COMMUNITY PARTICIPATORY ACTION RESEARCH

EXPLORING BARRIERS FOR PEOPLE FROM ETHNIC MINORITISED BACKGROUNDS USING CARE AND PUBLIC SERVICES IN SURREY

JANUARY 2022

RESEARCH BY ZAREENA LINNEY-WAINE

EXECUTIVE MANAGER SURREY MINORITY ETHNIC FORUM (SMEF)

Contents

1. INTRODUCTION

Surrey Minority Ethnic Forum (SMEF) has been commissioned to undertake 'Community Participatory Action Research.' We are supported and funded in this work by Public Health Surrey County Council and the Scottish Community Development Centre.
SMEF is a race equality organization and more recently faith has been included in our remit.
We represent more than 48 multi-ethnic community groups in Surrey and deliver project work in several groups across the County. We raise awareness of the needs and issues ethnic minority background residents are facing and offer support routes. Our vision is to have a unified and diverse community with an active focus on improved wellbeing for all in Surrey The "community led feedback" nature of this research makes us well placed to hear from minority ethnic background people and groups, we listen and have access and dialogue with a variety of different ethnicities and faiths across Surrey.

Through my community development work with SMEF delivered throughout Surrey, I had already identified a need during various workshops, that there are barriers to engaging with the public sector including health services, police, charities, and wider organizations.

I began to explore the topic of Inclusion and thought about how we can make our services more inclusive across Surrey.

The dictionary definition of Inclusion is "The action or state of including or of being included within a group or structure and the practice or policy of providing equal access to opportunities and resources for people who might otherwise be excluded or marginalized, such as those who have physical or mental disabilities and members of other minority groups."

In society, groups can be excluded or have barriers of engaging in services and communities and the structures that have been put in place. In Surrey we are not exempt from this happening to our residents.
Inclusion is a wide topic and encompasses areas around sexuality, gender, race, disability, and faith and more. Inclusion at a deeper level is a shared experience of shaping leading and being and this should not be tokenistic.

For the purposes of this research there is a recognition that "Inclusion" and barriers to engagement is a wider topic but as Executive Manager of a race and faith equality organization, I shall focus on these two areas. Inequalities around race have recently been highlighted through health equality reports especially at Covid times. Issues raised in the media including the Black Lives Matter movement and publicity around racism in sport have had people showing more of an interest to making positive changes in being more racial and faith inclusive.

I hope that we can as organizations can work towards making our organizations charities and sectors more inclusive, but not in a tokenistic way but through genuine work in collaboration and listening to needs identified from the ethnic communities in Surrey. This report seeks to identify areas for change to improve inclusion and give suggestions on actions services can take

2. THE RESEARCH PROPOSAL

During my work with SMEF prior to the research project, some members and people attending our groups had shared about barriers to engaging with services there was a reluctance to use services, some shared of fears and lack of information. Therefore, I decided to explore this topic further through this Community Research project.

Aim of project
The aim of the research was to engage with Surrey residents from ethnic minority background to gain their feedback on barriers for accessing services and ask their suggestions for improvements.

The research findings will be a first step to create an operational document to help with race inclusion for the health and care services in Surrey. This will be important to make the service provision is more inclusive and ensure ethnic minoritized groups can engage with services to improve their wellbeing and enhance their sense of belonging to their community.

3. RESEARCH PROCESS AND METHODS

This community participatory research project was conducted via focus groups a survey completed by Surrey residents from mixed ethnicities.

Focus groups: Four focus groups were organized, two were advertised on the social media and website and two were existing groups that were delivering in Surrey, during the focus groups I wanted to keep it simple, and two questions were asked at all four focus groups:

1. What are the barriers to people from ethnic minoritized background using care and public services?

2. How can we adapt the health and care services to make them more inclusive?

I noted all the feedback during the group discussion as it was shared and recorded for each session and filed the feedback. I read through the results and explored them with a colleague from Public and Health to identify the common themes emerging in all four-group.

Community Survey: I used the themes emerging from the focus groups to develop the questions. The survey was published online and advertised through social media to be completed over four weeks. Data was then extracted results analyzed.

4. RESEARCH RESULTS

A total of 104 residents from a diverse range of ethnic minority backgrounds took part in this research. 57 engaged in four focus groups and 45 individuals completed the on-line surveys. Participants ages ranged from age 20-75 years and they came from all over Surrey County predominately in Guildford and Woking and Camberley.

Two case studies were also collected.

Focus groups

Demography of focus groups participants

Four focus group were conducted.

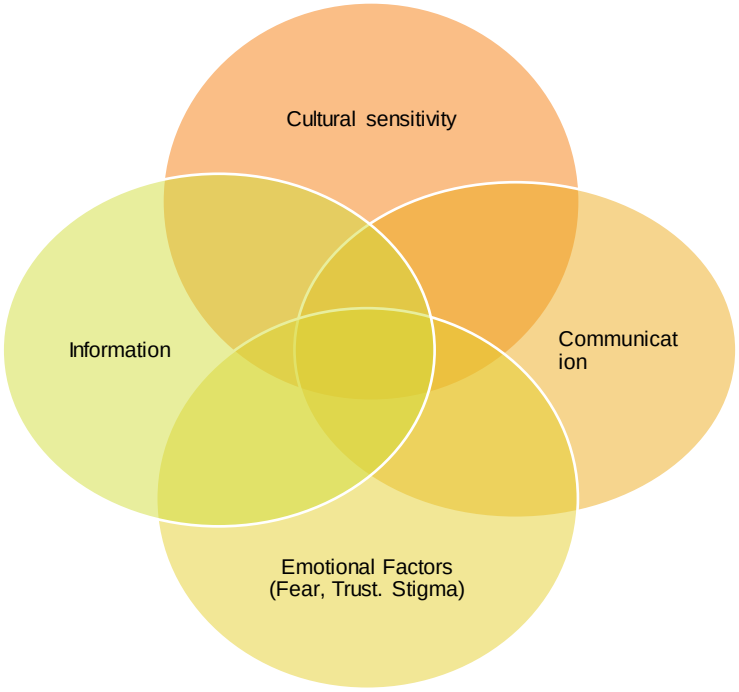
Group 1: 17 people engaged**.** Woking mixed - Pakistani, Syrian, Nepali, Indian, African (20-60 years)

- **Group 2:** 17 people engaged**.** Nepali women Nepali (20-75 years)
- **Group 3:** 8 people engaged**.** Men, mixed ethnicity - Nepali, Indian, Pakistani, Nigeria (20-75 years)
- **Group 4:** 15 people. Muslim women-Pakistani, Indian, African (20-75 years)

Key findings from focus groups

The analysis highlighted four key themes: communication, information, cultural sensitivity and emotional factors (mainly associated with fear, trust and stigma).

The feedback on each question were grouped according to these themes as shown blow.



Q1. **What are the barriers to people from ethnic minority communities using health and care services?**

Communication

- Had to find our own way as communities when there were no services that we knew of
- We are not clear how to report or contact some services
- Language barrier. We cannot understand what the doctor or even the receptionists are saying.
- Referral and form filling in difficult to understand and speak to people on phone.
- Language and terms we do not understand what they offer

Information

- We don't know what all services are for
- We are private about health issues lack of knowledge -where do I go?
- Information -material is not simple don't understand what they offer and how to contact
- Wait time for a check-up is very long
- We don't know a lot of our rights
- We don't know the system- Lack of understanding bribery and corruption how does it work over here

Cultural sensitivity

- We sometimes don't have many friends or family who can come with us for our appointment's
- Pictures not culturally sensitive for example Muslim group see picture of white lady drinking beer as part of training material around responses relating to mental health. Cultural sensitivity
- Stigma around organizations label us they should try to understand us.
- Don't want to be weak or shown as not being able to look after ourselves

- Impact of Cultural awareness nature on the various reasons preventing openness to health discussion and there a lack of support for our role as men.

- No support lack of understanding about our culture

- Lack of cultural understanding not understanding about our ways and culture
- Religious assumptions to our group they assume we were all one religion

- They don't understand our communities - We come as a family and shared they all attend appointments as a family

- We do not understand what the services offer

- Sensitive to us not the same for us we deal with things ourselves but sometimes we need others

Emotional factors (Fear, trust, stigma)

- Fear of services - due to historic lack of service on offer in birth countries and when they grew up experienced corruption and bribery – the key concerns were this created mistrust and fear of services and issues around fear and lack of trust and fear of stigma, judgement

- Fear due to misuse of power by police in the countries we came from

- Police could be bad to us from childhood we have a fear

- Language barriers

- We deal with these things ourselves

- Police in our country of birth behave as if they are supreme so we are frightened here too

- Doctors need to respect patients they do not explain operational information and we are frightened about processes and things they do.

- They talk harshly to us not kindly and we don't like this.

- Stigma of mental health

- Opening up-not wanting to appear weak judgement of others trust
- Stigma we prefer to sort things out ourselves

Q 2. How can we adapt health and care services to meet the needs and so they are more inclusive?

Communication

- Ways of contacting needs to be simple and clearly explained to us sometimes we do need to contact people, if a there has been crime or we need health care- we don't know how to - a simple what we do leaflet would help.

- I would self-refer to services, but I am scared to talk on the phone due to my English can they offer support with filling out forms and speaking on the phone to refer.

- Picture used inappropriate for example woman drinking beer in a pub by a professional- reference to Muslim and sensitive to the race culture of the group cultural sensitivity.

- No abstract concepts that don't explain simply and clearly what they are.

- No one size fits all model understand differences and adapt services

- Simple leaflet explaining what services do and what it is and if we must pay -Work with us as a family and give us clear information. Translators should be provided by NHS if we need.

- Men's sessions- communication for men

Information

- Nobody mentions that NHS or surgeries also have facility to provide translators, as we are pressurized to arrange one ourselves which sometimes is impossible.

- More events on our rights on healthcare.

- Support around health awareness events for men from ethnic communities

- We need career information to give to our children information

Cultural sensitivity

- Awareness about cultural event

- More space to discuss and improve communication and information

- More information and workshops on cultural awareness
- Cultural awareness training so they know about festivals and things that affect our communities.
- We are Nepali walking is in our blood, and they ask us to exercise they need to know our backgrounds.
- Not assuming religious beliefs
- More family working, we all go to appointment if one of us need to see doctor

Emotional factors (Fear and Trust and Stigma)

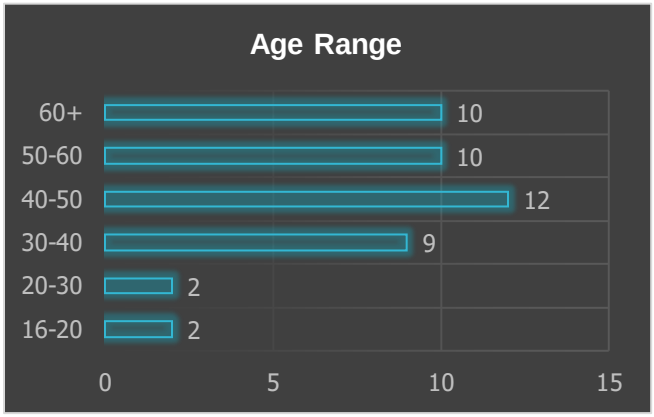
- More support groups for communities
- Meetings with Police- to build relationships
- Challenge stereotypes in the media
- More shared faith conversations
- Talk about mental health address the stigma-mental health workshop more work to address
- Helplines could help with privacy and fear of stigma
- Labelling by professionals Recognize English as a second language
- Professional need training to be culturally sensitive
- Media need to be worked with local and national
- Support forums where we can discuss fears and trust

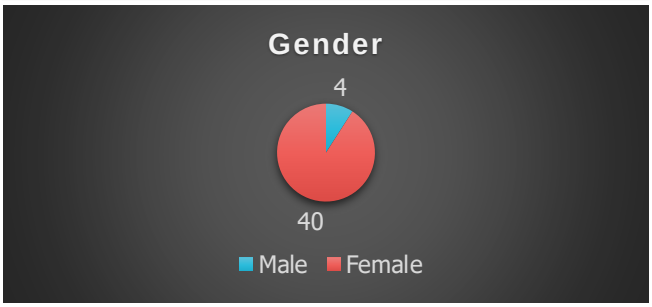
Community Survey

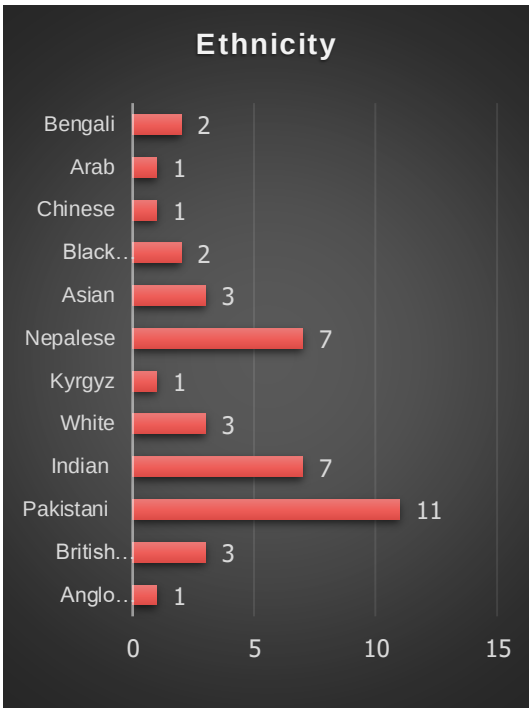
Demography of participants

Respondents for the community survey were mainly female. Participants age from 20-60 the majority of respondents were above the age of 40 and a good range of ethnicities took part, majority were from Pakistani, Indian and Nepalese background (Figure 1).

Figure 1: Demography of participants

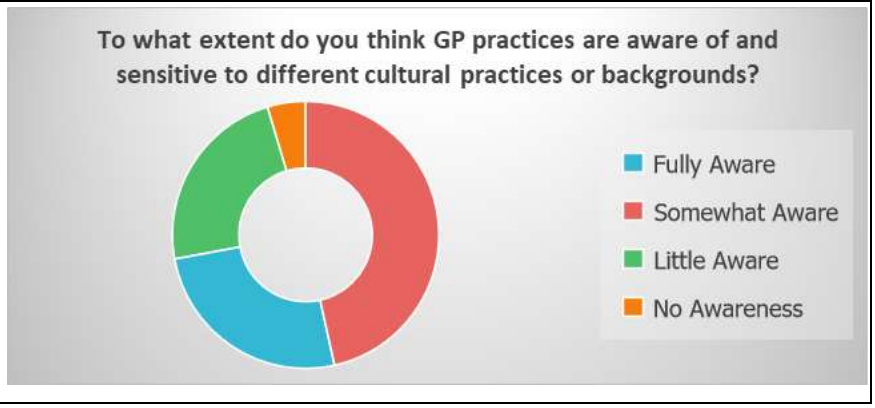






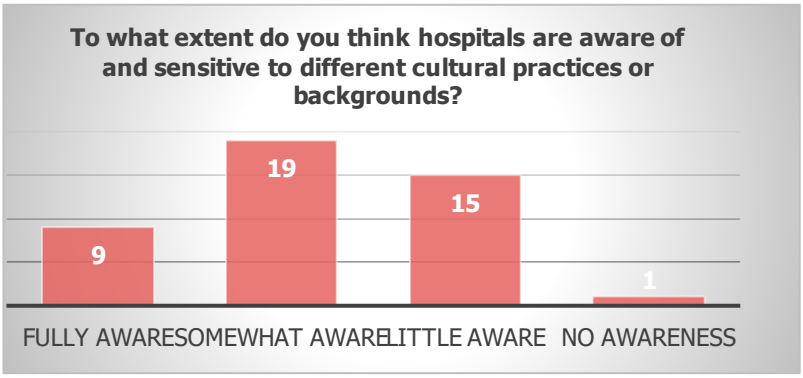
Key findings from the survey

The responses for each question in the survey are displayed below.

To what extent do you think GP practices are aware of and sensitive to different cultural practices or backgrounds?	
Fully Aware 25.5% Some Aware 46.% Little Aware 23.2% No Awareness 4.6%	

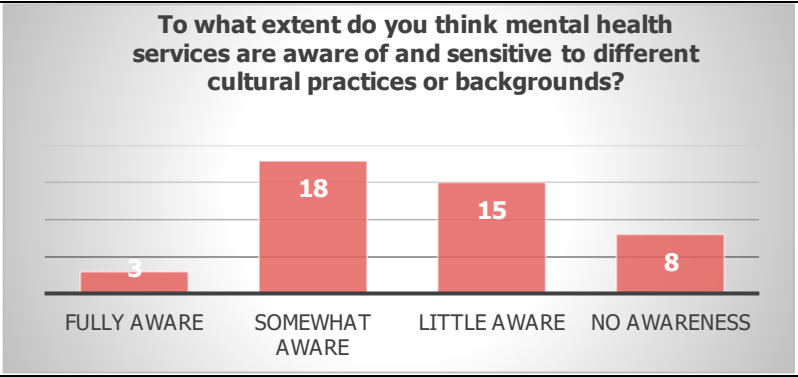
To what extent do you think hospitals are aware of and sensitive to different cultural practices or backgrounds?

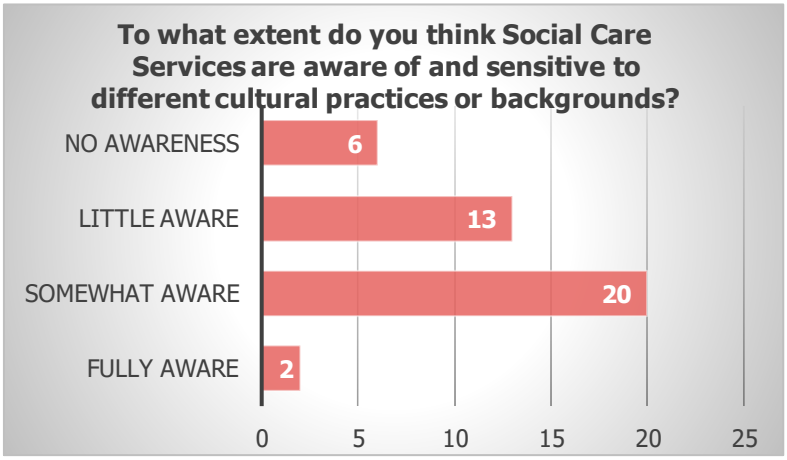
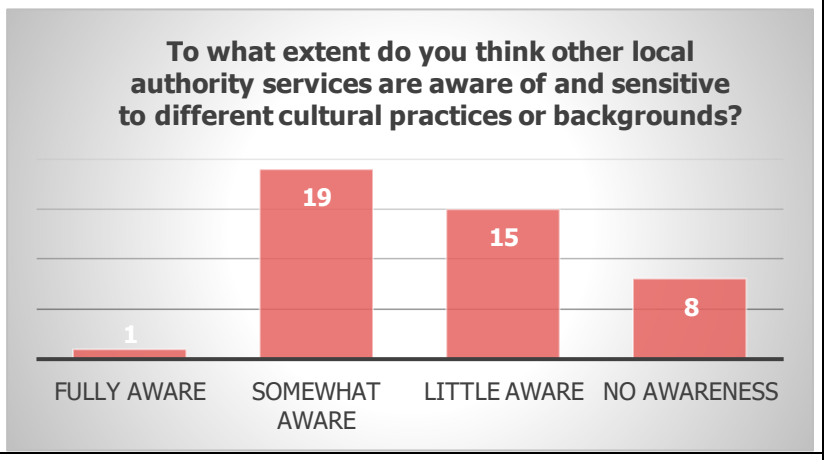
Fully Aware 20.9%
Somewhat Aware 44%
Little Aware 34%
No Awareness 2%

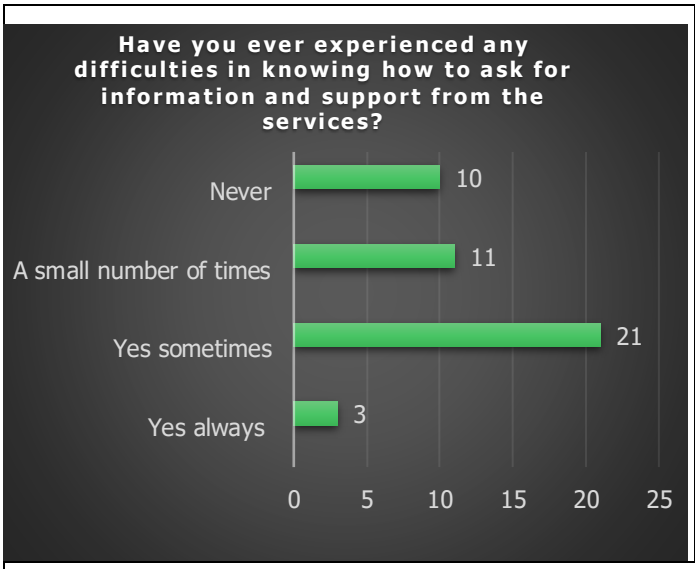


To what extent do you think mental health services are aware of and sensitive to different cultural practices or backgrounds?

Fully Aware 6%
Somewhat Aware 41%
Little Aware 34%
No Awareness 18**%**



Fully Aware 4.8% Somewhat Aware 48.7% Little Aware 31.7% No Awareness 14.6%	
Fully Aware 2.3% Somewhat Aware 44.1% Little Aware 36.5% No Awareness 18.6%	
Fully Aware 20.4% Somewhat Aware 34% Little Aware 29.5% No Awareness 15.9%	
Fully Aware 11.6% Somewhat Aware37.2% Little Aware 30.2% No Awareness 20.9%	

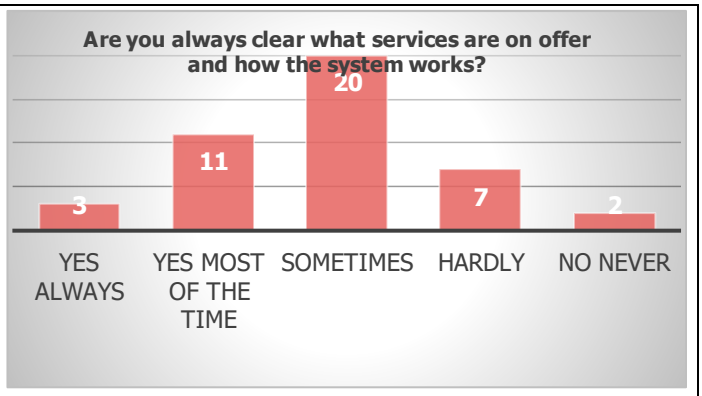


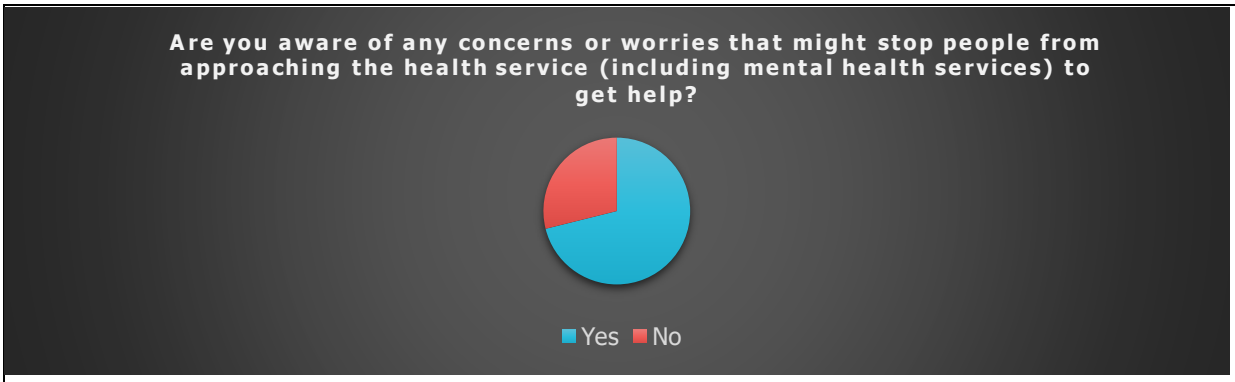
Yes always 4.5%
sometimes 47.7%
small num 25%
Never 22.7%

Have you ever experienced any difficulties in knowing how to ask for information and support from services?
If yes to any of the above, please say how

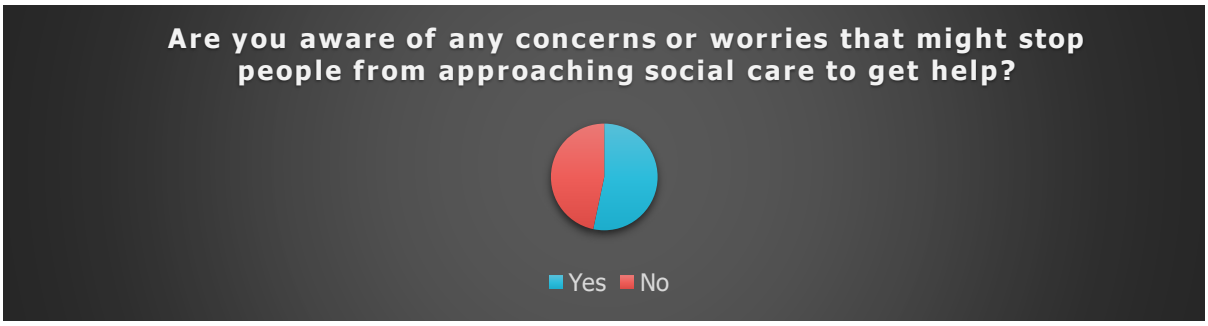
How can this improve?

Yes always 6.9%
Yes, most of the time 25.5%
Sometimes 46.5%
Hardly 16.2%
No never 4.6%

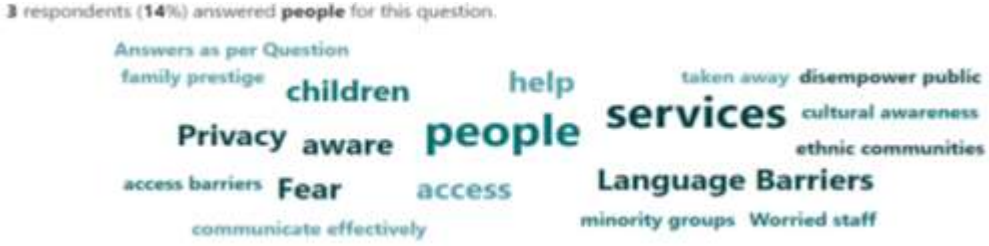


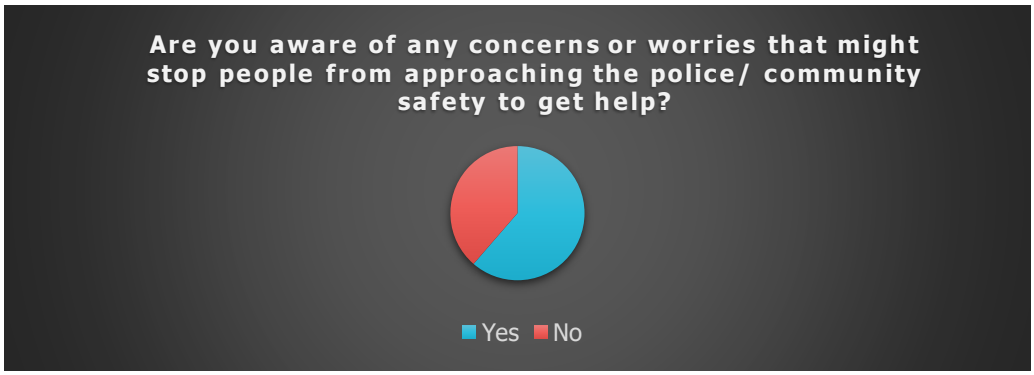


Any concerns or worries about approaching the/using the health services that you can think of?



Any concerns or worries about approaching /using social care that you can think of?



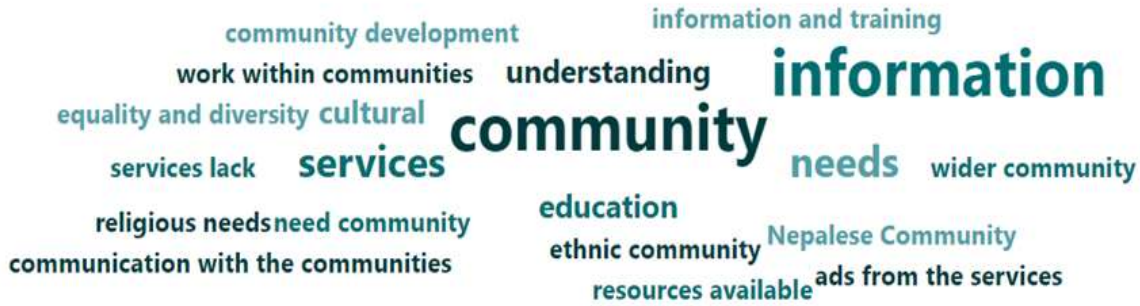


Any concerns or worries about approaching /using the police/ community safety that you can think of?

4 respondents (**17**%) answered **Police** for this question.

Do you have any suggestions to improve worries and concerns about services?

6 respondents (**25**%) answered **community** for this question.



6. CASE STUDIES

Case Study 1

Background (country of origin) impact using services/public/health/police.

Parents migrated from India in 1930 to South Africa, Government brought in acts that caused segregation. People divided into colour /group areas. Had to travel miles. Services were unequal and people had to show pass if they were black, there were separate amenities and transport separated for whites and non-whites. No freedom with services. If police were called, you wouldn't get a good response they were bias against non-whites. Even ambulances/hospital segregated. Leisure and travel services were segregated. This created a distrust of people from police, doctors and authorities.

"I was concerned to find that as I was a person of colour assumptions were made that I wouldn't understand or didn't know the language or wouldn't be interested so often I was not Included in discussions, choices or decisions"

What worked well?

It could have been wonderful and diverse communities, the non-whites tried to get on well- it was a bit integrated during my childhood, but it got worse there and because training and education was limited and an unequal system. I came to the UK. Hospitals were advertising for NHS workers from abroad, and I was pleased to be accepted as a nurse trainee.

What were the challenges?

When I first went to London and people said to ask police for directions, I was very wary, when I was training as a nurse, I met a few police and built trust for police and my views changed and I began to trust more.

When working I was shocked and pleased at how the wards were shared and open to all races and people were treated with respect and dignity and people worked together and mixed.

Moving forward suggestions?

Trust is important for provision and engagement in should be open and honest and always thinking ahead about their needs and be person centered – how can we be more inclusive? Where have they come from? What experience have they had from their country and why have they come here and how did they come here? Services need to recognize people have come to this country for lots of different reasons many hoping to improve their lives. Once this is identified what are their needs- language, social, forms of support? Financial, Education, health, leisure, housing live can improve.

Case Study 2

Background (country of origin) impact using services/public/health/police.

My birth country was Nigeria I moved to the UK in 2006, when I was 27 and had a young child, I was born with sickle cell anemia I was diagnosed at 10 months when I was baby.

What worked well?

In Nigeria if we knew the right people and had the right connections knowing the right people was important. In UK clinic times were specific times and in Nigeria it was a given day and longer time to wait and first come first serve and notes sometimes went missing.

After time and at my current hospital in the UK I am under a supportive sickle team.

What were the challenges?

Some of the nurses gave a lot of prescribed injections some staff weren't sensitive and didn't support when administering them in Nigeria, this gave me fear and anxiety and I had to have CBT and it was hard to have injections moving forward this affect me. Things went downhill when I had a baby, and I was referred to London hospital. In the past they didn't seem to know much and access and information about my condition was limited, and they didn't seem to know much in the UK. This has improved in different ways over the past few years.

Moving forward suggestions?

For me for sickle support especially education and information should be given so that people are aware. Last thing I need is to have an argument with others when they are not aware and to be treated insensitively, the advice to educate more and encourage sensitivity of the patient and recognize that

they may have had different experience in their birth country. Education with main professionals- paramedics, nurse, and doctors as to what sickle cell is and what emergency care is needed by patients.

7. Discussion and conclusion from results focus groups/community survey

Discussion- what have we learnt

We have learnt from responses and feedback from ethnic minority background Surrey residents that there are barriers in terms of inclusion and barriers to engaging in services. Planning and adaption is required across the services.

Feedback and responses show that there four barrier areas to accessing the services and inclusivity: Cultural sensitivity, communication, information, and emotional factors (fear, trust, and stigma)

The question as to whether there any concerns or worries that may stop minority ethnic people approaching services was a “yes” across all the services which challenges us all to improve things. Police, Health service, councils, charity sector and wider. Feedback from focus group and community surveys and case studies help to bring feedback conclusions for each area identified.

Cultural sensitivity
Conclusion on findings show that GP practices and police had little/some awareness on different cultural practices but an area to improve.

“Professionals are not understanding our ways”

Communication
It was shared that referral forms are difficult the language and the terms used can be hard to understand – to use clear language and simple terms

“We cannot understand what they are saying”

Information
Over 47% shared that they sometimes found information and communication difficult to understand across the services and were only sometimes clear on how services worked. People shared that sometimes there had been difficulties with not knowing how to get support from services. Language was a barrier especially if English is a second language. Respondents were only sometimes clear on what services were on offer. People shared that they

needed support. They wanted the information to be simple to describe what each service offered. Translation and more awareness provided about users' right and responsibilities were also highlighted as important.

The men wanted more support for them and highlight concerns around stigma and not wanting to look bad.

"I don't feel clear how to report and how to get help" J

Emotional factors: Fear, stigma, trust

Feedback showed majority of responders reported that they had either experienced barriers or had concerns/worries about engaging with a service.

Due to people experience in their own birth countries or their parents' experiences, a great deal of fear and mistrust was shared about services globally, there was a lack of understanding on processes in the UK and how to respond and link with police and services.

Experience from home countries can impact both positive and negatively impact. In the two case studies, we read examples of fear and how experiences in birth countries of Nigeria gave fear of nurses and injections and South Africa fear of police due to experience of prejudice and past experiences. These can be passed onto our children as they can pick up on fears and anxieties. Communication, information and training and support sessions, can help to build trust and understanding of one another both for the service provider and for the ethnic minority background resident. Working together can promote understand of the services and issues faced together.

"*Doctors need to respect patients they do not explain operational information and we are frightened about processes and things they do".*

"*They talk harshly to us not kindly, and we don't like this*." A

Another area discussed was the stigma of mental health not wanting to appear weak and as if we can't cope and the fear of being judged. Suggestions to overcoming fear were- to improve information and communication. To work together to educate through shared conversation and support group and meeting together.

Fear was mentioned several times in the focus groups and in the individual feedback in the case studies both different, but they explored historical barriers of fear created in birth countries through past experiences.

Racism and potential for prejudice was highlighted and the way people are spoken to or treated were also flagged as important factors in engaging effectively with different services.

8. RECOMMENDATIONS AND PLANNED ACTIONS FOR SMEF AND WIDER RECOMMENDATION/ACTIONS FOR PUBLIC AND CARE SERVICES IN SURREY.

I would recommend that Surrey services take onboard findings of this report developed based on the feedback from Surrey residents from ethnic minority communities.

Organizations are recommended to make individual plans using the four key areas, to improve inclusivity and improve organizational culture and services around race and faith.

For example- practical steps that you can take include:

Cultural sensitivity

To run workshops exploring different faiths and cultures – bearing in mind that there are nuances between mixed background and or be British born so one need to approach without making assumptions/labelling and with wider understanding. Listen to people journeys and think in a culturally race inclusive way. Additionally, providing training on community development, tackling stigma and support forums and training for professionals and workshops in communities.

Joint working with community members and groups such as Surrey Minority Ethnic Forum and other organizations to put in place and support with an action plan to encourage awareness from all staff and delivery.

Ensure pictures and images appropriate culturally sensitive and show mix of cultures not tokenistic but representative.

In the first case study it was highlighted that we should ensure assumptions must not be made about people of colour- each person is unique, diverse and seeks equality - they need to feel included and treated as individual work could be developed around this.

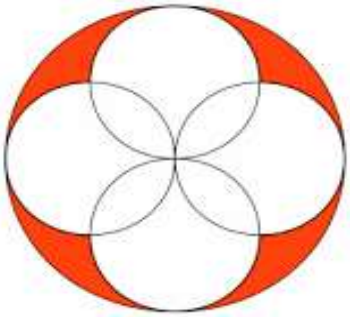
“I was concerned to find that as I was a person of colour assumptions were made that I wouldn’t understand or didn’t know the language or wouldn’t be interested so often I was not Included in discussions, choices or decisions.” A

Information: What information are you putting out? Does it explain clearly and simply what your organization does and is providing and how to get support. Jargon and abstract concepts and abbreviations are not helpful especially when English is a second language. Check your social media and website and emails to ensure information is layout out clearly.

Communication: Clear, and simple material. Consider if the information needs to be available in different languages. Are pictures and images appropriate culturally sensitive? Clarity describing what services do and how to contact services.

Fear and stigma and trust: This can be achieved through shared dialogue and building trust. Giving information about the services and how to access. Again, information is so key, education, positive profiling of ethnic minority background residents and images in media and our localized media and challenging stereotypes are practical steps that your organization can take, it can all form part of your organization action plan and create a more race inclusive culture. When asking how things can improve respondents' answers were training, workshops, and events to interact and clear information in the community.

Conclusion



A majority of people who took part in this engagement, said that they had some form of concerns and worries that stop them from engaging with social care, police and health including mental health services. These barriers included; low level of confidence, fear of judgement, lack of information, lack of empathy and lack of cultural awareness, fear of stigma, language barriers and fear of services. We idented four interlinking themes around communication, information, cultural sensitivity and emotional factors driving these barriers. To make an effective change, all these four areas identified need to be addressed in order to remove barriers for ethnic minority background communities in Surrey and increase engagement with the services.

"If SMEF and other organizations in Surrey, can work together and commit to inclusivity for minority ethnic background people we will see an enablement and improved wellbeing for all making a richer and more diverse, unified Surrey. "Zareena Linney-Waine" Jan 2022

Appendix

Topic	How can we improve this area?
Communication	
Information	
Cultural Sensitivity	
Fear and Trust	

Interesting clips

1.https://www.youtube.com/watch?v=maw6hmlNh44
2.https://www.youtube.com/watch?v=1I3wJ7pJUjg

3. https://www.youtube.com/watch?v=QWTv8NbItt0

Race inclusion useful terms

Equality- offering same rights and opportunities

Equity- offering same rights fair access The term "equity" refers to fairness and justice and is distinguished from equality: Whereas equality means providing the same to all, equity means recognizing that we do not all start from the same place and acknowledge and make adjustments.

Diversity- Understanding each person is unique

Inclusion Extension of all these things- the action or state of including or of being included within a group or structure.

the practice or policy of providing equal access to opportunities and resources for people who might otherwise be excluded or marginalized, such as those who have physical or mental disabilities and members of other minority groups.

Bias inclination or prejudice for or against one person or group, especially in a way considered to be unfair.

Stereotyping- a fixed thought about a people or people

Discrimination- being treated differently because of age, race, sex, disability and other protected characteristics

Can be direct, association or direct by perception, indirect

Positive action- Taking steps to reduce disadvantage from protected characteristics

Protected characteristics-
The characteristics that are protected by the Equality Act 2010 are:

- age.
- disability.
- gender reassignment.
- marriage or civil partnership (in employment only)

- pregnancy and maternity.
- race.
- religion or belief.
- sex.

9. ACKNOWLEDGEMENTS

Andrew Paterson - Policy and Research Officer Scottish Community Development Centre
Dr Negin Sarafraz-Shekary - Public Health Principal Surrey County Council

SMEF for the opportunity and all those that have contributed.

The CPAR programme was initiated and funded by Health Education England South-East and developed in collaboration with the Office for Health Improvement and Disparities (previously PHE), the Scottish Community Development Centre and NHE England and Improvement.