian carer commented that the GP had been supportive “Only for my health but not as a carer.”

Some positive comments were qualified however, examples include:

“Has been satisfactory after you get through to them, but could do better.” (Asian carer)

“Help is limited, but in some conditions GPs are supportive.” (Asian carers)

One carer thought that their GP might prove helpful: “I feel that my GP will support me in my caring role.”

Even this section that provided BME carers with the opportunity to provide positive comments yielded only negative refrain:

“ I feel lost and isolated so there has been no help or acknowledgement. I feel disillusioned.”(Black African/Caribbean/Black British carer)

“The GP could have done more to be supportive.” (Asian carer)

Carers were asked to think about their patient status and to think about what improvements they would like to see in the services at their GP surgery:

As a patient, what improvements would you like to see in the services provided by your GP?

There were some wide ranging responses to this question and themes included: access, recognition of the caring role, empathy and support, flexible appointments, the relationship between caring and health and recognition that some symptoms that the carer experiences may be stress related.

Access:

“To be able to see the GP at weekends.” (Black African/Caribbean/ Black British carer)

“Access and offer referrals where necessary.” (Mixed, Other Ethnic groups carer)

Recognition:

“Recognition of the carer and registering them at the Practice. Telling them that they have done a good job.” (Mixed, Other Ethnic group carer)

Empathy and support:

“More time with the doctor and not to be rushed. For doctors to be human and not be so detached and cold. For them to be polite and not to be rude or abrupt.” (Asian carer)

“More empathy and support.” (Asian carer)

Flexible Appointments:

“ I have experienced difficulties making appointments, more flexible appointments are required.” (Asian carer)

Caring and health

“Recognition that symptoms may be stress related and connected, therefore taking a holistic approach to health would help. Rather than just handing out medication, GPs should offer alternative treatment and therapies focused on lifestyle management.” (Asian carer).

Carers were then asked to think about being a carer and what improvements they would like to see in the services provided by their GP.

In order to assist you as a carer, what improvements would you like to see in the services provided by your GP?

In response to this question carers raised the themes of recognition of the caring role and the importance of follow up, liaison and referral to services that support carers. Other themes that have previously been raised were also discussed including: Flexible appointments, more understanding and help. Specific issues raised by individual carers included: emergency appointments, access to short term breaks, help with loneliness, data protection, private phone consultations, home visits to carers.

Recognition of the caring role:

“To provide recognition as a carer, and for this to be part of the ongoing conversation. For the GP to ask about support to help you. A lot of the things are just taken at face value.” (Black African/Caribbean/Black British carer)

“Not having to repeat yourself all the time, having to explain your needs as a carer. Not to feel invisible, to be properly understood, acknowledged and supported.” (Black African/Caribbean/Black British carer)

Flexible appointments:

“Flexible same day appointments.” (Other Mixed Ethnic group carer)

Liaison referral and support:

“That my GP would liaise with social care and get support for my daughter.” (Other Mixed Ethnic group carer)

“Flexible, later and weekend appointments, referral to organisations that support carers.” (Asian carer)

Other:

“Availability and the offer of emergency appointments for my child.” (Asian carer)

“Loneliness is the biggest hurdle.”

“To be able to speak to my doctor about my parents’ health and issues in appointments that I have missed is important to me”.

“Data protection is an issue here.”

“Help with health issues in relation to caring, e.g. back problems, information and support.” (Asian carer)

9 Feedback from participants at the Healthwatch Forum - August 2017

Healthwatch Forum:

How can BME carers be better supported by Croydon GPs?

Mind in Croydon Tuesday, 8 August 2017 from 10:30 to 12:30

Discussion notes

Improving recognition of carers

- Input into GP training for both GPs and staff.
- Educating the patients in recognising themselves as carers.

- Educate the public about carers.
- Get GP to work with other agencies such as social security, voluntary sector, patient participation groups.
- There should be financial incentives to GPs to recognise carers.
- What is a good GP? Good listener, empathetic, professional.
- Posters in all languages
- Professional - district nurses, health visitors, care workers are transmitters of information as they need to know the services, need to do assessments and agencies do services.
- What do other care organisation and agencies do and what can we learn?
- Awareness of illiteracy as someone cannot read posters, so don’t understand it. So, work through social workers to train carers and assess them.
- Gap between social services support patient and family carers.
- Need to set policy of no discharge without an integrated care plan - hospital to have carers’ assessment.
- Create a four-minute video about the role of carers to inform carers of what they can expect and need to know.

Improving carers’ health

- Standardised record-keeping of carers register (governed, accountable and enforced).
- Accountability of GP rather than carer - what is the role and job of GP?

- GP as signpost for support.
- GP to be culturally aware - both of sensitivity and cultural expectations, listening skills and empathy.
- Carers lead needed within the surgery - speciality lead.
- There are currently care navigators in Thornton Heath, and Broad Green, brought by Patient Participation Group pressure (Parchmore and Eversley).
- Patient Participation Group, awareness of carers needs required.
- What are GPs responsibilities? Guidance is currently unclear.
- Need to deal with carer as well as the cared for.
- All GPs to have same responsibilities with dedicated GPs dealing with carer and cared-for.
- Carers need support to take on their own health and wellbeing.
- Better communication - guided how to communicate better & vice versa.

Improving access to GP services

- Getting access to services is a challenge, especially on the practical ability of getting a double appointment, sometimes having to wait two weeks.
- Flagging for carers on booking, so that carers get a priority appointment to be used at the time, as there is a need for prioritised for appointments (rather than wait 2 weeks), with a set number of appointment slots over a certain period so no-one takes advantage.

- Breakdown the stereotype that BME always looks after their own.
- Emphasis on recognition: This is important, as you can only get prioritisation when you have recognition.
- Implementation of priority package of service of GPs including flexibility of services.
- Priority between carers based on conditions and seriousness of situation.
- Monitoring carer requests over a period to gauge demand and from that plan carer cover specified appointment slots (as this model already works in antenatal).
- Carer-defined GPs and or carers see the same doctor so there is a smoother process don't need to say the same thing to a new GP each time.
- Ability to deal with multidisciplinary need for support.
- English language for carers so they can self-identify.
- Training for carers on how to do with conditions.
- Carers patient programme (nor necessarily for GPs it could be nurses, who are sympathetic).
- Create a buddy system (stops people running to GPs).
- Advocacy training.

10 Example Telephone interviews with a BME carer.

Example A

Background: This is the second interview undertaken with a BME carer for the purpose of research into BME carers' experiences of GP services in Croydon.

Carer Profile: The carer defines herself as black African. She is caring for her son with autism who is shortly to turn 19. She has four other children and a partner that supports her. She is aged between 45-50. The carer has stated that she has flagged up with the surgery that she is a carer and she feels that this makes a difference that is she is unwell, the GP wants to get her better quickly. She has been offered flexible appointments. The carer stated that she last attended her GP about three months ago and probably visits about 4 times a year.

Carer Health Status: The carer stated that although her health is quite good, she has high blood pressure and does experience some stress from time to time. She has had a blood pressure check but doesn't currently need medication. The carer has been offered a health check once a year and she has had a flu jab.

General Points:

- The carer does have a preferred GP but doesn't see them that often. The GPs, she feels do give her enough time to discuss her needs
- The carer has found about the Carers Centre in her own right
- The carer says that she is generally satisfied by the services that she has received but then added that she has fairly low expectations. She says she has less expectations therefore she is less likely to be disappointed.
- The services have been quite responsive to her family's needs in particular they have shown flexibility treating her son whilst he was still in the vehicle outside the surgery

- The carer thought it was important that it is flagged up who has carer status. Then the carer can be acknowledged, and the carer might be entitled to extra care and support.
- Some GPs have been good, some have been fantastic, some don't have much of a clue - so service can be variable.
- GPs need to know the wider context of a carer's life. Apart from the illness that the carer has, they may not know what else is happening to you.
- The GPs may just be focusing on the medical side of a carer's situation, they have not mentioned how to access carer breaks for example. The carer noted that if you are not in the system, you may not get a great deal of support.

Example B

Background

The carer is aged 46, she defines herself as Black African in ethnicity terms. She has been caring for her son for 18 years and he was born prematurely by four months. He has cerebral palsy, the hospital didn't expect him to survive, and he has no speech, is doubly incontinent and needs 24 hour care and uses a wheelchair. The carer believes that her caring role is regular and substantial.

Carer Profile

The carer has special needs herself, she has osteoarthritis and she states that this is throughout her body and it is painful. She has also had to have spine surgery and knee surgery and has required support re pain management. The carer's heart is also inflamed

and has fluid build-up and she has suffered breathlessness for the last couple of years. This is currently being investigated.

The carer sees her preferred GP and visits about two or three times a month. About a year ago she had to be hospitalised as her health conditions had worsened. The GP understands the gravity of her health conditions as well as her caring role and recognises her as a carer. Access to her GP is very good and depending on the situation she can see her GP immediately and get a home visit when needed. Issues might involve getting cover for her son, but sometimes she can get to her GP because her son is at school. The carer's son is 18 and is going through Transition and she is getting good support from PIP.

General Points

- In a given month, the carer may visit her GP two or three times given her own health problems and caring role.
- In addition the carer has to learn to manage her pain on a daily basis.
- The carer was asked if she gets to see her Preferred GP, she sees different GPs in a month. "When I just call the GP, she is responsive, she does give me prompt access and responds to my needs."
- Access to the GP is easier when her son is in school.
- The carer confirmed that that it has also been possible to get home visits. The carer has some confidence and trust in her GP.
- She has always been offered a flu jab.
- She has not been offered a health check as she is not eligible.

The carer thought that some monitoring would be useful, an offer of blood tests for example. Having access to information about long term conditions would also be good.

Example C- Carer Interview

This is the third interview undertaken with a BME carer for the purpose of research in to BME carers' experiences of GP services in Croydon. . The focus of the interview was to establish in particular how GP services have supported the carer's own health as well as her caring role.

Background and caring role

This carer is female and a young Asian adult. The carer is currently caring for her father. The carer noted that in terms of her caring role, her father has breathlessness, Cellulitis and Sleep Apnoea. The carer seems to think her father also suffers from confusion and a significant part of her caring role is concerned with advocacy for her father and ensuring he gets the right and appropriate care.

Carer Health Status

The carer stated that she has suffered from anxiety for about 10 years but that this had been aggravated by caring (2 months ago) Her GP, she had confirmed had treated her condition with anti-depressants but this had not been effective. The carer felt that the GP should have addressed her anxiety so she has undertaken her own research and treated herself with natural remedies. The carer felt that the GP did not question her enough about her anxiety and assumed depression was the cause of her ill health. The carer stated that her condition was more about panic than

depression and that the GP should have investigated the greater context of her life, provided her with relevant information and given her access to appropriate therapies. The carer was also worried about the side effects of anti-depressants.

General Points:

- The GP has not specifically recognised her as a carer. The carer has not highlighted this herself as it has taken some time (as is common for carers) to recognise her caring role.
- The carer feels that as a consequence of her caring role, her own health has taken a back seat.
- The carer considers that what would have been helpful - If the GP had given her flexible appointments
- The carer thinks that in the past receptionists have been unhelpful, acting as gatekeepers insisting on knowing the reason for her wanting to have an appointment and therefore as a result having to divulge private details.
- The carer has since lodged a complaint and felt that the receptionist was rushing her as her shift was due to end.
- The carer was asked about her expectations of GPs and she stated that she would like to be able to book an appointment when she likes and when she can attend more easily and that the GP should be

able to listen and have empathy towards her situation. She would like the GP to recognise her expertise as a carer and provide her with options to assist her in her caring role. The carer would like to see a preferred GP but often as not see will see a range of GPs so the outcome is that it is difficult to form relationships and to engage with them. The carer felt that she had better relationships with the doctors at the Walk in Centre, she felt she wasn't rushed there and that they showed her understanding.

- In terms of support that the GP might have provided her, she said she has not received any referral to the Carers Centre or subsequent Carers Assessment.
- In terms of cultural issues, she feels that the role has fallen to her to become the carer of her father. She has a brother and sister but they are both working full time.
- The carer also has to assist her mother, where English is a second language. The carer feels that it is incumbent upon her to sort out her affairs.
- The carer made the point that if the GP had recognised her carer status that with the consent of her father there could have been sharing of information that would have proven helpful to her caring role.

- The carer was asked about opportunities provided by her GP either in terms of her own health or caring had been negative. The carer stated that the whole experience has been bad.
- In terms of priorities, she felt that in order to effect improvements in GP services, GPs should be prepared to listen to carers, to be patient and view them with respect as an expert in caring.
- The carer stated that the GPs made assumptions, that she had accompanied her father to GP appointments because her father couldn't speak English when in fact the key issue was her fathers' confusion. They have accused the carer of overreacting.
- The carer's recommendations were: GPs should ask carers questions and believe in their answers as the truth.
- In terms of perceptions of GP, the carer felt that these were quite bad. As a result of receiving inadequate support from primary care, the carer felt that she had to take the next step up and go to Accident and Emergency depts and this was just adding additional pressures for all concerned. The carer stated that she has lost faith in GPs. The carer felt that GPs are not doing enough to make a difference, more stress is placed on hospitals whereas they should allow an extra five minutes to

the consultation time and ask the right questions to get the best results.

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“My mother is a first generation Asian, she can’t advocate for herself so we have to stand and be the voice of the patient, you need the language to talk. It is a struggle when your parents are first generation and they need advocacy. This is because their literacy levels are low, they are not able to access information and they are unable to engage with the information provided to them.”

Croydon BME Carer



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