

Community Participatory Action Research Summaries

10th 11th and 12th May 2022. Time: 9:30-12:30



Health Education England Southeast (HEE SE), in partnership with the Office for Health Improvement and Disparities Southeast (OHID), NHS England & Improvements Southeast (NHSEI).

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The Scottish Community Development Centre (SCDC) would like to thank all of the researchers who contributed to this showcase event presenting their insightful findings from across communities in the Southeast. This showcase event will celebrate the researchers in completing their training as well as provide a platform to hear directly of the impact of Covid-19 on Black, Asian and minority ethnic communities to further inform our health and care services.

Throughout the COVID-19 pandemic, inequalities in health have become magnified amongst people from Black, Asian and minority ethnic communities. This Community Participatory Action Research (CPAR) training and mentoring project takes on board recommendation 2 of the

Beyond the Data report by 'supporting community participatory research, in which researchers and community stakeholders engage as equal partners of the COVID-19.'

HEE Southeast and partners (OHID, NHSEI and SCDC) provided training and mentoring for 40 researchers from BAME communities to develop their skills and knowledge to conduct research on the impact of Covid-19 amongst their communities.

This document summarizes the dynamic research that has taken place in community settings. The aspiration of the CPAR programme is to harness principles of co-production and enable systems and its leaders to use the community research to take action and inform policies and practice to address inequalities faced by ethnic minority communities in the Southeast.

To learn more about this project, please email tvpublichealth.se@hee.nhs.uk



Theme: **Inclusion**

Tuesday 10 May 2022

The research summaries within this booklet have been created by the Community Researchers, which for many, has been the first time that they have created a 'conference abstract' of their work. We have ensured that this is reflected in this document maintaining the researchers own reporting style.



Summary 1: Presentation

Tuesday 10 May 2022 – Time: 10:35 until 10:50

‘Investigate the impacts of COVID-19 among Nepalese community groups at Reading east and south locations, Berkshire UK’.

Integrated Research and Development Centre

Researcher/s: Krishna Prasad Neupane

Research Questions:

- a. What factors have contributed to the disproportionate impact of Covid-19 on BAME communities, specifically among Nepalese community groups residing at east and south Reading locations?
- b. What improvements to services can be recommended in order to address these factors and potentially improve health and wellbeing outcomes for these groups?

Research Approach:

Reviewed relevant research docs and reports.

Received training on: Community participatory action research concepts, community-led health research concepts and cycle and carried out qualitative research work employing face to face interviews and focus group discussion meeting.

Research Findings:

Living conditions: Living conditions can be seen to have directly and indirectly increased people's vulnerability to Covid-19, including multiple families living in shared households and financial pressures. There both cultural and material explanations for these living conditions.

Shared housing:

- Respondents reported living with extended families in shared housing. This directly increases the risk of spreading and catching Covid-19. It also puts older, vulnerable, family members at risk as they are in close contact with younger family members who will, in turn, be exposed to the virus at work, school or other social contact.
- There is a cultural element here, in that the Nepalese community is tight knit with family members looking after one another.

Financial pressures:

- Financial pressure also increases the likelihood of having to share accommodation. It also forced more members of households to work. For instance, a person who worked as a Nepali – English translator said they had to go to work during the pandemic in order to afford everyday household costs and to pay bills.
- Some people who were interviewed said they prioritised saving money over maintaining a healthy diet. An unhealthy diet reduces immunity and a person's ability to fight infection, and therefore indirectly increases a person's likelihood of experiencing severe symptoms.
- Another respondent pointed out that older people found it difficult to pay to top up their mobile phone credit, which prevented them



from contacting the GP. It is possible that financial circumstances are therefore leaving people more vulnerable, as it may prevent them from seeking help immediately.

- Among the Nepalese community, there is a cultural orientation to save money for supporting grandchildren, grandparents and other family members.

Communication:

The two key dimensions of communication that emerged from the research were language and internet use. Barriers in both these areas made it difficult for Nepalese community members to receive and understand information and advice related to Covid-19 that could help keep them safe.

Language barriers:

Respondents said that not being able to communicate in English made it difficult to receive services and access advice and support regarding health and related issues. In relation to Covid-19, this was a barrier to receiving medical advice on symptoms, staying safe and keeping healthy.

Those who received the information found it difficult to interpret and understand. Language and communication barriers make it harder to distinguish accurate information from information from untrustworthy sources.

People interviewed in the research said there were not enough interpreters available when needed which made it difficult for them to access required health care services and access medical advice.

Online communication:

Another communication barrier people experienced during the Covid-19 pandemic was around connecting with online services. Some people had limited access to technology that would enable them to go online, whereas others

did not have the required digital skills.

In general, where there was a regular flow of information either online, through e-newsletters or video clips, this was appreciated. Telephone conversations were also helpful for those who could communicate considered positive.

However, most community members who took part in the research preferred to have face-to-face interactions as, otherwise, they felt they could not adequately explain their conditions to service providers.

Sources of support:

One participant described how a Nepalese doctor at their local GP was able to translate guidance for them.

“Nepali doctor who worked in local GP helped to interpret medical information in this sense we are happy with GP services” (Interview respondent)

Instead of relying on formal sources of information, some families relied on informal networks for advice. Participants described how an inter-family support service had emerged which helped people to hear the latest information and advice. More generally, family members often interpreted for each other.

Voluntary and community groups were also identified as a source of support. In addition to supplying healthy food and other groceries, these organisations ran Covid-19 awareness sessions where translation was offered. Some also helped book GP appointments.

“Provided voluntary services by local charities at Covid vaccination centres was helpful for interpretation, fill out forms.” (Interview respondent)

Trust, fear and vaccine hesitancy. The issues of fear and trust were prominent throughout the interviews. These issues are clearly linked to



communication, since people are more likely to be fearful and mistrusting when they have little access to good quality information and advice. Combined, these issues can be seen to increase people's vulnerability to Covid-19 as they result in vaccine hesitancy and other beliefs or actions that go against main-stream public health advice.

Fear:

People who were interviewed recounted stories they had heard during the pandemic, which had been circulating around the Nepalese community in Reading. Examples of local stories included hospital staff feeling from hospitals due to the virus and news of people dying in Royal Berkshire Hospital, including young people and teachers. Respondents said that stories like these had spread fear and negative rumours in the local community.

Trust:

Respondents tended to have negative perceptions of local NHS services during the pandemic. For instance, one view was that hospitals were overloaded because GPs weren't doing their jobs properly in terms of providing good advice and services for everyday health concerns. It was felt that people had to make recurring visits to the GP before they received the correct diagnosis, leaving them suffering for longer and with worse health outcomes. This negativity towards GPs appeared to be connected to a feeling that GPs should have remained open during the pandemic.

"Our entire family members got corona symptoms however, we never got GP advice and services at this very difficult time and GP never bothered about our life." (Interview respondent).

"I am one of the extremely vulnerable and shielded patients and it is now 24 months' time I haven't seen my GP face to face, I have experienced extremely difficult to make phone contact to GP, as it took me one hour and fifty-

nine minutes to get contacted, I had recorded this, made it screenshot and produced to the GP receptionist but still did not trust for this. No one did contact me in its second phase." (Interview respondent).

More positively, the participant who had been provided with interpretation by their Nepalese GP added that their overall experience with this GP had been favourable.

"I rate GP's services very good as they made follow up calls to monitor my personal health condition and provide necessary advice whether I need any further support. I really received required services, support and help from my GP."

Another statutory service which was viewed positively in the research was Reading Borough Council's online information which was helpful in terms of finding information on vaccination centers, emergency contact numbers, interpretation and advice (including via video clips). The council's provision of food and other supplies to shielding families was also appreciated.

Respondents often talked about their experiences and perceptions of what they saw as the delayed government response to the pandemic. Referring back to the initial days of the pandemic, some thought that the decision to introduce restrictions as part of a national lockdown came too late. Others thought that public health policies and messages had been confused and incoherent.

"NHS local hospitals were confused whether staff members who got positive symptoms must stay in isolation or continue working. It was somehow like a research study whether this is ok or that is ok, with no precise policy introduced or decision made at decision making level."

It is well understood that mistrust of health services and other public institutions among BAME communities is often rooted in racism. A small



number of respondents expressed concerns about being treated differently due to their ethnicity. For instance, one view was that health services prioritised check-ups and other services for some groups over others, due to discrimination.

“In policy documents there seem to have equal rights for all however in real practice it is different, looking at service seekers’ skins, language, culture they never give us equal treatment”

Ethnic minority communities also have negative experiences due to cultural insensitivity. This can be as simple as not providing food that people are used to eating. One participant described how the food on offer in hospital can make a tragic situation even harder.

“As the hospitalised patients were not allowed to have homemade foods and drinks and some of the admitted patients didn’t like the taste of foods in hospital, they were not allowed to make visit by their family members. One corona patient in hospital requested to have some homemade rice but did not get it and sadly she died, it’s extremely a shame case.”

Following guidelines:

Research participants described how ineffective decision making had impacted on their ability to stay safe and follow health protection guidelines.

“In my home my close relatives visited us, we did not refuse them coming in my house, sadly we got corona positive by then as there was no strict rules applied by the local Government including hospital, it was only very late social distancing, using protective device like face masks strictly applied by local government.” (Interview respondent).

Perceptions of Covid-19 and vaccine hesitancy:

For some, mistrust and fear extended to Covid-19 and the vaccination programme. One view

expressed in the research was that Covid-19 was a simple flue and that we should not worry much about it. Some other people were ‘vaccine hesitant’ due to believing that negative side effects included infertility and becoming more vulnerable to other diseases.

Other beliefs which came through in the research included those traditional herbal remedies used in Nepal were effective for Covid-19, and that had they been used the disease could have been eradicated by now. There was also some uncertainty and confusion about how Covid-19 could be transmitted. This ranged from doubts over some very plausible transmission routes, such as via traffic light buttons, to belief in less scientific means of transmission, such as that the virus ‘spears’ could stick to the bottom of shoes.

“Back in Nepal, a range of herbs are available that are not found in Reading. Otherwise, we could have eradicated Covid-19 using them” (Interview respondent).

The impact of Covid-19 on the Nepalese community:

Covid-19 had a significant impact on both the physical and mental health of research participants. People had lost loved ones, had been seriously ill themselves and, in some cases, the impact would be felt for the rest of people’s lives.

In terms of physical health, Covid-19 had had a direct impact on people’s families, with many losing loved ones. Some participants described how the impact of Covid-19 on them, and their family’s physical health had also impacted on their mental wellbeing.

“In _____ school where my children study found positive symptoms to teachers, I have to take my children to school regularly, I started getting stress and felt panicking. After few days my son’s teacher died because of Coronavirus, and I started thinking



there might be a high risk in my family members, I started worrying too much as my old age mum lives with me.”

“Suddenly, Covid-19 invaded in the area beginning in 2020, my entire family at home was affected and got ill. It was a shocking situation, and we could not call an ambulance and to go to hospital, neither get help from relatives, friends and neighboring families. My wife got severely ill, I started thinking she will not live for long. I had to manage this terrible family crisis. I controlled myself, did not lose my patience and kept helping them by my level and capacity providing foods and other support, gradually days turned to better, but this is one of the most bitter experiences I have ever had, now our days turning to a full moon.” (Interview respondent).

People’s mental health also suffered as a result of lockdown and social distancing measures. Participants highlighted how living in isolation without having any face-to-face contact, in combination with being unable to exercise and travel, had increased their stress and anxiety levels.

Moreover, this was something which was seen to have lasting implications for individuals and communities. Social gatherings and celebrations are an important part of Nepalese culture, so having such limited social interaction would have been very difficult for many people. One research participant was concerned that the local Nepalese community might struggle to fully recover.

“We are gradually losing cultural knowledge, rich family ties, social life and inter family and inter-community interactions, which are vital to live a healthy and happy life. We are human being, therefore need to have regular interactions, support and sharing feelings with one another. Connecting to nature is very important.”

Learning and Reflections, Impact and Next Steps:

Outreach and engagement:

Outreach services are required for high-risk vulnerable households, including single parent households and those living in overcrowded conditions.

Local community groups need to be engaged with as partners in service design and delivery. This will ensure that services are culturally sensitive and will help to achieve some of the other recommendations below concerning interpretation and mental health.

In addition, local community leaders, or champions, need to be engaged with so they can help mobilise for current and future public health issues. Volunteers and groups should be provided with proper training to prepare them as champions. They would have a varied role that recognises their rich information about their local communities. This could include representing their communities in the design of services and also helping in the community to identify and support vulnerable households.

As part of this outreach, there should be a public health awareness programme for communities to provide accurate information on public health issues and services. This should include practical support for vulnerable households and individuals, including those living in isolation, single-parent families and those with multiple health conditions

Interpretation and language support:

Interpreting services need to be readily available for Nepalese and wider BAME communities who require this.

Translation should be provided by community representatives who are trusted members of their own community.



Translated versions of important public health information and other advice should be available.

More widely, public agencies should work together to identify communities experiencing language barriers and ensure ESOL classes, internet training and other support is available.

Training and support needs to be participant-centred and tailored in order to be culturally appropriate and so that it delivered in a location and time that people can attend.

Cultural, religious and ethnic diversity training:

Public sector staff, including health care workers should be provided with training in cultural, religious and ethnic diversity. Again, this should be designed and delivered with voluntary and community organisations who represent minoritised communities. Therefore, this training should not be considered in isolation of the other recommendations in this report. It should be developed in tandem with community engagement outreach programmes as well as interpretation services and mental health provision.

Culturally appropriate mental health support:

A key finding of this report is that Covid-19 and the resulting health protection measures have had a significant impact on the mental health of people in the Nepalese community. As part of outreach work, it is important to identify households in need of such support and to design culturally appropriate services with the people affected, including community organisations representing them.

Support should go beyond medicalised treatment for mental health, and focus on fostering social interaction, building community organisations and providing physical activity. Community and voluntary organisations need to be central to this provision and should be engaged with and

supported to contribute their expertise based on lived-experience. It is this kind of community support that will build community health and wellbeing, including mental health, in the longer term.



Summary 2: Presentation

Tuesday 10 May 2022 – Time: 10:50 until 11:05

‘What are the barriers to accessing maternal healthcare?’

Alliance for Cohesion and Racial Equality – ACRE Reading

Researcher/s: Evangeline Karanja

Research Questions:

- What are the barriers to accessing maternal services?
- Effect of digitalisation on access to maternal services
- Effect of covid-19 on access to maternal services

Research Approach:

Qualitative research. In-depth interviews with English speaking ethnic minority women and midwives.

Research Findings:

- Care and empathy need to be prioritised for each woman
- Information and communication streamlined for better understanding
- Follow-up of antenatal and postnatal classes attendance.
- Digital literacy
- Better interpreter service and availability
- Pregnant women’ health is important and should be prioritised
- Staff shortage needs to be addressed
- Need for more diversity in the senior management

Learning and Reflections, Impact and Next Steps:

More time is needed to do more research work: increase sample size. It will be great if the recommendations could be acted upon.



Summary 3: Presentation

Tuesday 10 May 2022 – Time: 11:05 until 11:20

‘Exploring barriers for people from Ethnic Minoritized backgrounds using care and public services in Surrey’

Surrey Minority Ethnic Forum

Researcher/s: Zareena Linney-Waine

Research Approach:

Asked 2 questions to four focus groups identified barriers and exploring their suggestions for change. Community Survey online to individual across Surrey from ethnic minoritized background. Questions formulated from the focus group finding. Interview two people and produced case studies in explore a key challenge area.

Research Findings:

Four key areas that are barriers to engaging- Information, Communication, Cultural sensitivity, Fear and Trust and suggestion for work in these areas.

Learning and Reflections, Impact and Next Steps:

Action planning for organisations in the four key areas.



Summary 4: Presentation

Tuesday 10 May 2022 – Time: 11:20 until 11:35

'Hearing from women about black maternity experiences in Oxfordshire'. (Video)

Healthwatch Oxfordshire

Researcher/s: Omotunde Coker

Research Approach:

What was their experience during pregnancy, birth and after birth?

Research Findings:

There are a lot of changes that needs to me made and also a few good feedbacks.

Learning and Reflections, Impact and Next Steps:

Continue to create an atmosphere for change and inclusion.

Summary 5: Presentation

Tuesday 10 May 2022 – Time: 11:35 until 11:50

'Young People's Voice'. (Video)

Fresh Youth Perspectives

Researcher: Caroline Davies

Fellow Researcher: Alicja Borowiak-Jatta

Filmmaker: Alice Ross in conjunction with the Young People of Sussex.

Research Question: Our researchers facilitated a discussion with 20 diverse Young People from Sussex to discuss their social emotional mental health in the pandemic and explore solutions and recommendations for the NHS.

Research Approach: We made a film to directly voice these themes with youth participants. Using

a variety of technical mediums so audio, info-graphics and direct to camera so Young People could select how they felt most comfortable to contribute to the film as well as also some filming, microphone sound and editing.

Research Findings: Watch the Youth Voice film for the answer.

Learning and Reflections, Impact and Next Steps: That Commissioners hear the authentic youth voice when making health decisions especially regarding mental health and racial intersectionality.



Theme: **Mental Health**

Wednesday 11h May 2022

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Summary 6: Presentation

Wednesday 11 May 2022 – Time: 10:35 until 10:50

‘The Impact of Covid 19 on Mental Health of Ethnic Minority Men in Reading’

ACRE-Alliance for Cohesion and Racial Equality

Researcher/s: Tariq Gomma

Research Questions:

The aim of the research was to find out whether people from BAME community were affected by the Covid and lockdown?

Also, to find out how covid19 affected men from the BAME communities.

This research was about how men’s mental health has been affected from the BAME communities. The research also focuses on the barriers stopping men from accessing the mental health services.

Research Approach:

Firstly, a questionnaire with appropriate and relevant questions focusing on the subject of mental health and covid19 which was administered to the focus group of the BAME community. The questionnaire was anonymous.

The result was obtained after the data analysed the findings been recorded and Recommendations been concluded.

Research Findings:

Most of the men were negatively affected by covid19 and lockdown Covid affected men mostly financially, physically and mentally.

Men are unlikely to talk about personal issues. Men are lonely and isolated.

Most of the men don’t know how to access mental health service.

Mental ill people are stigmatized and discriminated. Misconception and stereotype against mental ill health people is evident.

Learning and Reflections, Impact and Next Steps:

This research is a wakeup call, opening door and also great opportunity for me to discover myself. I cannot describe the magnitude of experience I gained from doing this research, it taught me so many things and important lessons in life plus living values and objectives, it taught me to always look ahead not back, look up not down, feel positive not negative there is no impossible and there is always light and hope at the end of the tunnel, this research taught me to be strong and motivated and always look and think ahead, because of that I decided to move further and learn more about the subject of mental health, I decided to join West Lancashire college on online course about Mental Health.



The recommendations are:

- More Funding from the Government and the local authority towards MH.
- NHS to simplify the access of mental health Services [doctors/Clinics....
- The role of Charities/Organizations/ Communities to provide Awareness, Advocate and Education toward MH.
- School, Colleges and Universities should consider MH courses to student and make them aware and tackle bullying.
- Individuals should support each other and provide support if needed.
- Initiate and create Support and conversations Hubs for positive talks.
- Keep people informed and updated; use systems for doing so that can adapt quickly. Immediate intervention when early signs spotted prevention of Mental illness is more practical than treating mental illness. Volunteers who have been trained and screened to enable to deliver support through local volunteer and community groups. Talking about mental health issues will increase the understanding of mental health.



Summary 7: Presentation

Wednesday 11 May 2022 – Time: 10:50 until 11:05

‘CPAR -Impact of Covid on Women and Health Care Services’

Reading Community Learning Centre (RCLC)

Researcher/s: Hemamalini Sundhararajan

Research Questions:

Research questions were focused on topics to gather a general understanding of how Ethnic Minority Women are managing themselves and more specifically during this period of COVID Pandemic. Broadly the topics covered were on, awareness about NHS services and helpline phone numbers, how they go about booking a doctor appointment, their level of comfort for booking GP appointments and challenges in accessing healthcare systems. Further the research probed on the impact of COVID over Physical and Mental health, and their awareness of support systems including their participation in the vaccination drive. Generic demographic questions like age, years of UK residence and challenges for accessing healthcare systems along with their suggestions were also covered.

Research Approach:

With an objective to identify areas of improvement specific to address challenges faced by ethnic minority women, we brainstormed and came up with a structured set of questions which would enable us to cover various aspects of the research requirements.

The English questionnaire was translated into traditional Chinese, simplified Chinese, Arabic and Kurdish versions. The questionnaires were handed to learners of RCLC through staff members and the tutors. The non-learners received the questionnaires via members and leaders of social and religious communities as well as educational institutions. Those who were unable to understand the questions in English could respond with the support from somebody in their families or an interpreter arranged by RCLC in one of the following languages: Tamil, Punjabi, Hindi, Mandarin Chinese and Cantonese, Nepalese, Arabic and Kurdish.

103 women responded to our questionnaire which was distributed personally and electronically. The responses were captured on Excel worksheets with appropriate mapping and data analytics performed to arrive at holistic interpretation of the responses for quantified research outcomes.



Research Findings:

The research findings highlighted multiple challenges faced by Ethnic Minority Women in Reading, especially during the COVID pandemic. Significant among them being:

Challenges with reaching out to health care systems on their own, due to language barriers (53% of respondent reported lower than average English Proficiency). Further complicated due to absence of interactions within the closed circle of friends and relatives limited awareness of NHS services. For example, only 50% of the respondents knew about "119" Covid related services which was provided with multiple language interpretations. Limited access to GP and delay in responses was reported as a deterrent to seek medical support with nearly 26% of the respondents, even though they had genuine health related issues.

Learning and Reflections, Impact and Next Steps:

Having had prior interactions with Ethnic Minority women through Reading Community Learning Centre (RCLC), this research opportunity provided a platform to have a structured approach in summarising the challenges and formulating an action plan for implementation.

Even though there was no prior experience of conducting research, the programme team ensured that appropriate guidance was being provided right from formulating the questions, administering of the questionnaire, data entry, data analysis and reporting. This has helped me to improve my skills around conducting research.

The eagerness with which the research team and RCLC & external respondents offered their time and support for this research initiative, indicated the collective spirit and a sense of togetherness for the common objective of the Community

Development. Feel proud to be part of the team. As part of the research report, we have recommended:

- Enhanced support in overcoming the language barrier through extended interpretation services right from booking of GP appointments and enhanced courses.
- Increased digitalisation of services to enable the reach and awareness of healthcare support services



Summary 8: Presentation

Wednesday 11 May 2022 – Time: 11:05 until 11:20

'Barriers to accessing Cardiovascular services by Surrey's BAME Communities'

Surrey Minority Ethnic Forum

Researcher/s: Jasmine Kapoor

Research Approach:

Covid highlighted the co-morbidities amongst the BAME communities. The cause of death amongst covid patients was frequently listed as heart attack.

I regularly read published literature to understand what the barriers in Surrey's BAME communities were in seeking help from health professionals.

I organised an interview guide and personally interviewed 13 respondents from different ethnic groups. I organised a focus group with Bangladeshi women.

5 Health Events in different boroughs of Surrey facilitated by Hospital Consultants.

Research Findings:

- Language barriers
- Cultural incompetency by Receptionists at GP Practices
- Transport issues
- Poor awareness of Healthy Diet and Exercise

Next Steps:

Work closely with Health care providers to increase uptake of CVD services.



Summary 9: Presentation

Wednesday 11 May 2022 – Time: 11:20 until 11:35

“The new normal”, exploring the impact of covid-19 on the black population of the Banbury community’

RCCG Lighthouse Parish

Researcher/s: Tumi Onanuga

Research Questions:

1. To what extent did the difference in mediums of information, influence response on the news of the virus.
2. To what extent did coping methods and mediums of information impact mental health during the pandemic
3. To what extent did these varying factors (coping methods & mediums of info) manage perspectives on the ‘new normal’.

Research Approach:

We undertook a survey with fifteen questions to explore how our participants, who were black community members in Banbury, gained and managed information about the virus and how this influenced perspectives on the new normal.

Research Findings:

Our participants ranged between the ages of 24-55 years old males and females and a total of twelve participants. In our survey we found that many of the participants initial reactions to news of coronavirus which officially broke out in the UK in mid-February 2020, averaged between being ‘shocked’, ‘scared’ and ‘sad’. With many being full-time workers at the time, they expressed that the impacts of the virus which came shortly after its announcement in the UK, slowed the pace of

their lives to a halt. Many expressed that a major part of their lives the virus negatively impacted was their finances, delaying medium-long term plans for an even longer period than anticipated. This, following the responses of our participants led to a negative effect on their general wellbeing and mental health with many unsure of what to do with themselves without the news/government’s updates.

Objectives:

To what extent did the difference in mediums of information, influence response on the news of the virus.

The main variations in the mediums of information that participants expressed ranged between the news from the ‘television’, and ‘social media platforms. We found that participants who received information and updates on the virus from social media portrayed and expressed shock and fear than those who managed their information from the news.

Current thoughts on covid: They are more confident that the virus will soon be a thing of the past or would become something the general public ‘will have to live with like the flu’, as one participant expressed.

However, the participants who managed information on the virus through the news expressed more uncertainty when asked about their current thoughts on covid-19 and the future.



Some within this group also showed apathetical responses or replies.

Similarly, the main differences in mediums of information in this research also influenced the perceptions of the vaccine, with more participants who got updates from social media only or both social media and television, leaning towards being vaccinated already or preparing to get vaccinated.

More findings: We also found that participants who initially found out about the virus from social platforms, were more likely to embrace the discovery of the vaccines and the mandates of double jabs and boosters that followed.

To what extent did coping methods and mediums of information impact mental health during the pandemic

We found out that those who expressed to have been updated through only social media or both social media and television, had coped higher than those who relied solely on television. In this regard we asked participants to weight their thoughts and feelings using a number scale between one to five. One being the lowest possible outcome of coping with the news of the pandemic and five being the highest. We noticed more numbers three and below on the coping scale with television participants, and more fours and fives with social media platform users. A large majority of participants expressed that they coped with the virus by getting as much information as they could. However, when asked how their choice of mediums of information impacted their mental health, all participants expressed negative emotions between being frustrated, uncertain and fatigued.

To what extent did these varying factors (coping methods & mediums of information) manage perspectives on the 'new normal'.

When asked how the pandemic affected the normal routine and regulation of their lives, most participants expressed their responses within the themes of restrictions and stress. Many identifying that they did not cope well mentally and the inability to go to work took a toll on them individually as well as their family unit. We however found that more participants who used social media as a means of update on information were more stressed in the initial displacement however adjusted within a shorter period, than television watcher. In this we found that television watchers were more likely to be frustrated and stressed by restrictions around shopping, working and general social distancing rules, with a longer adjustment period.

As previously indicated when referring to current thoughts about the pandemic and progress in the future, television watchers were more inclined to be apathetical or pessimistic towards what to expect in the future than social media watchers.

We therefore noted that social media users adapted quickly and therefore coped better as a result of a likely herd-influence. This means television watchers were more isolated being that they could not see the reactions of others as they received the news on covid and therefore had felt more negatively during and after their routines were disrupted. Though not all social media users were optimistic towards the future after the pandemic, they were more likely to be accepting of the vaccine. Similarly, more social media watchers also had a shorted adjustment period than television watchers who relied on solely on the news.



Learning and Reflections, Impact and Next Steps:

- During the research we found that though some of the information shared on social media were false, the presence of community and a support system online positively aided some of our participants. We however reflect on these findings, concluding that more than one medium of information is more reliable to dispel fears and misinformation.
- We reflected that though in the world of work the new normal is favourable to some given the number of companies that have now adopted either hybrid working or remote working models, the new normal for a lot of our participants began once they began to consistently rely on their mediums of information more than before. We conclude that the frequency at which people relied on news or social media for information had a bigger impact on mental health as it distorted reality in bigger ways than expected. Those who sparingly watched the news before the pandemic, only watched the news during though not without interruption rather an accelerated consumption of information.

Recommendation:

We recommend the regulation of news outlets and all mediums of information, manage the impact of fear mongering and hyper-consumption of information, as these were the silent killers of mental health and social interactions during the pandemic.



Summary 10: Presentation

Wednesday 11 May 2022 – Time: 11:35 until 11:50

‘How were families of BAME Prisoners effected by the pandemic?’

Mothers 4 Justice (M4JU)

Researcher/s: Tanagrajabu Nala-Hartley

Research Questions:

How were families of BAME prisoners affected by the Pandemic.

Research Approach: Through the M4JU outreach work we conducted a series of interviews with mothers and sisters of BAME prisoners or families that had been in an encounter with the criminal justice system. M4JU has regularly throughout the pandemic, been holding regular talks with moms and sons or sisters to understand their take on why there are going in and out of prisons or how there are affected by the preschool to prison route. The CPAR focused on whether the Pandemic exacerbated the situation, or it remained the same.

Research Findings:

We picked up that there were already underlying factors, but these were emboldened by the pandemic in terms of structural inequalities.

Learning and Reflections, Impact and Next Steps: It would be great to have access to a bigger cohort and perhaps also have focus groups. As a start it wasn't a bad way of getting an understanding and wider views from a community that rarely has a voice, it was great to also get that point of view which is rarely platformed. Especially regarding the stigmatisation of the subject matter.

It would be great to see the format shared widely as a template to look at rate of recidivism in relation to some of the aspects that were raised e.g., Poverty, Education and have recommendations on how to change and implement lasting change for future generations and help the rehabilitation process.



Theme: **Access to Health Services**

Thursday 12th May 2022

The research summaries within this booklet have been created by the Community Researchers, which for many, has been the first time that they have created a 'conference abstract' of their work. We have ensured that this is reflected in this document maintaining the researchers own reporting style.



Summary 11: Presentation

Thursday 12 May 2022 – Time: 10:35 until 10:50

'Impact of COVID-19 on the BAME population in Berkshire, UK'

Jacquah Health Foundation

Researcher/s: Jessica Jacquah

Research Questions:

Impact of covid -19 on the BAME communities?

Why vaccine Hesitancy among the BAME community?

Why is the BAME community suffering from Diabetes more vulnerable to covid – 19 Pandemic?

Research Findings:

Quantitative Method for data collection.

Survey questionnaires in according to data protection guidelines.

Coding generated.

Learning and Reflections, Impact and Next Steps:

People need evidence and reassurance of their wellbeing after taking the vaccines. Using the local trusted members of the BAME communities to share the sensitive vaccine information.

Creating awareness within the BAME communities to bridge the gap between GP visits and participants.



Summary 12: Presentation

Thursday 12 May 2022 – Time: 10:50 until 11:05

'Health Awareness: Barriers to Cancer Screening in Crawley'

Citizens Advice in West Sussex

Researcher/s: Parmila Mannan, Kuljinder Johal, Sandra Carrillo de Fuente

Research Questions:

What are the barriers, if any, that people from diverse backgrounds face when accessing cancer screening services in Crawley?

Within this, we tried to understand: The knowledge those in the community had surrounding cervical, bowel and breast cancer, People's experiences of accessing cancer screening services in Crawley, to use both of these things to identify community-led solutions to reduce barriers.

Research Approach:

A wide range of channels were used to recruit participants including sharing flyers via social media, at places of worship, and reaching out to community and grassroots groups who took the lead by cascading information to their networks. We managed to reach 116,945 people through sharing the information on community Facebook groups.

Our interview guide was led and reviewed by community members and structured in a manner that allow us to understand more about possible systemic, cultural, and lifestyle barriers.

We held 8 semi-structured interviews with members of the diverse communities in Crawley,

and two in-depth qualitative surveys. A flexible methodological approach allowed us to gather extra insight whilst ensuring the needs and preferences of the community were met.

Semi-structured interviews allowed us to be flexible and adapt our questions depending on the interviewee's experience; this encouraged a two-way conversation and allowed us to gain rich qualitative data. It allowed residents to open up about sensitive topics, whilst the researcher was able to tailor the interview to ask further questions.

Thematic analysis was then used to analyse all forms of qualitative data, and themes that occurred in a third of the transcripts were considered recurrent.

Research Findings: The key barriers that were identified were:

A lack of knowledge and awareness about symptoms, what cancer screenings are, and how to access them. Being unaware of symptoms or what screenings are available can prevent people from accessing life-saving screenings and early treatment.

Telephone systems to book appointments create difficulties for those unable to call at 8 am due to work or other responsibilities.

Work and other commitments clash with the time of GP appointments. Participants struggle to get appointments with their GP, as most only offer



appointments during the working/school day, and many are unable to attend these. Since the beginning of the pandemic, several appointments have moved online which can increase accessibility barriers for those whose first language is other than English. Limited affordable public transport for those who cannot drive or who cannot rely on friends or family to attend appointments could be a barrier to accessing cancer screening services.

The fear of catching COVID-19 by attending medical appointments could prevent some members from accessing medical appointments.

Learning and Reflections, Impact and Next Steps:

The community members provided solutions to the barriers identified:

Increase in communications, including translated materials, via awareness campaigns on cancer symptoms, screening services, interpreting services, and community transport.

- Increase attendance of NHS professionals in community events, schools and workplaces to raise awareness of symptoms, and normalise the conversation around cancer.
- Extension of GP opening hours to include after 6 pm appointments and Saturdays.
- Increased flexibility on the system to book appointments to improve accessibility.
- Awareness of interpreting services, and an increase in face-to-face appointments, especially for those who experience language barriers.



Summary 13: Presentation

Thursday 12 May 2022 – Time: 11:05 until 11:20

'Attitudes to Cancer Screening in Brighton and Hove'

Trust for Developing Communities, Hangleton and Knoll Project

Researcher/s: Terry Adams, Kalishia Davey, Aleya Khatun

Research Questions:

Interviewers asked questions about Background – awareness of cancer and screening services, Systemic barriers – access to screening, Lifestyle barriers, Cultural barriers and ideas for improvements.

Research Approach:

Our team of ethnically diverse community researchers spoke to 24 people with whom they had trusted relationships. They carried out twelve in-depth individual interviews, six male and six female as well as holding a focus group with twelve females. All the participants were Brighton and Hove residents from Black, Asian and ethnically diverse backgrounds. Countries and languages represented included Turkish, Bangladeshi, Nigeria, Jamaica, India, Kenya, Sudan, Uganda, Iran and Eritrea.

Research Findings:

We found that Trusted relationships in community groups are key:

- Cancer knowledge differs across genders
- There are barriers to accessing information
- There are logistic difficulties

Learning and Reflections, Impact and Next Steps:

Our recommendations are:

- Accessible and culturally appropriate information
- Culturally welcoming environments
- Peer support combined with learning opportunities
- Flexible transport options
- A commissioning focus on quality outcomes



Summary 14: Presentation

Thursday 12 May 2022 – Time: 11:20 until 11:35

‘Cancer Screening’

Sussex Interpreting Services

Researcher/s: Fares Hadison, Jingyi Sun, Magda Pasuit, Aleceia de Juan, Oana Patap

Research Questions:

Interviewers asked questions about:

- Background – awareness of cancer and screening services
- Systemic barriers – access to screening
- Lifestyle barriers
- Cultural barriers
- Ideas for improvements

Research Approach:

Our team of 5 bilingual community researchers engaged with 82 individuals (9 Spanish speakers, 38 Polish speakers, 2 Farsi speakers, 1 Kurdish Sorani speaker, 12 Chinese Mandarin speakers, 20 Romanian speakers) with whom they had trusted relationships. Each researcher used the same set of questions to explore the issues but applied whatever was the most appropriate methodology for their community and in some cases focused on one type of cancer screening over others. In total they collected data via 49 written surveys, 2 focus groups, 25 in-depth individual interviews.

Research Findings:

- Past experience of cancer, personal or through friends and family, influence attitudes to screening (positively or negatively depending on the individual).
- Comparisons between the NHS and health systems in the country of origin were common and differences caused anxiety for patients particularly if they didn’t understand why.
- There is a belief that the NHS system, especially going through the GP for everything, puts an unnecessary barrier in the way of effective screening.
- Easily accessible, good quality linguistic support was crucial for people to understand and take up screening invites.
- There are other logistic challenges to taking up screening invites; travel and childcare costs, taking time away from work or domestic responsibilities, distance to a venue etc.
- Covid has had a negative impact on access to cancer screening.
- People find it difficult to talk about cancer without professional help and guidance



Learning and Reflections, Impact and Next Steps:

Our recommendations are:

- Accessible and culturally appropriate information; translated, using imagery that people identify with, focused on positive outcomes from screening.
- Reassurance about the training, experience and qualifications of screening practitioners who may not be doctors.
- Consistent language support through the entire process; invitation letter and associated information leaflets, help making appointments, face to face interpreting at appointments, advocacy for individuals who may require additional support to say what they want etc.
- Discussion opportunities with health professionals which incorporate emotional support for participants who are afraid or uncomfortable.
- Flexible and free transport options.



Summary 15: Presentation

Thursday 12 May 2022 – Time: 11:35 until 11:50

‘Understand the reasons for poorer health outcomes of minority ethnic women during pregnancy’

Surrey Minority Ethnic Forum

Researcher/s: Ambreen Muzaffar and Attia Aslam

Research Questions:

24 questions.

Research Approach:

Interview and Focus groups

Research Findings:

Experience of women about information and attending outpatient appointments during pregnancy.

Experience of care and support received during pregnancy

The financial impact of covid-19

Experience of first-time mums and those who were not born in the UK

Learning and Reflections, Impact and Next Steps:

To raise awareness about health information and to remove barriers so women from ethnic minority backgrounds can enjoy and feel socially included by increasing cultural awareness amongst health and care providers.

To consider the socioeconomic status of families in relation to available health care services/ care planning. Improve access to face-to-face appointments to reduce the impact of digital exclusion. To help improve their wellbeing and cognitive skills. To help improve maternity health literacy.

We would like to thank all of the organisations, researchers for their valued contributions to this event.

We would like to express our thanks to everyone who has contributed to this event.

