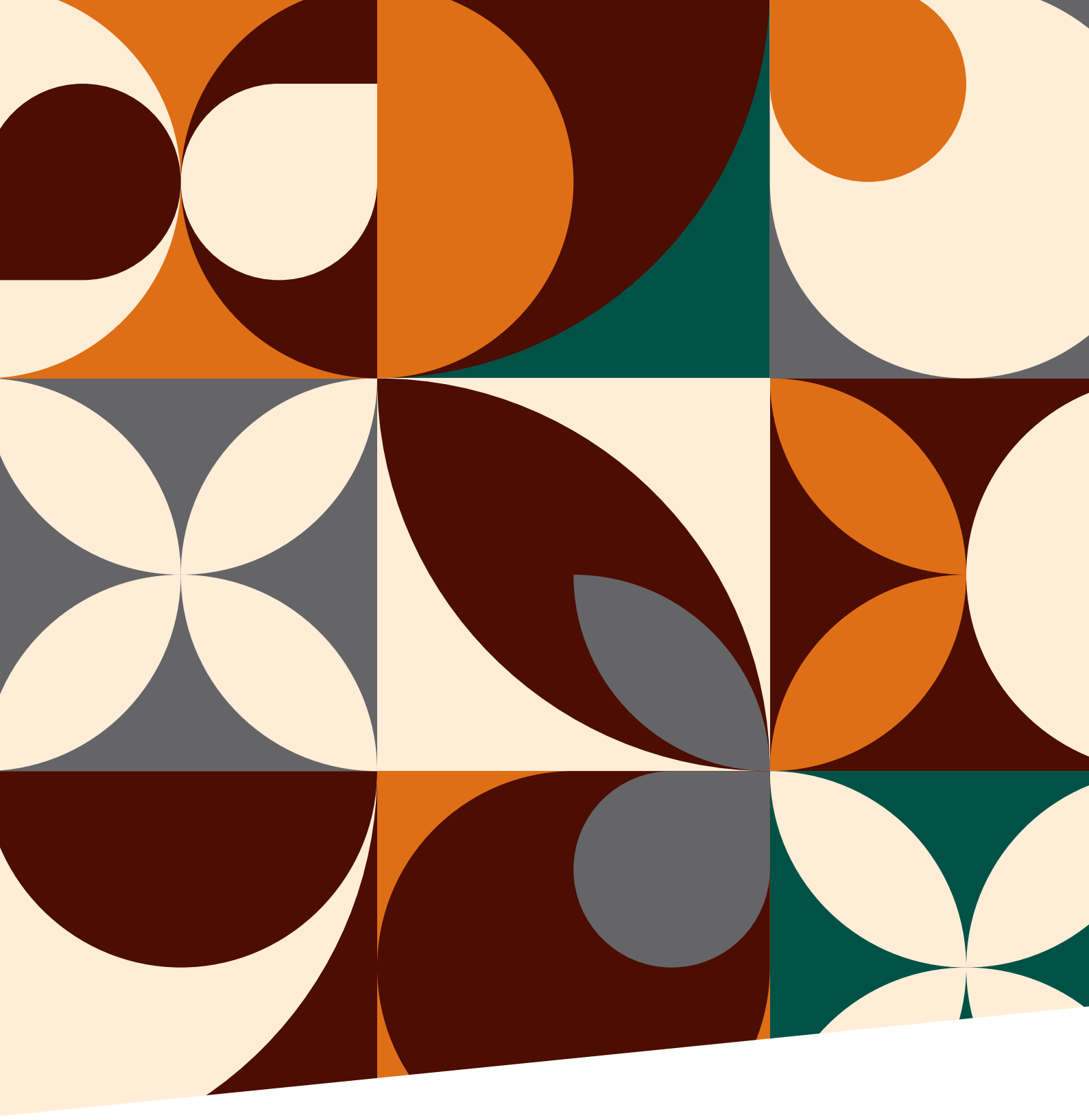


Community Participatory Action Research 2021–2022

acre
Reading Community Learning Centre
READING VOLUNTARY ACTION
Reading Borough Council Working better with you
University of Reading
scdc scottish community development centre
NHS Health Education England
NHS England and NHS Improvement

ABBREVIATIONS USED THROUGHOUT

ACRE: Alliance for Cohesion and Racial Equality

BAME: Black, Asian and minority ethnic

CPAR: Community Participatory Action Research

IDRC: Integrated Research and Development Centre, Berkshire, UK CIC

HEE SE: Health Education England South East

NHSEI: NHS England and Improvement South East

OHID: Office for Health Improvement and Disparities

PAR: Participatory Action Research

PHE: Public Health England (NB, PHE became the Office for Health Improvement and Disparities during the course of this programme).

RBC: Reading Borough Council

RCLC: Reading Community Learning Centre

RVA: Reading Voluntary Action

SCDC: Scottish Community Development Centre

UoR: University of Reading

Below: CPAR team with Professor Adrian Bell (UoR) during the showcase event

Introduction

Throughout the Covid-19 pandemic, inequalities in health, especially mental health, have become magnified amongst some Black, Asian and minority ethnic (BAME) groups disproportionately affected. Public Health England's report, Beyond the data: Understanding the impact of Covid-19 on BAME groups (2020), demonstrates the widening of existing health inequalities and as a result Health Education England South East implemented a programme of work to support Community Participatory Action Research (CPAR), in which researchers and community stakeholders engaged as equal partners. A partnership involving Reading Borough Council (RBC), Reading Voluntary Action (RVA), the Alliance for Cohesion and Racial Equality (ACRE), Reading Community Learning Centre (RCLC) and the University of Reading's Participation Lab were successful in gaining a grant to train and support 5 local researchers in Reading to co-produce and carry out the research with the support of a part-time facilitator, Dr Esther Oenga. Over the last year, they have worked tirelessly to research and evidence the striking inequalities facing minority ethnic communities in accessing healthcare in Reading and this report outlines their key findings and recommendations on a range of issues from men's mental health and maternal services to the challenges of accessing health care services by ethnic minority women and the impact of Covid-19 on Nepalese community.

The five community researchers were trained by the Scottish Community Development Centre (SCDC) in Community Participatory Action Research (CPAR), an approach which stems from a type of research known as Participatory Action Research (PAR) and grounded in the principles of equal partnership, collaboration and community action. Centred around the notion that communities themselves have the skills and expertise to best understand local needs through their lived experiences, PAR seeks to disrupt traditional power relations between researchers and the researched by locating knowledge generation at the local level and enable communities to explore and action issues that matter most to them. The use of participatory methods helps to break down barriers between communities and service providers and it is this community-centred approach that creates and strengthens the relationships and trust that are foundational to lasting social change. This hopefully gives more control to the people who are actually living the experience, and their engagement with pinpointing problems and finding solutions ensures that projects and their impact are relevant and hopefully sustainable into the long term. In the words of my late colleague, John Ord, who started many community research teams in Reading:

> "Community researchers are not blank sheets – they hold tacit or implicit knowledge of their community and 'know' it intuitively in a way that non-residents do not. They also have experience – and the need to know and what to do derives from their direct engagement in the world. . . . what carries understanding and skills/knowledge forward is a collective and co-operative search for the truth of *residence* – not simply what is lacking but what counts as asset; the skills and awareness that people already have and this is what the research with the community releases."

The benefits of CPAR are clearly evidenced throughout this insightful and powerful report as it centres the voices and lived experiences of local communities, but it is not without its challenges. This project required a substantial investment of unpaid time, additional resource and emotional labour that wasn't reflected in the funding application or original timeline. The success of the project is a testimony to the commitment of the community research team and partnership to evidence the impact on Covid-19 on BAME communities in Reading so that healthcare institutions and organisations can work with communities in Reading in the most crucial stage of this CPAR project – the development of NEXT STEPS and ACTIONS that will provide real INTERVENTION and CHANGE. We hope this report acts as a catalyst for this collective action in addressing health inequalities in Reading.

DR SALLY LLOYD-EVANS, PARTICIPATION LAB, UNIVERSITY OF READING

We are privileged to have been a partner in this community research project. The community researchers have been committed to ensuring the voices of their communities have been heard and that commitment is illustrated throughout this report. Let's ensure this marks a change in how we all work. Join us by reading the findings and recommendations, act where you can and share the results across your networks.

RACHEL SPENCER, CHIEF EXECUTIVE, READING VOLUNTARY ACTION

Tackling health inequalities: summary of recommendations

Based on the community researcher's detailed findings and recommendations, outlined in the next section of this report.

ACCESS TO MATERNAL HEALTHCARE SERVICES FOR ETHNIC MINORITY COMMUNITIES

- Streamline information and communication for better understanding.
- Ensure antenatal and postnatal classes are more accessible.
- Offer face-to-face services where possible and provide support with digital literacy when services are online.
- Provide better resources for translation and interpretation.
- Prioritise pregnant women's health, empowering them to make more individualised birth plans.
- Address staff shortages, ensuring more consistent care with the same midwife.
- Increase diversity in senior management and provide cultural awareness training to all staff working in maternal services.

ACCESS TO HEALTHCARE SERVICES FOR ETHNIC MINORITY WOMEN

- Speak to ethnic minority communities about vaccination and common medical problems in community or religious settings.
- Use a range of methods to provide information about health and wellbeing, including text messages, websites, social media and translated leaflets.
- Improve the availability and quality of translation and interpretation services – these should be available throughout a patient's journey, beginning at the moment they book a GP appointment.
- Improve GP services with longer opening hours and shorter waiting times on the phone.
- Provide translated information about helpline numbers and how to use them; support and train helpline staff to make these services more accessible and culturally sensitive.
- Reduce waiting times for hospital appointments and ensure face-to-face consultations are available for ethnic minority communities with additional barriers to accessing services online or over the phone.
- Increase awareness of regular health checks for the over 60s, NHS mental health services, and opportunities to express their views if patients have been treated unkindly or indifferently.
- Continue to provide community courses and activities which meet the needs of ethnic minority women, including IT, stress management, psychological first aid, exercise classes, visits and walks.

IMPACT OF COVID-19 ON THE MENTAL HEALTH OF ETHNIC MINORITY MEN

- Increase government funding for mental health services and make them easier to access.
- Ensure mental health issues are identified at the earliest possible stage, by increased training and awareness among all staff in public services.
- Recognise and support the role of the voluntary and community sector in providing awareness, understanding, advocacy and education around mental health issues, and responding to changing needs in communities.
- Promote mental health awareness in schools, colleges and universities.
- Develop conversation hubs offering professional and peer support.
- Support members of the community to conduct their own research and help improve services.

IMPACT OF COVID-19 ON THE NEPALESE COMMUNITY IN READING

- Provide outreach services for high-risk vulnerable households, including single parent families and those living in overcrowded conditions.
- Engage local community groups as partners in culturally-sensitive service design and delivery.
- Engage and train local community leaders and champions to mobilise for current and future public health issues, represent their communities in service design and help identify and support vulnerable households.
- Improve the availability and quality of translation and interpretation services for Nepalese and wider BAME communities.
- Identify communities experiencing language barriers and ensure ESOL classes, internet training and other support is available in community settings.
- Train public sector staff, including health care workers, in cultural, religious and ethnic diversity. Design and deliver this training in partnership with voluntary and community organisations who represent minority communities.
- Provide culturally-appropriate mental health support, going beyond medicalised treatment and fostering social interaction, physical activity and community organisations.
- Recognise and support the importance of voluntary and community organisations in building community health and wellbeing, including mental health, in the longer term.

Research overview

BACKGROUND AND AIMS

The aims of this research, set out in Public Health England and NHS Health Education England's Community Participatory Action (CPAR): Training and Mentoring Guidance Document, were to:

- Train individuals from organisations drawn from BAME communities in CPAR to tackle health issues related to Covid-19.
- Equip the BAME community researchers with the skills to later deliver CPAR to help in addressing wider inequalities.
- Share learning from CPAR across networks in the South East and beyond.

The programme was designed to support recommendation two from PHE's report Beyond the data: Understanding the impact of COVID-19 on BAME groups (2020):

> "Support community participatory research, in which researchers and community stakeholders engage as equal partners in all steps of the research process, to understand the social, cultural, structural, economic, religious, and commercial determinants of Covid-19 in BAME communities, and to develop readily implementable and scalable programmes to reduce risk and improve health outcomes."

METHODOLOGY AND ETHICAL CONSIDERATIONS

The 5 community researchers from Reading were among the 41 community researchers recruited by HEE and PHE in February 2021, through 15 voluntary organisations and social enterprises. They each received two-day training and ongoing follow-up mentoring support from the Scottish Community Development Centre. The training and mentoring were designed to equip researchers with the knowledge and skills to design, undertake and present their own community research (see Healthy Dialogues, CPAR Training and Mentoring Interim Report, October 2021). Krishna Neupane's report gives more details of the training and support received by the community researchers (see page 29).

The research carried out by the community researchers did not require formal ethical approval, but the researchers were trained and supported to carry out the research in line with the standards of accountability, ethics and reporting of the participating organisations. Researchers learned about compliance with GDPR and implementing the principles of consent, confidentiality and safe storage of information, and how to deal with issues arising when working with the public. They were supported by participating organisations to ensure their own health, safety and wellbeing during the project. The project was conducted between February 2021 and May 2022.

The Reading community researchers have presented their findings at several events and meeting, including an in-person showcase at the Museum of English Rural Life (MERL) on 4 April 2022 and an online showcase hosted by RVA on 16 June 2022. They participated in an online showcase alongside the other community researchers from across the South East on 10–12 May 2022. This was hosted by HEE SE, in partnership with the Office for Health Improvement and Disparities, NHS England and Improvement and the Scottish Community Development Centre.

FORMAT OF THIS REPORT

The following pages contain the final reports produced by the community researchers in Reading, who each set out their own research methods, findings and recommendations and acknowledgements. The final section contains profiles of the community researchers and partners, along with their reflections on the value of community-led research, including its economic value and the importance of resourcing it properly, and the project acknowledgements.

Right: CPAR team at RVA offices

Community researchers: findings and recommendations

Barriers to accessing maternal healthcare services faced by ethnic minority communities as a result of Covid-19 and digitisation

EVANGELINE KARANJA, ACRE

INTRODUCTION

The MBRRACE-UK report (2021) showed a stark disparity in the racial variations of maternal mortality rates. Black women are four times more likely to die, while Asian women were two times more likely to die than white women during pregnancy, delivery or postpartum. Apart from a slight drop in the maternal mortality rate for Black women, this bleak picture has not changed in over a decade (*Beyond the data,* 2020).

Public Health England's report, *Covid-19: understanding the impact on BAME communities,* demonstrates the widening of existing health inequalities and as a result, Health Education England South East is implementing a programme of work to support community participatory research, in which researchers and community stakeholders engage as equal partners (Beyond the data, 2020).

A key component in establishing equality in maternal healthcare provision is the examination of women's experiences of accessing these services. My involvement in voluntary community work in the past two years has allowed me to engage in community talks and hear what problems women are facing.

The topic of maternal health is one that sparked my interest in listening to many women's pregnancy journeys, the highs and the lows. I was especially interested in hearing the experiences of women who could speak English fluently. As previous research has shown, language has been a big contributing factor in the barrier to accessing maternal health care. However, what is the experience of ethnic minorities who can speak and understand the English language in accessing maternal healthcare services?

RESEARCH FOCUS

Health care services must consistently and competently strive to meet the needs of the whole population. However, past research has shown that patients from ethnic minority backgrounds have faced inequality when accessing healthcare services. Hence there is still a great deal of work to ensure that all patients, regardless of their background have equal access to healthcare services.

This study aims to explore the experiences of pregnancy, childbirth, antenatal and postnatal access, in women and healthcare professionals in the Black ethnic minority and highlight the effect of the Covid-19 pandemic and digitalisation.

1. What are the barriers to accessing maternal services?

2. What was the impact of covid-19 on maternal services?

3. What is the effect of digitalisation on maternal services?

RESEARCH METHODS

This research was qualitative, using individual interviews with open-ended interview questions so that in-depth information could be collected. This allowed me to better explain the research questions to participants, and to better understand their answers. It also enabled me to observe people's behaviour as we spoke, as this can provide extra information about how someone is feeling about an issue.

The advantage of an in-depth interview method is the rich data collected. However, the disadvantage is that it is time-intensive which limits the number of participants. I interviewed 9 respondents: 6 mothers and 3 midwives all within the Black ethnic minority with a good understanding and knowledge of the English language. Consent was given, confidentiality was agreed upon with respondents and all sessions were recorded.

Data collection occurred between November 2021 and January 2022. The analysis of data involved transcribing the recordings, reviewing the data, and taking notes of the findings that were emerging.

RESEARCH FINDINGS

1. WHAT ARE THE BARRIERS TO ACCESSING MATERNAL SERVICES?

This study focused on the lived experiences of English-speaking ethnic minority women, who were pregnant or delivered within 6 months of the Covid-19 pandemic. During the pandemic, maternal services became increasingly digitalised, and most of the women who were interviewed had to engage with online and digital services during their pregnancy and first few months after delivery.

Figure 1 shows several barriers to accessing maternal services as expressed by the participants.

1.1 INTERACTION WITH HEALTHCARE PROFESSIONALS

1.1.1 Different midwives every time.

All participants mentioned that they saw different midwives at all their antenatal appointments. They all felt that they had to re-explain their history and situation every time they met a new midwife. A common sentiment that arose in women requiring regular input from secondary care during the antenatal period was ineffective communication between their community midwives and hospital midwives or obstetricians and vice versa, sometimes resulting in the omission of crucial clinical information. The participants were not allowed to bring their partners to these appointments.

> "One of the things that I didn't like is the fact that I didn't have the same midwife throughout my pregnancy, I was always changing, so you know for one appointment I would see this midwife, next one I would see another one and she wouldn't know the history. And so yeah, I didn't like that." *Participant 4*

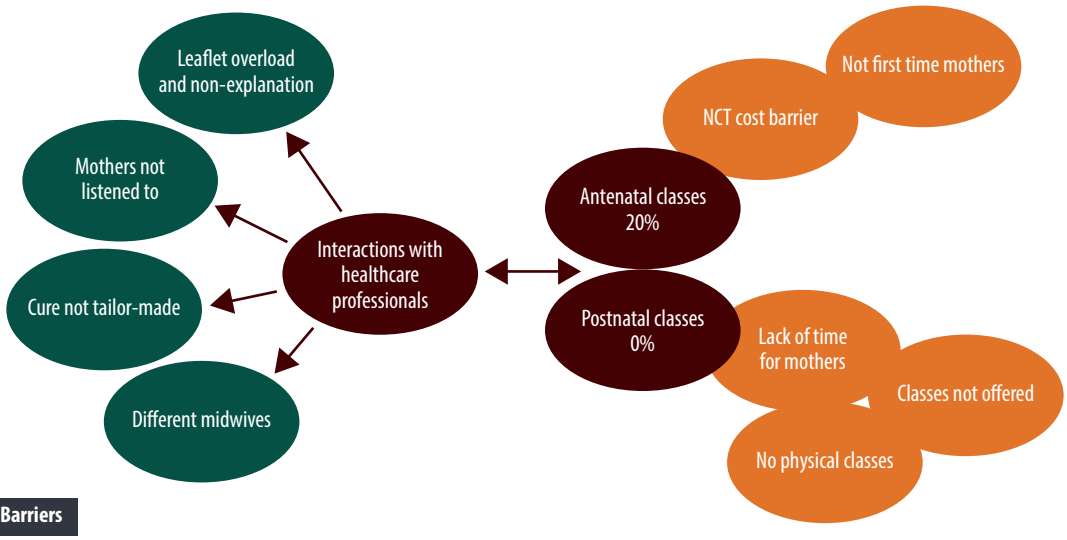


Figure 1. Barriers

> "I think it was at least three different midwives. I didn't have a consistent midwife. It wasn't good, because there was no consistency. You know, having a child when you're being faced with all of this pandemic and stuff, it's so unnerving to have so many changes as well." *Participant 2*

Two participants did mention that when they had a consistent midwife who followed up with them, it created a very good bond and person to rely on. They also mentioned that midwives from the same ethnic background did provide them more care and attention in hospitals.

> "Midwife was a good advocate. Proactive and very good in signposting where to find help." *Participant 6*

1.1.2 Leaflets

The participants all reported some level of provision from the health care professional and almost everyone agreed they would have preferred more thorough discussions. Most participants received information about their pregnancy in the form of signposting to books or websites, but they expressed that their individual information needs would have been better met by one-to-one discussions.

> "To give someone a leaflet and information and say, 'Read up about this and this and this, and these are . . . these are kind of the options'. Rather than take the time to educate the person. To say, look, we're just going to break it down to you in two sessions. This is what we want to talk about and cover here." *Participant 2*

> ". . . they just sent me leaflets for exercise." *Participant 6*

1.1.3 Not involved in decision making

Most of the participants reported feeling like they were not involved in the shared decision making with the healthcare professionals. The participants all reported some level of provision from the healthcare professional and almost everyone agreed they would have preferred more thorough discussions.

> "You were not given enough information to justify why they wanted to go the route they wanted to go." *Participant 4*

> "It was so traumatic. It was absolutely disgusting that they could have avoided a lot of things, in terms of when I was dilated, going to the hospital once. People to see where the baby's positioning was. That could have been noted down, and it could have been avoided the second time when I came in and them saying they have to do a C-section." *Participant 2*

1.1.4 Mothers not listened to by healthcare professionals

In this study, most participants spoke English fluently. Despite the high standard of English spoken, most participants felt that they were not listened to by the healthcare professionals. According to past research, the findings reflect how pregnant women are being put at greater risk due to clinicians focusing on their pregnancy, rather than the woman's own health (MBRRACE-UK report, 2021).

> "So, if you're birthing a human being, the best position to be in has always been on all fours. But there's never been that sort of an option for me. And I wonder, right, is it because of the age? Is it because of the colour?' You know, all these things pop up." *Participant 2*

> So, again, it just made me feel like this is just them saying this is just the easiest way for us to make sure we're just doing our rounds, we're meeting our checks and able to tick things off. That's how it felt." *Participant 2*

> ". . . they were not allowing me to have the time to be pregnant, to have the time to go into the full experience of having a natural birth." *Participant 2*

"The doctors were fixated on complexities; they did not listen or give enough satisfactory explanation for what and why it would be done. The care and explanation of why I couldn't have the option that I wanted, was just so blasé and tick-box and just making sure that you know, they're doing what they have to do." *Participant 6*

1.2. ANTENATAL CLASSES

Antenatal care is the care you get from health professionals during your pregnancy. Antenatal classes help you prepare for your baby's birth and give you confidence and information. They're usually informative and fun, and they're free on the NHS. You can learn how to look after and feed your baby.

Only 20% of the participants attended the antenatal classes. The participants listed several reasons why they did not attend these classes.

1.2.1 Cost of classes

The participants were offered the National Childbirth Trust (NCT) classes. The NHS only offers free antenatal classes to first-time mothers, for other follow-up pregnancies the mothers are referred to NCT classes that they have to pay for. National Childbirth Trust (NCT) classes are expensive for many people, and this is a major barrier to accessing services, as illustrated by the following quotes.

"Based on affordability you have to pay for it." *Participant 2*

"We were asked if we wanted to attend antenatal classes, we should go on the NCT Facebook page and book. The NCT Facebook page increased the pricing for the virtual antenatal classes. Yeah, they increased their pricing. So NCT antenatal classes are already expensive. They're over, I think, £100. Yeah. So, in the light of everything that was happening last year a lot of people were being made redundant, people were on furlough. Yes, you have to pay for those out of your own pocket. So, I think the pricing, when I checked, was about £180 and I decided, no, I wasn't going to spend £180." *Participant 6*

1.2.2 Not 1st-time mothers

The participants who had children already did not see any benefit in attending any prenatal classes. They felt like they already knew how to take care of new-born babies.

"It wasn't my first time." *Participant 3*

"I just thought that being online wouldn't be as beneficial as if they were in person, and because I already have two children, I thought that I would just pass." *Participant 4*

The midwives interviewed expressed their concern and the outcome of this low antenatal class attendance.

"The low attendance has had a very negative impact, especially on the care of the babies. The mothers, they come to the ward, and they look clueless." *Participant 9*

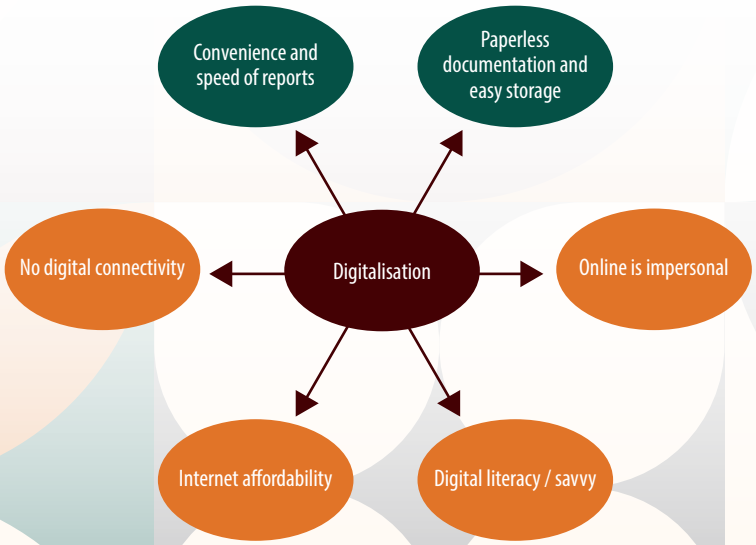
"I think that one has come across babies/mothers coming back to the hospital with babies who have not been properly fed, who have lost a lot of weight." *Participant 9*

1.3. POSTNATAL CLASSES

This is the care given to the mother and her new-born baby immediately after the birth and for the first six weeks of life. The main purpose of providing optimal postnatal care is to avert both maternal and neonatal death, as well as long-term complications (The Open University).

None of the participants attended the postnatal classes. The participants listed several reasons why they did not attend these classes.

Figure 2. Effect of digitalisation



1.3.1 Lack of time for mothers

Some of the participants cited the lack of time as a major barrier to attending postnatal classes. They felt that once they were home, they had to take care of the home and older children as well as the new-born baby, leaving very little time to attend to anything else.

> "No, no classes. There was no time. They offered me but I didn't go." *Participant 3*

> "...so you're dealing with the mental load of having an older child at home, trying to work, ordering a prescription online and then you have leaflets. It's more stuff, more mental load for you." *Participant 6*

1.3.2 Online classes were a deterrent

Several participants reported that they would have much preferred physical classes over online classes. They felt that the physical classes would be more impactful than being online.

> "I was told they would be online. I did not attend." *Participant 4*

> "COVID had just started, we didn't even have online things set up by then." *Participant 1*

> "Was online. Did not attend." *Participant 2*

1.3.3 Postnatal classes not offered

One participant was never offered postnatal classes and even enquired if it was something she was supposed to do. Two participants required postnatal physiotherapy but were told there were no classes and to just use the leaflets provided for exercise.

> "No, I haven't heard anything about that, no." *Participant 5*

> "Physio was not available. They sent leaflets for exercise." *Participant 3*

> "No, there were no antenatal classes offered." *Participant 6*

The midwives interviewed expressed their concern and the outcome of this low antenatal class attendance.

> "Major gap after mothers have given birth and that is after they have given birth successfully and everything works well and there are no complications, but I feel at that point in time, because of the shortage of staff they don't get one to one support. And many of them go home with lots of emotions and lots of baggage, breastfeeding ashamed that their nipples are getting cracked or they don't want to breastfeed in front of their partner. And so complex information." *Participant 7*

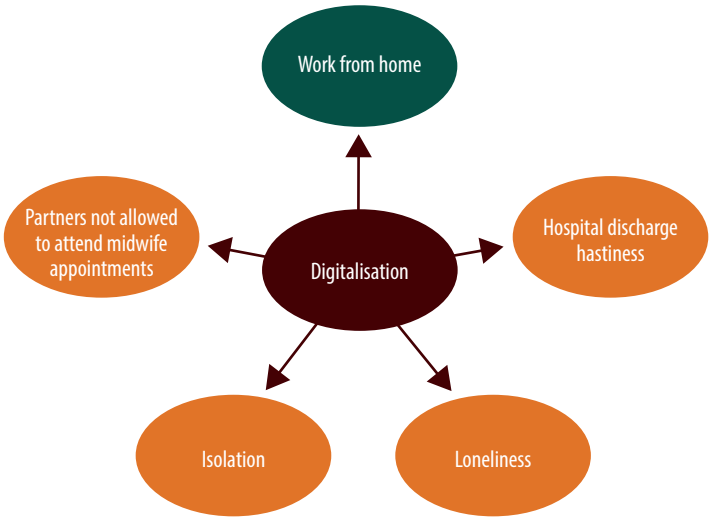
2. EFFECT OF DIGITALISATION

With the Covid-19 pandemic, there was quick adoption of digital technology in the NHS and significant changes in the delivery of services. The way that patients now access primary care has fundamentally changed. We witnessed the near-overnight restructuring of the initial method of patient contact, moving from the majority of appointments being face to face to the majority now being remote consultations. This was needed to free up space in hospitals, enable remote working and reduce the risk of infection transmission.

The maternal health care services saw a huge increase in remote appointments, especially antenatal and postnatal classes. It was important to explore the effect digitalisation had on maternal services, and there were a range of barriers that women faced as a result of these service changes, as described below. Figure 3 below shows the advantages and disadvantages of digitalisation in accessing maternal services.

Digitalisation did provide some advantages.

Figure 3. Effect of Covid-19



2.1 PROVIDES CONVENIENCE/EASE AND SPEED TO REPORT RESULTS

All participants used apps to track their pregnancy not recommended by the NHS. One of the participants had an app to report blood test results.

> "via Bluetooth monitor. You have to periodically test your blood before a meal and after a meal and it syncs to your phone, to the app on your phone and it automatically uploads the readings to your phone. I guess if you had to go in to be monitored, you had to go into hospital every time." *Participant 6*

2.2 PAPERLESS DOCUMENTATION AND EASE OF DATA STORAGE.

The digitalisation of hospital records means that midwives have to directly input data into computers as they see their patients. Midwives reported that this had reduced the amount of paper filling and resulted in ease of data storage.

> From the midwife's perspective: "...advantages of digitalisation, of course, it is good to go paperless, but it is easy to keep the notes as well." *Participant 7*

The digitalisation of maternal services also had some disadvantages.

2.3 NO DIGITAL CONNECTIVITY

To be able to participate in the online classes you would need to have a digital connection at home, a mobile device with video ability. There is an assumption that everyone is connected digitally. One participant had no internet at home and her device had no video capabilities.

> "Covid-19 had just started; we didn't even have online things set up by then." *Participant 1*

2.4 INTERNET AFFORDABILITY

Some women mentioned how the pandemic brought the loss of jobs and as a consequence, some people cannot afford to have an internet connection. Although this did not affect the participants directly, they did mention that they knew people who had been affected by this.

2.5 DIGITAL LITERACY

Digital literacy refers to an individual's ability to find, evaluate, and communicate information through typing and other media on various digital platforms (Wikipedia). Being digitally literate increases your productivity and efficiency since you can achieve more in less time.

> "Yeah, and also you have to be digitally savvy, know what you're doing because you might also have the gadget, but just know how to maybe call people using it. The Echo app, would just be the Lloyds Pharmacy, but I think now it's called the Echo app. On the Echo app and you order your prescriptions, you order the medicine, so the pre-surgery medicine, physically search for the medicines, so. . . is relying on your ability to read and to type." *Participant 6*

2.6 ONLINE IS IMPERSONAL

Most participants felt that the online classes would be impersonal and not intuitive. They would not have the same feel as you would on face-to-face classes.

> "Was online. Did not attend." *Participant 2*

> "I was told they would be online. I did not attend." *Participant 4*

The midwives concurred that digitalisation during Covid-19 was the safest way to provide some of the services. However, this created other problems as the participants could hide their identity with the camera off and you would not be able to tell if they were fully engaged.

> "How many can log in, people from BAME, how many can pull on their screen, comfortably say their problem? Seriously, unfortunately, the online has not helped because they can even hide their identity and not participate." *Participant 7*

MIDWIVES' VIEWS

> "The mothers are no longer engaging physically, antenatally, like before they deliver, so they are not...Go to antenatal classes where they will interact, which has really... has had a very negative impact, especially on the care of the babies. The mothers, come to the ward and they look clueless. You know when they meet together, all physically, everybody says their experiences, the midwife demonstrates physically, they can participate. As opposed to watching online." *Participant 9*

3. EFFECT/IMPACT OF COVID-19

The Covid-19 pandemic has had a profound impact on healthcare systems and potentially on pregnancy outcomes. The modern world has rarely been so isolated and restricted. Multiple restrictions had been imposed on public movements to contain the spread of the virus. People were forced to stay at home and social interactions were at a bare minimum. The Covid-19 pandemic has magnified the health inequalities and affected the members of Black, Asian and minority ethnic communities. The Public Health England report, *Beyond the data: Understanding the impact of Covid-19 on BAME groups* demonstrates the widening of existing health inequalities. Figure 4 below shows the findings on the effect of Covid-19.

3.1 WORK FROM HOME

Three participants were able to work from home during the pandemic. This gave them plenty of time to rest and meant they did not have to commute to work.

3.2 ISOLATION AND LONELINESS

During the pandemic, social interactions were at a bare minimum. Most participants found that they could not interact with others freely, making the participants isolated and leading to loneliness. One participant said that there were no baby group classes or other opportunities to meet up, and she felt that this affected the child as she had no interactions with other children.

> "No participation from mothers stayed home for 6 months"
> *Participant 1*

> "It was difficult in the beginning because of the sudden change of you know not being able to see friends. . . missed seeing me pregnant"
> *Participant 2*

3.3 PARTNERS NOT ALLOWED TO ATTEND MIDWIFE APPOINTMENTS

Most women reported feeling isolated during their pregnancy due to the pandemic. During Covid-19 the partners were not allowed to accompany mothers to midwife appointments. This was particularly a problem for those who felt that they would have benefitted from the presence of a companion when important information relating to their pregnancy was being relayed to them.

> "You couldn't attend them with your partner." *Participant 6*

There is a need for paternity classes for men. Most ethnic minority men tend not to attend any antenatal or postnatal classes with their partners. This becomes difficult for the mother who has to do it all on her own. During labour, the partners are not able to be helpful as they have not attended antenatal classes. This causes a lot of stress on the mother as she is alone.

3.4 HOSPITAL DISCHARGE TIME

The hospitals were under pressure during the pandemic to discharge patients quickly because they needed more bed spaces and to minimise the spread of the virus. The participants reported feeling rushed after they gave birth.

> "But they're not really explaining to you the aftermath, the after-care, what it's going to mean for you when you have a C-section." *Participant 2*

> Midwives' quote: "Too quick discharge from hospital, pressure for beds and lead to many re-admissions." *Participant 9*

3.5 DISREGARD FOR MOTHER'S PREVIOUS HISTORY

Participants felt that the health professionals did not consider previous similar occurrences in their previous pregnancies. There was a lack of consideration of women's previous conditions/situations in occurrences in previous pregnancies. The participants reported that they felt not cared for.

> "I was rated high risk for pre-eclampsia and I had gestational diabetes in my first and second pregnancy. Surprisingly discharged after 24 hours after c-section surgery. It was too premature because in my first pregnancy I had preeclampsia that resulted in me spending 10 days in the hospital. Second pregnancy I had the same conditions throughout the pregnancy but was discharged 24hours after the C-section. Within 3 hours after being discharged, I'd come back home and had to call an ambulance to go back into the hospital as I was experiencing pre-eclampsia." *Participant 6*

4. ADDITIONAL FINDINGS – MIDWIVES

I interviewed midwives and they had additional barriers/ challenges when caring for ethnic minority women as shown in Figure 4 below.

4.1 LANGUAGE BARRIER

Midwives described this as a prime feature in barriers to effective communication. Understanding the English language allows one to ask questions, understand what the mother requires and give consent. If one has limited English, the care given might not be comprehensive enough until they're able to find an interpreter.

4.2 LACK OF COMMUNICATION

The midwives' participants reported a lack of communication resulting from the language barrier among the ethnic minority women. The information being provided by the professionals to the people, they are not understanding it and they are not accessing it.

> "You can imagine it's a lot because actually in maternity it's more of communication like the 90% of the care." *Participant 9*

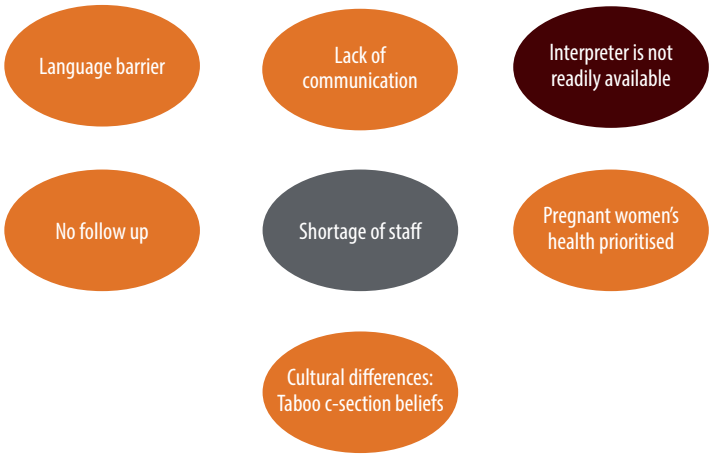
4.3 AN INTERPRETER IS NOT READILY AVAILABLE

With language barriers, an interpreter is required. However, on occasions, interpreters are not readily available at that moment.

4.4 NO FOLLOW UP WITH MOTHERS

No follow up from midwives of mothers who gave birth. Mothers do still need support after they give birth. There needs to be a follow-up, especially with postnatal classes.

Figure 4. Midwives' findings



4.5 SHORTAGE OF STAFF

The shortage of staff has put a lot of pressure on healthcare professionals therefore mothers do not get one-to-one support after they give birth. Often being given many complex leaflets to take home and read.

> "The pressure on the maternity department is high, so few staff and the birth rate has increased." *Participant 9*

4.6 PREGNANT WOMEN'S HEALTH IS IMPORTANT AND SHOULD BE PRIORITISED

Ethnic minority women need to prioritise their health when pregnant. This is usually not the case because they look after everyone else in the household and not themselves.

4.7 THE CULTURAL DIFFERENCES

Family members can be a major barrier. Some cultures deem it taboo to have a C-section. This becomes very challenging as the mother can refuse to sign the paperwork, not turn up to appointments and make it very hard to provide her with the care necessary. This puts the life of the mother and baby at risk. Partners can also be a barrier. In some cultures, the man is the spokesperson, and the woman is not allowed to speak. This makes it very hard to assess and diagnose the woman properly.

RECOMMENDATIONS AND ACTIONS

These are some recommendations from the research shown in figure 5 below.

INFORMATION AND COMMUNICATION

Good communication forms the foundation of good clinical care, and therefore, it is unsurprising that issues surrounding different aspects of communication were identified. Streamlined communication means you are not only giving infinite ways to interact but also building an effective relationship with each of them. All parties are better able to understand the information:

- More time needs to be allocated for 1-to-1 interactions.
- Information and communication are streamlined for better understanding.
- Consistency with the same midwife or better management/understanding of patient records.

ANTENATAL AND POSTNATAL CLASSES

This could be implemented in a range of ways, including the following:

- This could be arranged similar/in close timings with during midwife appointments.
- Midwives explain clearly the need for these classes.
- The cost of NCT classes needs to be addressed so that it is not a barrier.
- Paternity classes for the men and the need for partners to attend these classes.
- Follow-up of antenatal and postnatal classes attendance.

DIGITAL LITERACY

Not all mothers who took part had internet access or the skills to use online services. Online services can be impersonal and mothers can benefit from face-to-face provision. In order to improve this situation:

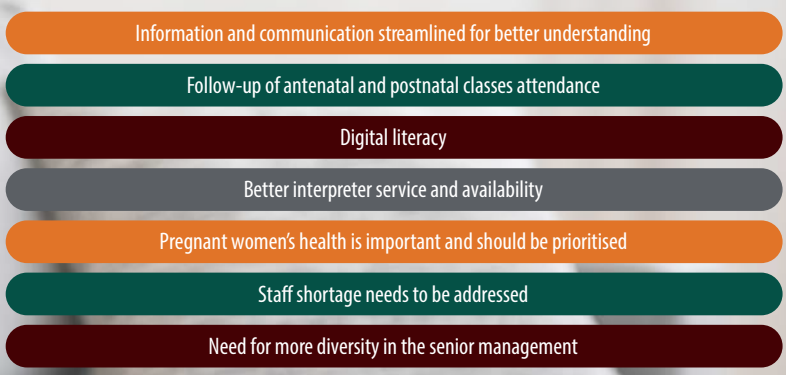
- Classes should be provided on using online services and wider digital literacy.
- Face-to-face services should be offered where appropriate and where possible.

BETTER INTERPRETER SERVICE AND AVAILABILITY

The mothers who were interviewed spoke good English. Many ethnic minority women do not speak such good English, and midwives identified language as a barrier.

- Better resources for translation should be provided, including readily available interpreters.
- Mothers' language needs are captured right at the beginning of the pregnancy and interpretation should be provided wherever needed.

Figure 5. Recommendations



PREGNANT WOMEN'S HEALTH IS IMPORTANT AND SHOULD BE PRIORITISED

- Before the woman gets pregnant, she needs to understand her anatomy, her physiology, how her body functions and how hormones will affect her when she is pregnant, how to live well, eat well and deliver safely.
- People need support to be able to prioritise and understand their own health. This will help them to present their pregnancy issues to the professional. This will help them know their body, their health issues, problems they are likely to face, and they can make an action plan, or a birth plan that is more individualised and tailor-made to the successful outcome of their pregnancy.

STAFF SHORTAGE NEEDS TO BE ADDRESSED

Midwives identified staff shortages as a key issue which had direct effects on the quality of care for pregnant women and mothers.

- More maternity health professionals are to be trained and employed to ease the burden on existing staff.

NEED FOR MORE DIVERSITY IN SENIOR MANAGEMENT

This recommendation reflects the fact that change needs to be led from the top. Diversity in management sends out an important message to the rest of an organisation. However, this is about more than symbolism, and greater diversity at the top will help to drive change at other levels.

- The working culture needs to change in the maternal healthcare profession.
- Cultural awareness training should be provided to all NHS staff working in maternal services, so that services are culturally sensitive.

We must all play a part in the solution – whether through advocacy, recognising the impacts of our own bias, validating a mother's experiences and concerns, or simply being the one person to listen and act. I chose to seek out the mothers in my community and hear what their experiences had been. I chose to get their voices heard through this research so that we can improve our maternal services, reduce the inequalities gap and save lives.

REFERENCES

Fenton K, Pawson E, de Souza-Thomas L. *Beyond the data: Understanding the impact of COVID-19 on BAME groups.* Public Health England, 2020. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_beyond_the_data.pdf. Accessed 24 February 2021.

Knight M, Bunch K, Tuffnell D, Patel R, Shakespeare J, Kotnis R, Kenyon S, Kurinczuk JJ (Eds.) on behalf of MBRRACE-UK. *Saving Lives, Improving Mothers' Care - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2017-19.* Oxford: National Perinatal Epidemiology Unit, University of Oxford 2021.

The Open University, *Postnatal Care Module: 1. Postnatal Care at the Health Post and in the Community. Open Learn: Health Education and Training (HEAT)*. https://www.open.edu/openlearncreate/mod/oucontent/view.php?id=335&printable=1.

ACKNOWLEDGEMENTS

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.

Thank you to the mothers and midwives who gave such invaluable contributions to this research. I would like to express my gratitude to my facilitator Esther, the research trainer Andrew, who guided me throughout this project and helped me finalize my project. Dr Sally Lloyd-Evans of University of Reading for the support on recorders and transcribing of the interviews. Thank you to ACRE for giving me the opportunity to participate in this research. Thank you to the partners, RBC, RVA, RCLC, UoR and ACRE. I would also like to thank my friends and family who supported me during my study.

Challenges to accessing healthcare services faced by ethnic minority women in Reading during the Covid-19 pandemic

DONNA MA AND HEMAMALINI SUNDHARARAJAN, RCLC

INTRODUCTION

This survey was carried out by Reading Community Learning Centre (RCLC) as part of the Community Participatory Research Project (CPAR), 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.

The purpose of the survey was to identify challenges encountered by ethnic minority women in Reading when accessing healthcare services during the Covid-19 pandemic, and to review how they have been affected physically and mentally. We aim to use our findings to make recommendations and check if further research will be necessary.

RCLC is a charity organisation in Reading that has the mission to reach out and empower isolated and vulnerable women to develop their skills, confidence, welfare, inclusion, social status and independence through learning, support and friendship. RCLC collaborated with other organisations in Reading on this project, some of whom pursued related areas of enquiry. Reading Borough Council (RBC) was the lead organisation in this project in partnership with Reading Community Learning Centre (RCLC), Reading Voluntary Action (RVA), Alliance for Cohesion and Racial Equality (ACRE) and University of Reading (UoR).

RESEARCH FOCUS

Currently Reading has a population of 161,780, with 35% belonging to ethnic minority communities. The aim of our research is to promote good health, education, culture and wellbeing, to make changes in accessing healthcare services and reduce inequalities.

Covid-19 has worsened existing health inequalities, with ethnic minority communities having a disproportionately high rate of serious illness and mortality from Covid-19 when compared to the wider population as a whole.

A range of economic, social and cultural factors are likely to contribute to the disproportionate impact of Covid-19 on ethnic minority communities. Our research has explored some of these factors. For instance, we have been interested in how people receive and interpret messages, including how they are affected by language barriers. Furthermore, we have investigated how much trust ethnic minority communities have in government authorities and public health information. Cultural factors may play a role here, such as cultural beliefs and values.

The two community researchers of this project are also from ethnic minorities. They both have over 6 years of working experience and social contacts with ethnic minority women in Reading.

RESEARCH METHODS

The research methods that we have adopted are a survey, phone and personal interviews. 103 women responded to our questionnaire which was distributed personally and electronically. 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, Arabic, Nepalese and Kurdish.

Those with a low level of English language tended to respond better to the questions verbally in their first language. In these cases, the interpreter wrote down their answers in English either in person or over the phone. It was a challenge for the participants from countries that have a different healthcare system to understand the questions in the first place. The interpreter sometimes needed to explain the question before he/she could write down the answer for them.

PARTICIPANT PROFILE

The survey covers a wide range of women from ethnic minority communities aged from under 25 to above 75. They came from 24 different countries, including China, Nepal, Pakistan, Bangladesh, Syria, Poland, India, Russia, South Korea and Kurdistan.

- 8 respondents out of 102 (8%) said they could not communicate in English at all. 53 (52%) rated their English (on a scale of 1-10) as 2-5; 31 (30%) rated their English 6-9; and only 10 out of 102 (10%) gave their English the highest rating of 10.
- 10 out of 101 (10%) lived on their own and the rest in a household of between 2-8 people. 35 out of 102 respondents (34%) said they were living with one or two children (defined as people who were under 18), 19 (19%) lived with 3-4 children, 3 (3%) had 5-6 children and 45 (44%) lived with nobody under the age of 18.
- 26 out of 102 people (25%) have lived in the UK for under a year and 34 (33%) for over 10 years (see figure 1).
- 48% of the respondents lived in RG1, 18% in RG2 and 11% in RG6. The others spread all over the rest of Reading.

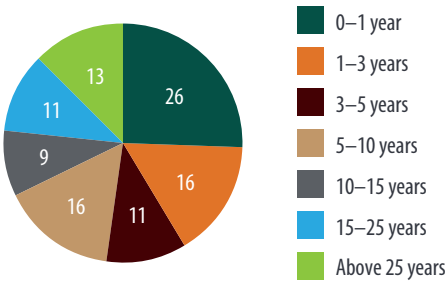


Figure 1. Number of years respondents have lived in the UK

RESEARCH FINDINGS

The key findings are presented below using charts generated from an excel spreadsheet. The total number of respondents varies slightly from question to question. This is a result of giving respondents the option of answering the questions they felt comfortable answering. Each question was answered by the majority of respondents.

5.1 COVID-19 AND ITS IMPACT

Figure 2 shows that 75 out of 103 respondents (73%) did not have anybody in the household who had tested Covid-19 positive. 16 people (15.5%) said someone in their household had tested positive. 12 people (12%) didn't answer this question.

Out of the 18 confirmed cases reported, 10 were classified as mild, 5 bad and 3 very bad. The research was conducted before the introduction of the 'booster' vaccination in the UK. Figure 3 illustrates that 85 out of 97

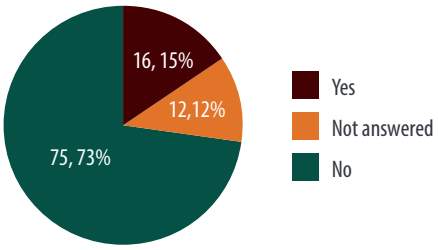


Figure 2. Whether or not anyone in the household of the respondents had tested positive for Covid-19

respondents (87%) said they had received two jabs. Only 2 (2%) had received one jab, and 6 (6%) had not yet taken any but they were planning to. 4 respondents (4%) said they didn't intend on being vaccinated at all.

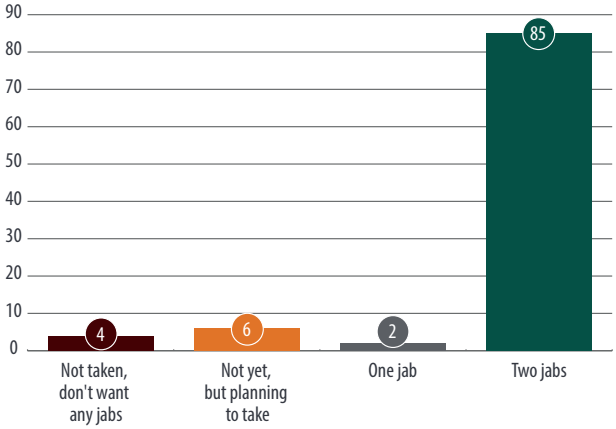


Figure 3. Covid-19 Vaccination status

A couple of respondents gave more detail on why they had chosen not be vaccinated, with one saying she avoided taking medicine in general. Normally she took it for only when it was urgent because she believed that she was fit enough to fight Covid-19. Another respondent thought she could protect herself without any jabs.

The survey asked respondents to indicate on a scale of 1-10 how well-informed they felt about the Covid-19 pandemic. Figure 4 highlights that the majority felt well informed with 85 out of 99 (86%) giving 6 or above, in contrast to 14 (14%) who gave 5 or below.

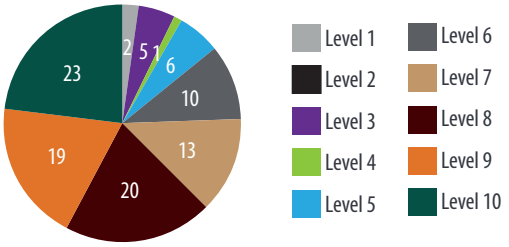


Figure 4. Knowledge level about Covid-19 pandemic (1 not informed – 10 well informed)

The health of respondents was affected by Covid-19 in other ways in addition to the direct effect of the virus. For instance, 21 out of 99 people (21%) reported that their physical health had become worse during the pandemic. 26 out of 100 people (26%) said that their mental health had become worse during the pandemic.

Statements from participants highlight some of the reasons people's physical and mental health suffered during the pandemic. For instance, some respondents found that, without their busy daily routines, it was difficult to get regular exercise, particularly in the first few months of lockdown when there were restrictions on being outdoors. As a result, some reported putting on weight and other health issues experienced by participants included stomach and skin conditions.

In terms of mental health, many found lockdown and social distancing measures difficult, with little social contact with friends and even family. This was particularly difficult for some ethnic minority women who described how they already felt isolated in the UK due to living alone or due to close family members living in other countries.

Another layer of stress and anxiety was created due to increased financial pressures. Many respondents and others in their households had been put on the UK Government's furlough scheme and had less income as a result. Some had lost their jobs, with one respondent reporting that it took 4 months to receive universal credit. Financial hardship created tension at home, made worse by being stuck indoors. One person also described how difficult it had been following the death of her father from Covid-19.

A few people mentioned positive impacts of the pandemic on health and wellbeing, including being able to find more time to exercise at home and go for walks, feeling loved and supported by family and friends and appreciating health more than before the pandemic.

5.2. CONNECTIONS OUTSIDE OF THE HOME

Many ethnic minority communities place a great importance on connections outside the home, including social, cultural and religious gatherings. In addition, ethnic minority women can find themselves particularly isolated without these activities, due to some of the factors discussed in the above section.

For this reason, the survey asked women how frequently they left their home and also about what groups they interacted with. Figure 5 shows that 49 respondents out of 100 (49%) left home daily, 34 (34%) more than once a week, 10 (10%) once a week and 7 (7%) rarely or never.

The reasons for going out included: school runs; taking children to the parks; walking for physical exercise; shopping; access to services, entertainments and restaurants; work (key worker in a supermarket); and English classes when the college was open. Some people said they only went out in their own gardens due to being vulnerable to Covid-19.

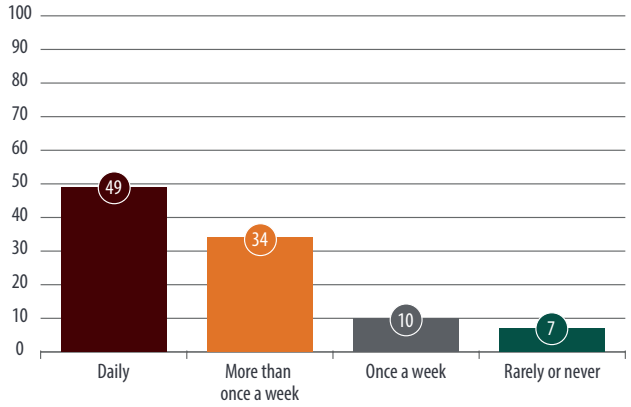


Figure 5. Frequency of leaving home

In terms of interactions with groups, figure 6 shows that 17 respondents (17%) said they belong to both religious and community groups. 28 (28%) selected community groups and 10 (10%) said religious groups. 44 people (44%) said they do not interact with any social groups.

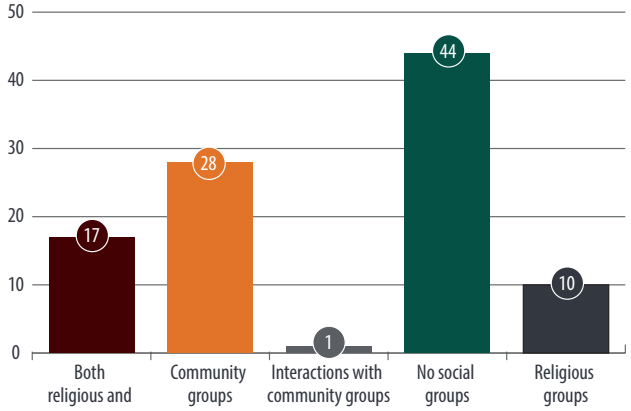


Figure 6. Interactions with groups

The data fits with what we know about many people from ethnic minority communities, and this form of group activity will have been largely missing during the Covid-19 pandemic.

The survey also asked respondents who they were able to talk with when feeling lonely, anxious or stressed. Figure 7 shows that a majority of respondents had at least one person they could talk to, with the most frequently selected options being friends and family (both local and distant). However, 9 respondents (9%) said they did not talk to anybody when feeling lonely, anxious or stressed.

Respondents were also asked what practical support they had received during the pandemic. Slightly less than 30% of the respondents said they received practical help or support during the pandemic from families, friends, community groups and social workers.

Online connectivity is another important way for people to maintain social contact, particularly during the pandemic when other forms of social contact were restricted. Figure 8 shows that 84 people out of 103 (81.5%) said they had access to the internet. 14 (13.6%) said they had no internet access, while 5 (4.9%) did not give an answer.

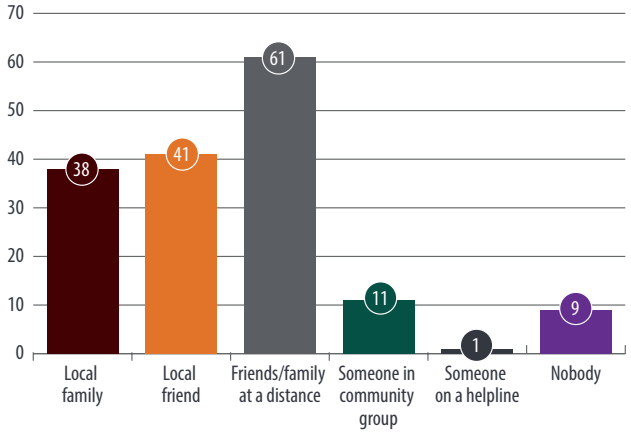


Figure 7. Who respondents talk to when feeling lonely, anxious or stressed

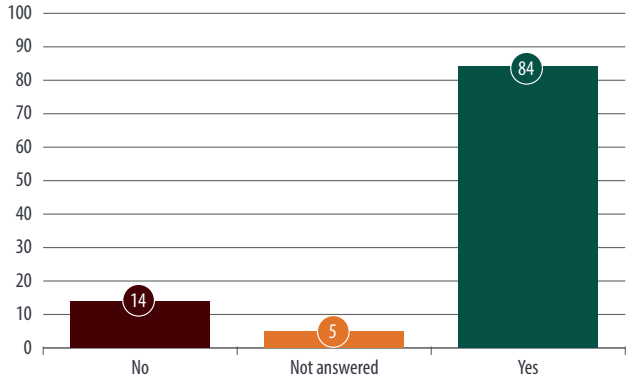


Figure 8. Internet access

5.3 BARRIERS TO ACCESSING SERVICES

Ethnic minority communities are known to face a number of barriers when accessing services, and our survey sought to establish which barriers were faced by women from ethnic minority communities in Reading.

5.3.1 Awareness of services

As illustrated in figure 9, almost everyone who responded was aware of the GP service. A majority was aware of the optician, dentist and emergency services. Online services, services to do with mental health and help with health costs were less recognised.

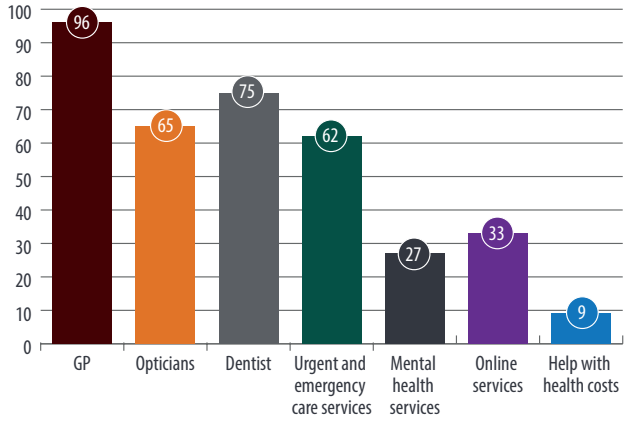


Figure 9. Awareness of NHS services

When asked which emergency numbers they were aware of, 88 respondents (85%) knew 999 and 77 (75%) knew 111, whilst only 51 (50%) knew 119.

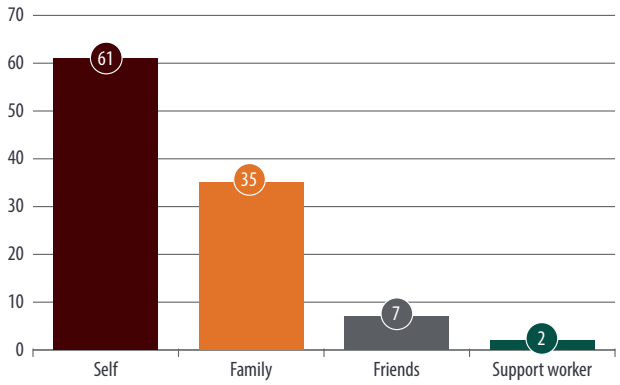


Figure 10. Booking of GP appointment

5.3.2 Challenges faced when accessing GP

Just over half the respondents had visited the GP in the last 12 months.

As shown in figure 10, more than half of the respondents, booked their doctor appointments by themselves. Around a third did it through their family members. Only 7 people said they were helped to do this by friends and 2 by social workers.

Figure 11 highlights that 30 out of 103 respondents (29%) said they had avoided going to the doctor or the hospital because of the pandemic, compared to 68 respondents (67%) who said they did not. 8 (3.9%) did not answer this question.

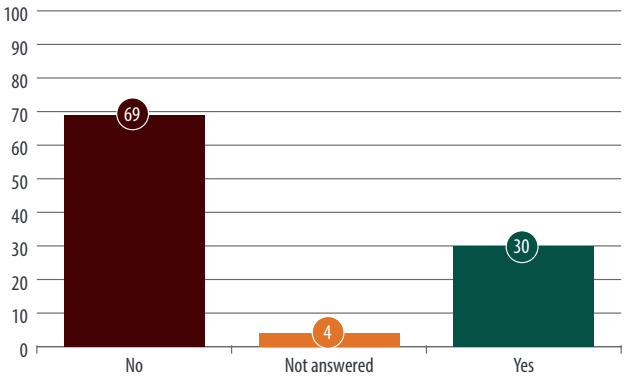


Figure 11. Whether or not respondents avoided visiting doctor/hospital due to pandemic

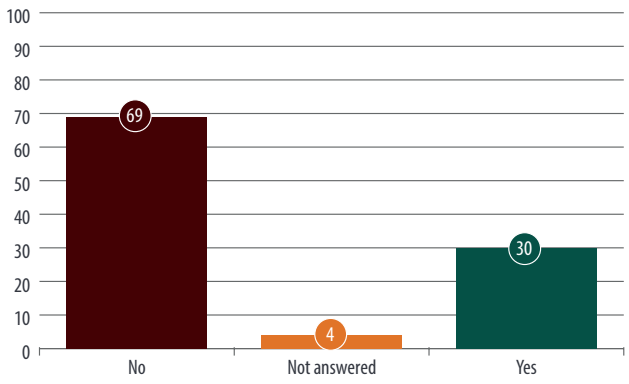


Figure 12. Whether or not respondents didn't contact GP despite having genuine requirement

Figure 12 shows that 27 out of 103 respondents (26%) stopped contacting the GP even when they had a genuine requirement whilst 68 (66%) didn't. 8 respondents (8%) did not answer this question.

5.3.3 Reasons for being reluctant to contact services

Although most respondents were able to contact health and care services during the pandemic with relatively little difficulty, the proportion of respondents choosing not to, even though they had a health-related concern, is significant and concerning. The reasons for this will be varied, but a reluctance to contact services may be tied in with uncertainty about whether to make use of services at a time of national emergency, such as during the Covid-19 pandemic. For instance, one person related that they were:

> "feeling very stressed as not easy to make appointments to see the doctor and having medical examinations at hospital" (Interview respondent)

> One person also commented that they "prefer[ed]" seeing people in person rather than online meetings" (Interview respondent)

Issues of trust and fear are also important when it comes to being confident enough to contact services. Sometimes, a lack of trust stems from prior negative experiences. For instance, one respondent was charged for using maternity services because her visa application was delayed due to the pandemic.

5.3.4 Translation and interpretation

The responses to questions around translation and interpretation may shed some more light on why people have not contacted required health and care services.

Figure 13 shows that 46 respondents out of 98 respondents (47%) didn't need an interpreter. 37 (38%) were arranged by NHS or themselves. 15 (15%) would have liked to have an interpreter. Some respondents described this issue in more detail.

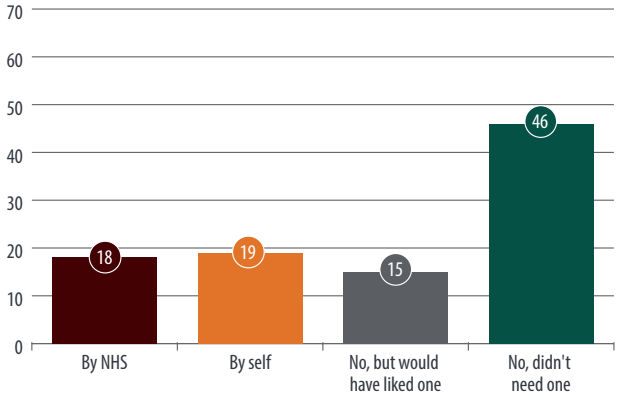


Figure 13. Whether, and how, interpretation was arranged for GP consultation

"Poor quality of translation service: imperfect and inaccurate"

"Relying on translation by a family member could cause a lot of inconvenience" [the daughter had to travel more than an hour to come to speak to the GP for a phone consultation]

The following case study, conducted as part of this research, illustrates how language barriers exacerbate other issues, including Covid-19, pre-existing health conditions and financial hardship.

5.3.5 Removing barriers

In addition to asking what barriers people faced, the survey asked respondents what could be done to help them access healthcare services. They were given a range of options to choose from, which were prioritised as follows:

- 50 people selected "translation support (face-to-face or on the phone)"
- 39 selected "longer opening hours for the health service"
- 36 selected "translated information on the services in your area"
- 33 selected "health care staff who understand your culture"
- 25 selected "better transport to the health services"
- 22 selected "reducing the cost or free travel to access health care"

The survey asked respondents how they would like to receive information about the health services they can access. The options provided were prioritised as follows:

- 69 selected "text messages"
- 48 selected "from the GP surgery"
- 22 selected "translated leaflets"
- 18 selected "websites"
- 6 selected "Facebook page"

CASE STUDY: MR

I am MR from Nepal living with my step-mum. I am a 66-year-old widow. During February 2021, I got affected by Covid, with the symptoms of digestion problems. These symptoms were very severe and I couldn't digest any food. I was admitted in Royal Berkshire hospital for one month and 26 days. I have difficulty in walking due to my ankle being operated twice in the past.

During the Covid treatment, I had the problem with understanding the English language when I was at the hospital. Sometimes a Nepali nurse talked to me but other times clinicians called my nephew to interpret on the phone. The language challenge also continued when I went for physiotherapy.

I was asked to come every day to the hospital for exercise as my lungs were severely damaged and I had to have a surgery. I was unable to travel on buses and had no one to take me to the hospital. I am on universal credit and could not afford the taxi, so I only visited 2 to 3 times a month using the taxi.

Mostly, I got help from friends and family members. Also, I received support from RCLC staff with booking GP appointments and coordinating with RVA, who provided me with a laptop for online language proficiency improvement classes. RCLC also supported me to register for Readibus (Reading Council provided bus facility) which I am using to visit the GP.

In summary, it has been very difficult due to limited mobility issues with COVID related illness and a broken ankle. I need help with shopping, transport to hospital, cooking and other household chores. Furthermore, language barriers are adding to existing difficulties of life.

RECOMMENDATIONS AND ACTIONS

For Reading Borough Council, NHS and Reading Community Learning Centre (RCLC)

ACTIONS

- Encourage vaccination by inviting someone from the NHS to speak to ethnic minority communities in community or religious settings about the facts and the consequences.
- All partners should use a range of methods to provide information about health and wellbeing, including text messages, their website, social media and translated leaflets.
- Longer opening hours at GP surgeries would be beneficial to women from ethnic minorities.
- Assign more staff to answer the phone to shorten the waiting time on the phone when making an appointment at GP surgeries.
- Translated information about helpline numbers and how to use them should be made available.
- Better support and training for helpline staff to make this service more accessible and culturally sensitive.
- Shortening waiting times of hospital appointments will be beneficial.
- Face-to-face consultation should be an option for ethnic minority communities who face additional barriers to accessing services online or over the phone.
- Patients should be made aware that there are opportunities to express their views if they have been treated unkindly or indifferently.
- Translators supplied by the agencies must be qualified to ensure high quality of service.
- Prevention is better than cure. NHS staff could be invited to go to communities and religious groups to give information about common medical problems which may affect that group e.g. diabetes and hepatitis.
- Patients aged 60 and over should be provided with regular health check-ups and be made aware of the availability of these checks and how they can increase quality of life. This will involve efforts to remove the language barrier in communicating medical information.
- Awareness of NHS mental health services should be increased by publicising that this support system is available, especially to ethnic minority women.
- Interpretation services should be available to those who don't speak English as their first language. These should be available throughout a patient's journey, beginning at the moment they book a GP appointment.
- RCLC should be supported to continue to provide courses and activities to meet with the needs of the women of ethnic minorities e.g. IT course, Mindful Stress Management course, Psychological First Aid workshop, exercise classes, visit to the Museum of English Rural Life (MERL).

RECOMMENDATIONS FOR FURTHER RESEARCH

- It would be interesting to see if attending groups makes a difference to mental health or resilience.
- Another survey targeted at men and women of non-ethnic minority backgrounds will reveal if there are any significant differences in their responses.

The impact of Covid-19 on the mental health of ethnic minority men in Reading

TARIQ GOMMA, ACRE

INTRODUCTION

This research investigates the impact of Covid-19 on the mental health of men from black and Asian minority ethnic communities (BAME) in Reading. It was carried out as part of the Community Participatory Action Research (CPAR) programme, which 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 NHS England and Improvement.

In Reading, the research was supported by different partners such as Reading Borough Council (RBC), Reading Voluntary Action (RVA), Reading Community Learning Centre (RCLC), University of Reading (UoR) and Alliance cohesion and Racial Equality (ACRE). This research was conducted by the community local researcher from the beginning to the end through the support of training and mentoring sessions. The community played a great role in responding to the questionnaires.

RESEARCH FOCUS

Men are known to be reluctant to discuss health and wellbeing, and this can be a particular issue among ethnic minority communities. Culturally, men are often socialised into believing they have to be in control of their emotions and that to show emotion is a sign of weakness and failure. It is also known that Covid-19 has had a disproportionate impact on ethnic minority communities in terms of higher mortality and hospitalisation.

This research aims to explore how men's reluctance to talk about health and wellbeing could be a factor in increasing the likelihood of being seriously ill or dying from Covid-19. For instance, if men are reluctant to share their health and wellbeing concerns they may not seek help for Covid-19 or may avoid getting vaccinated. Alternatively, Covid-19 may be creating extra pressure on their mental health.

RESEARCH METHODS

The questionnaire focused on men from ethnic minority backgrounds. A total of 63 questionnaires were administered among different ethnic communities such as Sudanese, Nigerians, Bangladesh, Serialeon, Libyans, Eritrean Ghanaian, and Kenyans among others. A range of different ages took part in the survey with most being in the 41-59 age group (29) and the 31-40 age group (22). 9 respondents were aged 18-30 and 3 were 60 or over. 29 participants were employed, 23 self-employed, 6 were students and 5 were unemployed. More than half (34) were married, 21 were single and 8 categorised themselves as divorced. See figure 1 for a full breakdown.

The survey is anonymous, not identifying anyone's personal details. In many cases the questionnaire was administered face-to-face, whereas other questionnaires were completed by participants in their own time and returned to the researcher.

Research respondents were reached via working as a taxi driver. It was possible to talk to customers, introducing the community research, explaining what was involved and asking if they were willing to participate by filling the questionnaire. Participants who agreed were then able to complete the questionnaire during the journey. They were then thanked and given a fare discount in appreciation, which was generally welcomed.

Another way in which respondents were reached was by using the taxi base office and message system service connected to all drivers to ask fellow drivers to participate in the survey. Drivers were then able to complete the survey while in the office base during break times. A handful of additional respondents participated in the survey in this way.

Confidentiality was maintained on the data provided. All the respondents gave their consent to participate on the research. Research assistants from Reading Men's Group (We Men) supported administering of the questionnaire. The questionnaire was designed to cover four key areas:

- Impact of Covid-19
- Mental Health
- General Health
- Demographics

Figure 1. Demographic details of respondents

Age	18–30 9	31–40 22	41–59 29	60 and over 3
Ethnicity	Black African/Caribbean 37	Black/White 5	Arab/Asian 18	Others 2
Marital status	Married 34	Single 21	Divorced 8	Civil Partnership 0
Employment status	Employed 29	Self-employed 23	Student 6	Unemployed 5

RESEARCH FINDINGS

After analysing the data gathered from the questionnaires on how Covid-19 has affected BAME men's mental health, the following findings were established:

NEGATIVE EFFECTS

Most people were negatively affected either financially, mentally, psychologically or physically by Covid-19 and lockdown. 54 out of 63 respondents (86%) replied that they were affected by the pandemic. Only 9 people (14%) said they had not been affected (see figure 2).

Based on personal observation and some comments made by participants, respondents who were worst affected were people living alone and receiving social care services who had limited or no time from support or care workers, friends, and family members.

Figure 3 shows the ways in which men were affected by the pandemic and lockdown.

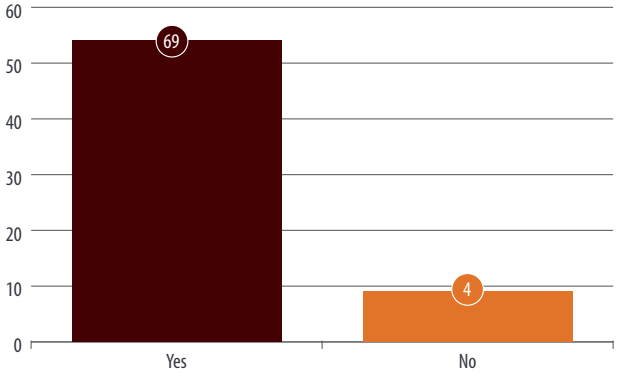


Figure 2. Whether pandemic and lockdown affected respondents

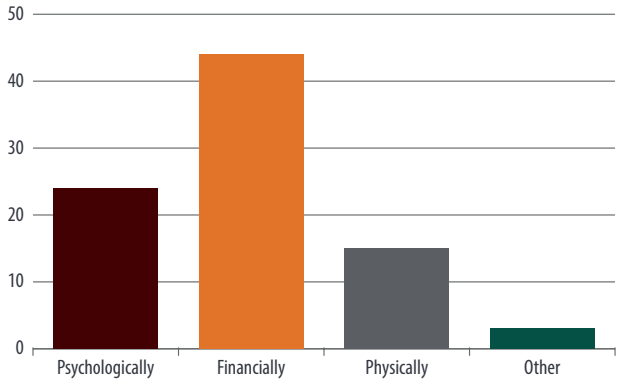


Figure 3. How Covid affected people

The survey asked people to say how they were affected by Covid-19. The most common way that people were affected by the pandemic was financially, followed by psychologically and physically.

FINANCIALLY

Many people we interviewed lost their jobs or business and or had a reduction in their earnings during the lockdown. Some people who worked on zero-hour contracts or were self-employed could not benefit from government support either. This increased the stress individuals and families experienced because of the financial difficulties.

MENTALLY

There is no doubt that the last 2 years since the pandemic began in February 2020 have been very stressful. The lockdown and the restriction of movement intensified isolation and self-isolation especially for those who were shielding. The situation was made worse about unmet needs especially those who are cared for, as a result of the lockdown, service closures and shielding rules.

Some people felt very isolated at home as individuals or as family with the caring roles largely absent or forgotten. Some people did not even have the opportunity to have someone to talk to at the time about their experiences.

At a more general level, news about the severity of the pandemic and the deaths experienced nationally and worldwide has made the last two years a worrying time for many people.

Generally, and for those with clinical symptoms, their mental health was regressing even more, because of the lack of preventative and maintenance services being withdrawn.

There is a strong correlation between mental illness and poverty. Financial worries, and living conditions such as housing and poor diet can adversely impact on mental health, while poor mental health can cause great deal of instability which will lead to people losing their jobs and poverty.

PHYSICALLY

Some people experienced a psychological barrier to going out, and restrictions to movement resulted in people having to stay home and getting less exercise.

SUPPORT

Figure 4 shows that slightly more than half of the participants (36 out of 63 responses) declared that they received help during lockdown.

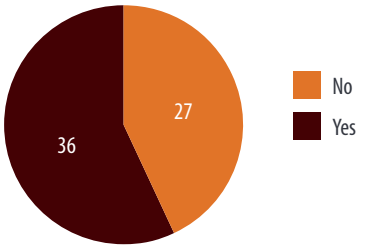


Figure 4. Whether any help was received during lockdown

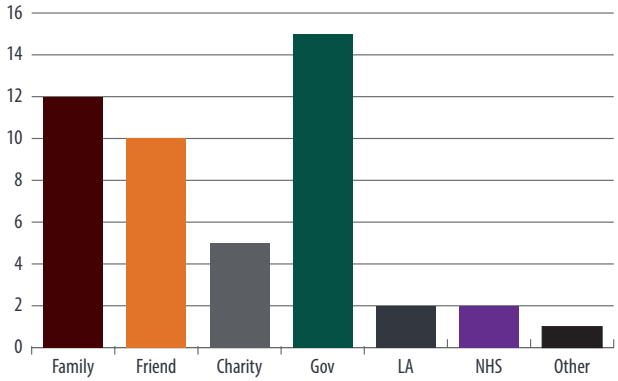


Figure 5. Sources of support

Figure 5 shows that the most common sources of support for participants were government, family, and friends. Fewer people said they received help from charities, local authorities and NHS.

Figure 6 shows that there is a low awareness of mental health services among men who took part in the research. 43 said they didn't know how to seek or access mental health services, whereas 20 said they were aware of these services and how to contact them.

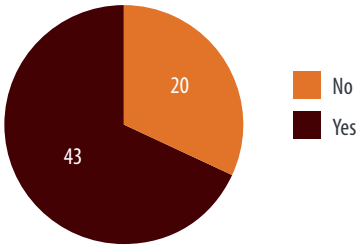


Figure 6. Whether or not respondents are aware of mental health services.

SEEKING HELP

Most respondents answered that they would seek professional help if experiencing mental health issues. Figure 7 shows that 35 out of 63 men said the were very likely to do this, which is over half of all respondents. However, 9 respondents said they were very unlikely to seek professional help, highlighting that a significant minority of men may be unwilling to get help when needed.

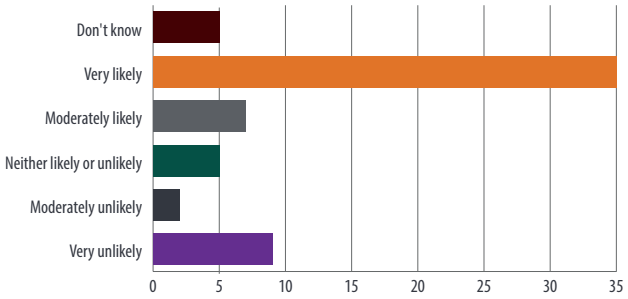


Figure 7. Likelihood of seeking professional help if experiencing mental health issues.

WHO RESPONDENTS TALK TO ABOUT PERSONAL ISSUES

The survey asked participants to indicate who they would talk to about personal issues. Figure 8 shows that 33 people said they would talk to friends and 29 said they would talk to family. This was followed by 21 who said they would talk to their doctor.

Out of the options presented, the least-selected answer was religious leader, which 8 people said they would contact. 7 people said they would prefer not to tell anyone, which reflects the earlier findings that some respondents said they would be unlikely to talk to someone about personal issues and that they would be unlikely to seek professional help if they experienced mental health issues.

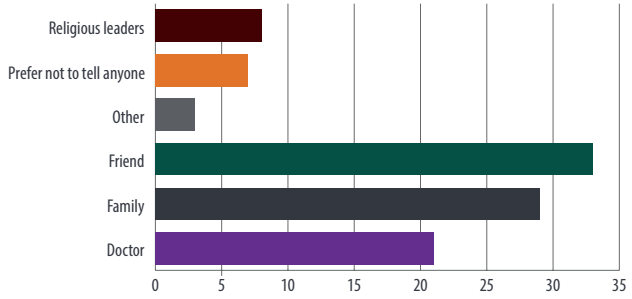


Figure 8. Who respondents talk to about personal issues

ACCESSING MENTAL HEALTH SERVICES

Respondents were asked to what extent they agreed that it is easy to access mental health services. They were also asked if they knew of any mental health services. These questions were asked in order to help understand whether or not people were aware of what support was available, whether provided by the NHS, charities or any other sector.

Figure 9 shows that 21 people either agreed or strongly agreed that mental health services are easy to access, whereas 15 disagreed or strongly disagreed. 18 out of 63 said they didn't know how much they agreed with the statement and 11 said they neither disagreed or agreed.

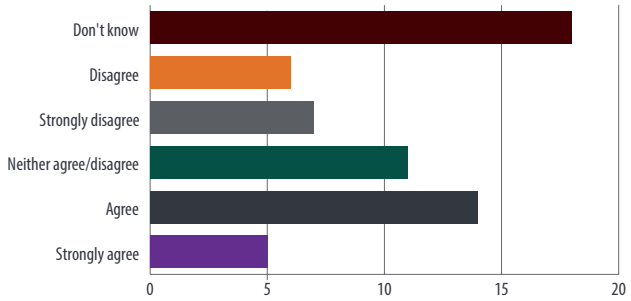


Figure 9. How much respondents agree with the statement: It is easy to access mental health services

This level of uncertainty about how easy services are to access can be explained by the finding shown in figure 10, with a large majority of respondents, 43 out of 63, saying they don't know any mental health services.

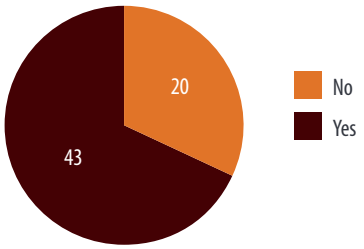


Figure 10. Whether or not respondents know any mental health services

BARRIERS TO ACCESSING MENTAL HEALTH SERVICES

The survey gave people the chance to describe any barriers that prevented them from accessing mental health services. Their answers can be categorised as follows:

LANGUAGE BARRIERS, INCLUDING APPROPRIATE ACCESS TO INTERPRETERS.

This highlights a need for translated information. Some respondents would like to see written information translated. However, others have difficulty reading or can't read at all and would prefer someone to talk to who can translated information for them or read them translated information. This could be done using videoconferencing such as Zoom or face-to-face.

DIFFICULTIES IN REGISTERING OR MAKING AN APPOINTMENT DURING THE PANDEMIC.

Some respondents expressed frustration about how difficult it was to get an appointment with psychiatric doctors or mental health practitioners. They said that it wasn't easy to get a referral and, if they managed to get referred, it took a long time to see anyone.

LACK OF UNDERSTANDING OF SOCIAL CARE SYSTEMS

The research has already established that most respondents were unaware of what mental health services were available. A few respondents mentioned that there was a lack of clear guidance and information about how to access these services.

DISCRIMINATION

BAME people often feel the colour of their skin is a reason they are not offered services. They felt that white British people would be likely to receive mental health services ahead of them. Institutional racism is another barrier, with a lack of cultural sensitivity and adequately-trained staff.

STIGMA

As this research has shown, there is a reluctance within many BAME communities to discuss the topic of mental health. A stigma around mental health exists, with people thinking it will bring shame on them, so they avoid talking about it altogether, and this may make it harder for them to access support.

CONCLUSION

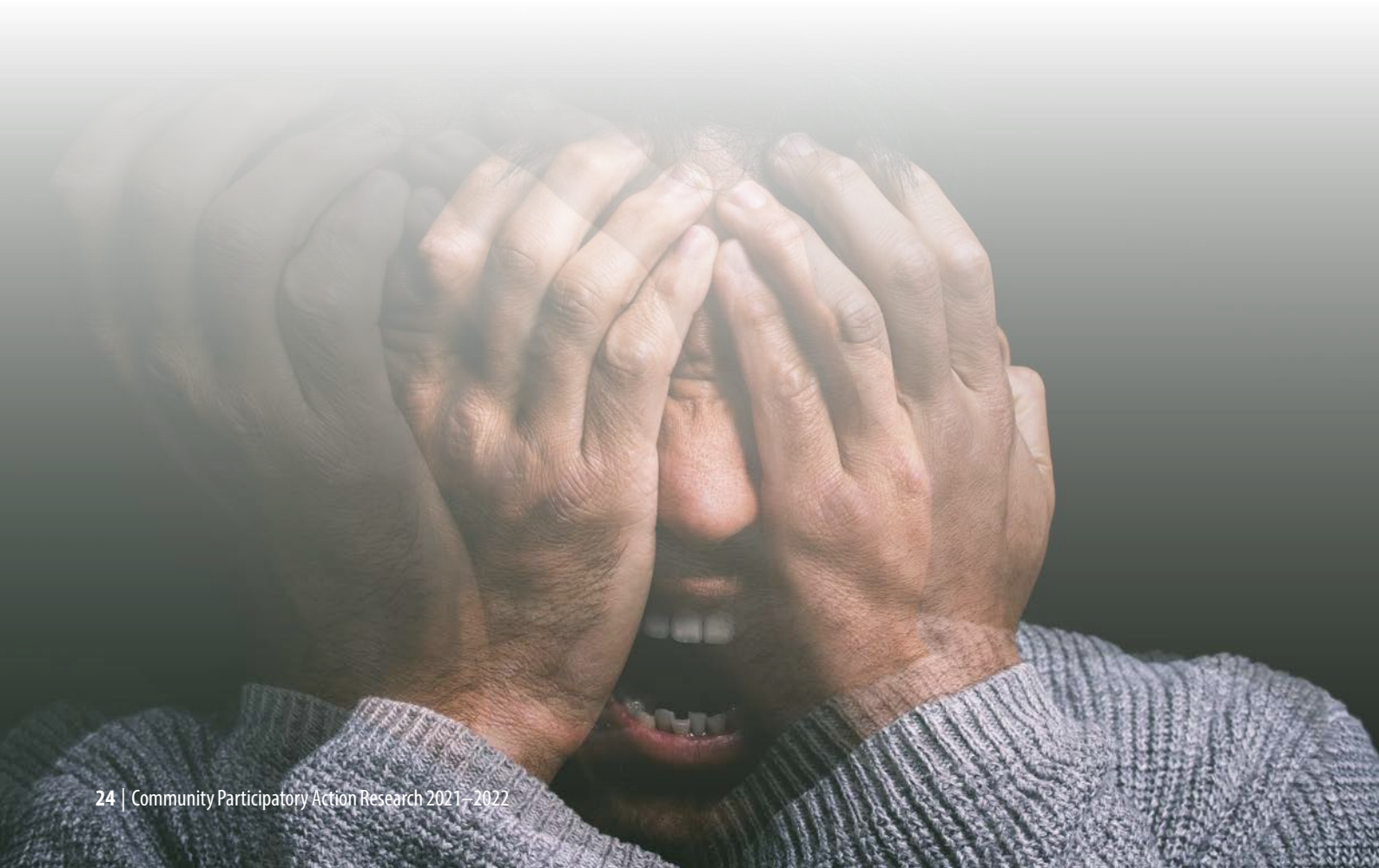
The findings of this research highlight the value of preventative approaches. They should make us think carefully about taking the early signs of mental ill-health seriously rather than only focusing on treating mental health when an individual's situation worsens.

On the 20 June 2020, a 25-year-old Libyan refugee attacked people with a knife in Forbury Gardens, Reading. Three people were killed in the incident and others injured. The young man who carried out the attack was known to mental health services in Reading. Although this example is thankfully rare, it highlights what can happen if inadequate early intervention and support for mental health is available. It is the opinion of this researcher that tragic incidents can be avoided if relevant authorities take immediate action when the signs of mental ill-health are apparent.

The research has explored the fact that BAME men are particularly likely to hide their feelings from people, even those closest to them, avoiding showing signs of weakness. This can result in them becoming increasingly isolated, leading to worsening mental health, drugs/alcohol addiction, criminality and even suicide. The research therefore sought to find out more about how BAME men Reading think about mental health and also how the Covid-19 pandemic and lockdown has impacted on men's mental health.

The research highlights the need for mental health providers and other services to offer help and support rather than simply challenging difficult behaviour. It should be easier for BAME men to get referred for mental health services, and service providers need to be aware that many BAME men will find it difficult to talk about mental health due to stigma and cultural beliefs about mental health.

At a practical level there is a need for clearer, easy-to-access information that reaches people where they are, and also for translation (both written and face-to-face). For communities, it is important to talk about mental health and to look for signs that someone is struggling. Individuals should be able to talk to someone they trust, say you they feel and ask for help.



RECOMMENDATIONS AND ACTIONS

Based on the findings of this research, the following actions and recommendations can be made:

- More funding from the UK Government, the NHS and Reading Borough Council towards mental health.
- The NHS should make it easier and simpler to access mental health services.
- The role of voluntary and community organisations in supporting people across all communities, and particularly those struggling with inequalities, should be recognised and appreciated. This sector should be supported as a key partner in terms of providing awareness, advocacy and education around mental health.
- School, colleges and universities should promote mental health and raise awareness of mental health for all students and staff.
- Support and conversation hubs, offering professional and peer support should be developed.
- People should be kept informed and updated, and systems for doing so that can adapt quickly and responsively to changing needs in communities.
- Staff in public services should be fully trained to identify mental health issues and provide immediate and appropriate intervention before the situation worsens.
- Identifying early signs of mental health issues will prevent people's mental health from worsening, and is more effective than only treating mental illness further down the line.
- Trained volunteers, with adequate screening checks, can help deliver services through local volunteer and community groups.
- Talking about mental health issues in communities will increase the understanding of mental health.
- Based on the early positive outcomes from the CPAR programme, community members should be supported to conduct their own research into the issues that affect them to help improve services and bring further benefits to communities.

ACKNOWLEDGEMENTS

I would like to express my sincere gratitude to CPAR and partner organisations RBC, RVA, RCLC, UoR and ACRE, for letting me to be part of this incredible and unique research. I'm extremely grateful to Victor Koroma at ACRE who arranged for me to do this research.

I would like to express my deepest thanks to my wonderful research mentors and advisors Andrew Paterson and Esther Oenga who provided ongoing support throughout the process. This research would not have been possible without their thoughtful comments.

I am also thankful to my fellow Community Researchers participating in the CPAR programme for their considered comments and for sharing their learning. I would like to extend my deepest gratitude to Herjeet Randhawa and colleagues at RVA for all the unconditional support in this very unique and intense research.

I would also like to pay my special regards as well to Reading Men's Group (We Men) for their unlimited help and support provided during the research period. In particular, Chukwuemeka Obiora, Victor Besong and Anthony Darway from We Men were a great help in conducting the survey research.

To conclude, I cannot forget to thank all the participants who took time to complete the questionnaires and provided me with such useful comments and answers.

Appendix 1: Questionnaire

A. COVID-19 QUESTIONS

1. HAVE YOU TESTED POSITIVE FROM COVID-19?

- ☐ Yes
- ☐ No

2A. DID YOU HAVE ANY HELP DURING THE LOCKDOWN?

- ☐ Yes
- ☐ No

2B. IF YES, FROM WHOM?

- ☐ Family
- ☐ Friend
- ☐ Charity
- ☐ Government
- ☐ Local authority
- ☐ NHS
- ☐ other (please describe)

_____

_____

_____

_____

3A. HAS THE PANDEMIC AND THE LOCKDOWN AFFECTED YOU?

- ☐ Yes
- ☐ No

3B. IF YES, HOW (PLEASE TICK ALL THAT APPLY)

- ☐ Psychologically
- ☐ Financially
- ☐ Physically
- ☐ Other (please describe)

B. MENTAL HEALTH QUESTIONS

4. HAVE YOU OR SOMEONE CLOSE TO YOU EXPERIENCED EPISODES OF MENTAL HEALTH ISSUES?

- ☐ Yes
- ☐ No
- ☐ Prefer not to say

5. IF YOU HAVE A CONCERN ABOUT YOUR PERSONAL ISSUES, HOW LIKELY ARE YOU TO TALK TO SOMEONE ABOUT IT?

- ☐ Very likely
- ☐ Moderately likely
- ☐ Neither likely or unlikely
- ☐ Moderately unlikely
- ☐ Very unlikely
- ☐ Don't know

5A. WHO WOULD YOU TALK TO ABOUT PERSONAL ISSUES? (PLEASE TICK ALL THAT APPLY)

- ☐ Friend
- ☐ Family
- ☐ Doctor
- ☐ Religious Leaders
- ☐ Other (please describe)
- ☐ Prefer not to tell anyone

6. IF YOU ARE EXPERIENCING ANY SORT OF MENTAL HEALTH ISSUES, HOW LIKELY ARE YOU TO SEEK PROFESSIONAL HELP? (FOR INSTANCE, THERAPY AND TREATMENT)

- ☐ Very likely
- ☐ Moderately likely
- ☐ Neither likely or unlikely
- ☐ Moderately unlikely
- ☐ Very unlikely
- ☐ Don't know

7. WHAT HELPS YOU TO COPE IN TERMS OF YOUR MENTAL HEALTH?

- ☐ Taking part in physical exercise
- ☐ Reading
- ☐ Writing my dairies
- ☐ Going to religious congregation
- ☐ Smoking
- ☐ Drinking
- ☐ Traditional healers
- ☐ Others (please describe)

8. WHAT EXTENT DO YOU AGREE OR DISAGREE WITH THE FOLLOWING STATEMENT? "IT IS EASY TO ACCESS MENTAL HEALTH SERVICES"

- ☐ Strongly agree
- ☐ Agree
- ☐ Neither agree nor disagree
- ☐ Strongly disagree
- ☐ Disagree
- ☐ I don't know

9. DO YOU KNOW ANY MENTAL HEALTH SERVICES?

- ☐ Yes
- ☐ No

10. IF APPLICABLE, WHAT BARRIERS DO YOU EXPERIENCE WHEN TRYING TO ACCESS MENTAL HEALTH SERVICES?

_____

_____

_____

_____

11. WOULD YOU TALK TO YOUR GP ABOUT ANY MENTAL HEALTH CONCERNS YOU HAVE?

- ☐ Yes
- ☐ No
- ☐ Don't know

C. GENERAL HEALTH QUESTIONS

12A. DO YOU DO ANY FORM OF EXERCISE?

- ☐ Yes
- ☐ No

12B. IF YES, HOW OFTEN? (PLEASE TICK ONE BOX)

- ☐ At least once a day
- ☐ More than once a week
- ☐ Once a week
- ☐ Once a month or less

D. DEMOGRAPHIC QUESTIONS

14. PLEASE CIRCLE WHICH ANSWERS APPLY TO YOU.

Age group	**18-30**	**31-40**	**41-59**	**60 and over**
Ethnic group	Black African/ Caribbean	Black/White	Arab/Asian	Other (please describe)
Marital status	Married	Single	Divorced/ separated	Civil partnership
Employment status	Employed	Self-employed	Student	Not employed

Thank you for completing this survey

Investigating the impact of Covid-19 on the Nepalese community in Reading

KRISHNA NEUPANE, INTEGRATED RESEARCH AND DEVELOPMENT CENTRE (IRDC), BERKSHIRE, UK CIC

INTRODUCTION

The research work was carried out between April 2021 and January 2022 as part of the CPAR programme. 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 NHS England and Improvement.

The study revealed that the Covid-19 pandemic caused health complications across the UK, and particularly within BAME communities. Some explanations put forward for this include: higher rates of poverty, other adverse impacts of inequality and increased vulnerability due to existing medical conditions within BAME communities.

In addition to experiencing higher rates of mortality and long-term illness from Covid-19, BAME communities are likely to experience a lasting legacy from Covid-19. This includes the psychological impact of fear, stress, loss of family and friends, and isolation and social distancing. Covid-19 and its economic impact are also likely to exacerbate poverty among many BAME communities.

RESEARCH FOCUS

With the above in mind, the research sought to explore the following areas of inquiry.

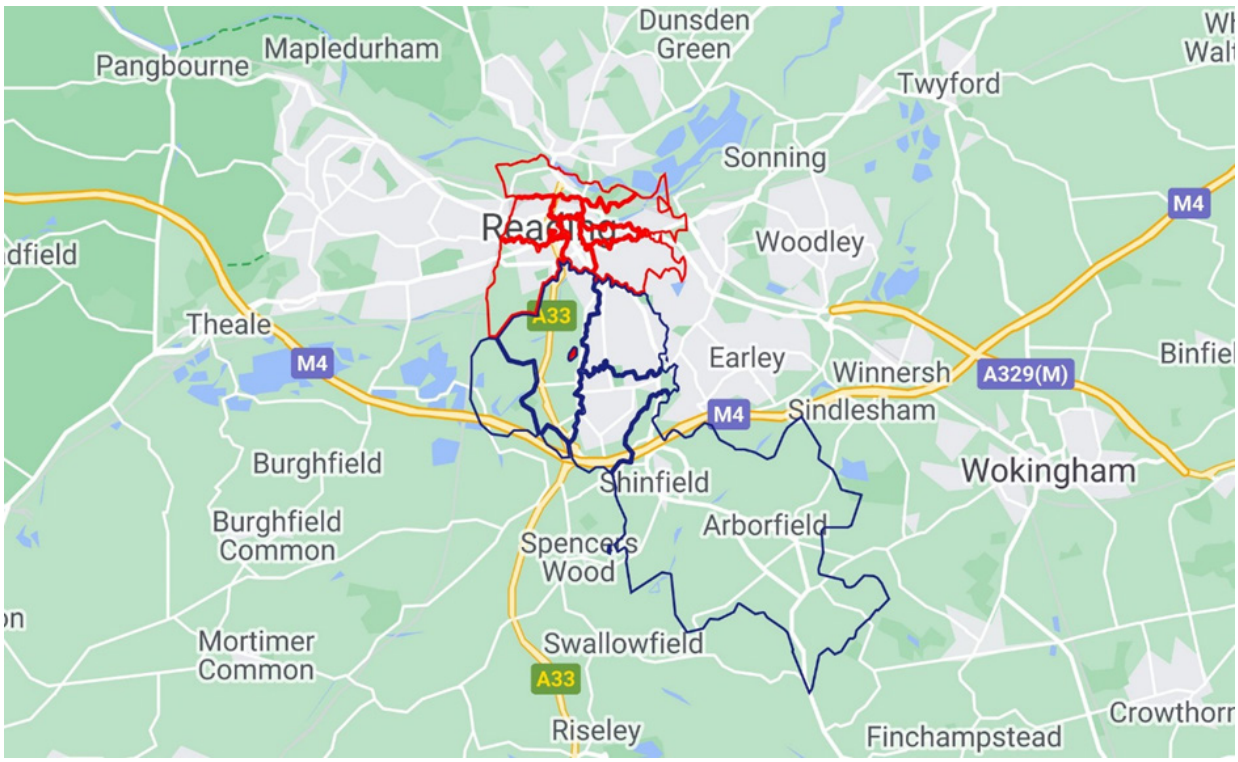
- What factors have contributed to the disproportionate impact of Covid-19 on BAME communities, specifically among Nepalese community groups residing at east and south Reading locations?
- What improvements to services can be recommended in order to address these factors and potentially improve health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

STUDY AREA SELECTION

Reading is the principal regional and commercial centre of the Thames Valley. The borough of Reading is home to 167,700 residents with the wider urban area of Reading reaching into the neighbouring Wokingham and West Berkshire local authority areas.

RG1 and RG2 postcode locations under Reading Borough Council territory were purposively selected for this study. In general, the east Reading location is relatively more densely populated and many mixed Nepalese groups or families reside in this area. In the RG2 area, there is evidence that more poverty and inequalities exist compared to other locations in Reading.

Map of RG1 and RG2 postcodes. Red boundaries show RG1 postcode district; blue boundaries show RG2.



RESEARCH METHODS

TRAINING AND SUPPORT

The CPAR programme provided participants with ongoing training. This included the following:

- Initial training consisted of two training sessions. Firstly, participants took part in a 2-hour online training session on community-led health. This was followed up by another 2-hour online session on community led-research. In addition to being introduced to theory and methods of this approach, the community researchers were shown the Community Participatory Action Research cycle (see figure 1). The cycle tries to show how research is an ongoing process of planning, acting and reflecting and is part of wider action in communities.

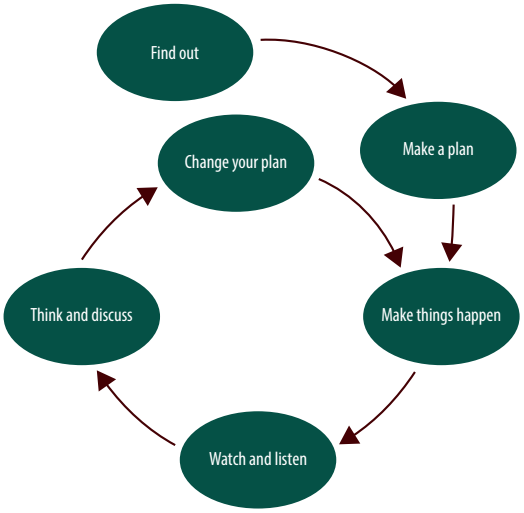


Figure 1. Community participatory action research cycle (Source: SCDC training materials, 2021)

- Continued mentoring support was then provided by Scottish Community Development Centre (SCDC) and a CPAR facilitator from Reading Voluntary Action (RVA). This included support to plan research, collect and collate information, tabulate and analyse data, and to bring findings together into a final report.
- Shared learning sessions were held at key points in the programme, and enabled community researchers to share, and learn from each other's research projects.
- A virtual session on creative research methods was provided by Dr Sally Lloyd-Evans, University of Reading. This gave an insight into a range of community participatory research tools before commencing the research work with community groups.

CONDUCTING THE RESEARCH

A total of eight face-to-face interviews were conducted; four at each location. Similarly, three focus group discussion meetings were held; one at each location and the third one was conducted with a mixed group from both locations. All interviews, except one, were conducted in Nepali language and then transcribed to English. This may have led to some inconsistencies, for instance, due to the difficulty of translating colloquial phrases.

RESEARCH TIMELINE

Timeline for research work support: The project's actual lifetime was nine months commencing from April 2021 to January 2022. The duration was break down into five different phases; training, planning-mentoring, planning-getting started, research mentoring and learning, completing research and presenting findings.

Source: SCDC training materials, 2021

IMPLICATIONS OF SELECTED RESEARCH APPROACH

This research project explored 'depth and breadth' of the actual health and wellbeing issues of local community groups. Face to face interview and focus group discussion tools are considered widely accepted, valid and reliable tools to gather community information. It explored and drew up real voices, feelings or worries of local community people. The findings and recommendation parts in the project report have been transferred as suggested programme activities or events.

This research work covered part of RG1 and RG2 of Reading Borough Council's territory (see map). Respondents for the research study represented a good range of parameters such as; age, sex, sub-group, education level, profession and residency. Likewise, the level of participants varied from those who had a low level of literacy-were limited to conversation and writing English, to fluent in speaking and writing English.

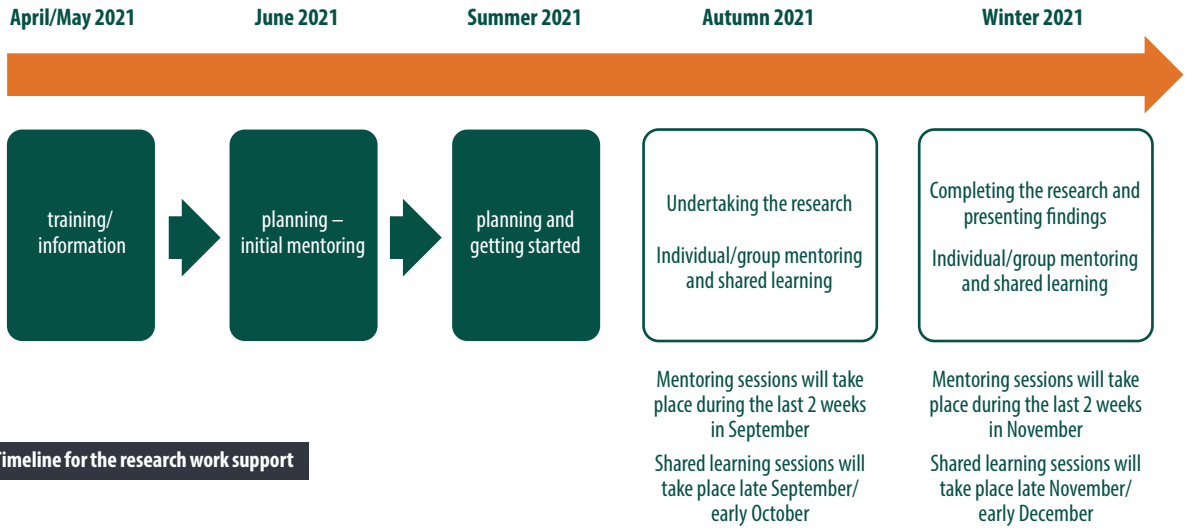


Figure 2. Timeline for the research work support

RESEARCH FINDINGS

Analysis of the interview data highlighted three major factors which could explain any disproportionate impact of Covid-19 among Nepalese community groups. These were as follows:

- Living conditions
- Communication
- Trust, fear and vaccine hesitancy

More detail on these findings is set out below. The last part of the findings section describes the impact of Covid-19 on the Nepalese community, which also came through strongly in the research.

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 are 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 puts more members of households to work pressure. 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 contributed to reduce 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 access services and receive advice and support regarding health and wellbeing related issues. In relation to Covid-19, this was expressed as one of the major barriers 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)

FEAR, TRUST 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 fleeing 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 centres, 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 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 a 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 flu 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 that 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 neighbouring 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 bitters 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."

RECOMMENDATIONS AND ACTIONS

Based on the above findings, the following recommendations can be made.

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 minority 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

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.

LEARNINGS REFLECTION FROM THE CPAR PROJECT

Plan your research carefully: In order to be successful, it is important to plan your research carefully. To do this well you will need to review existing evidence and speak to a range of people from the community and service providers, which will help you to explore and identify your research queries.

Formulation of research questions: Based on your initial planning, you will need to think about what it is you want to find out and why, including what you will do with the research findings. It is advisable to do this prior to conducting your research. It will be helpful to get feedback from others and to pilot your methods and questions with a test group before using them to conduct your research.

Make sure you have the required time and other resources: Prior to proceeding with your research, there may be useful to estimate the time it will take, as well as what material and funding you will require to complete your project. It is important not to underestimate what is required or to take it lightly as even the best research can be hampered by a lack of time and resources.

Seek endorsement of your research queries with community groups: Your research will be more relevant and proceed more smoothly if you speak to people from the community you are researching beforehand. This will help ensure there is a common understanding of the project within the community. To do this, you could organise informal meetings to share your research queries and aims. It may be useful to explain how it is funded and why it is being conducted. This will help to avoid confusion and misunderstanding between community groups and the researcher, and is key to progressing and completing the research as planned.

Prepare well for your interviews: According to a common saying, 'to hunt a cat you have to prepare as if you are going to hunt a tiger'. A research interview may look like a straightforward undertaking. However, in order to adequately prepare your interview and focus group meetings, you have to be confident, get organised and well prepared. You should prepare an interview checklist on a piece of paper or in your diary, and arrange necessary equipment (such as recording devices) accordingly. Doing so will not only save you time and but also help to ensure no mistakes are made.

It is important to establish a suitable interview time and venue with respondents in advance. One-off communication with respondents may not work and, ideally, you should have a phone chat to reiterate the aims and format of your interview, as well as take people through consent forms for the interview. This may also be a good opportunity to establish the approximate time required to take part in an interview and to discuss a suitable venue. If you can arrange these small but important details in advance you should be able to conduct your research effectively with a degree of confidence and peace of mind.

Greet and say 'thank you' to respondents: Greeting and thanking respondents at the time of interview and in all email and phone communication will help maintain a good connection and build strong and lasting research relationships. A small gift, if you have anything to give, will also help to build an effective relationship and show your appreciation for the time participants have given you.

FUTURE RESEARCH AREAS

Based on the findings and recommendations of this research, two potential areas for future research are:

- Investigating the role of youth to help address the language and technological barriers faced by older generations and transfer good culture and family relationships to new generations.
- Exploring how to improve English language courses for people who do not speak English as a first language, including ways to make these more interactive, accessible and engaging

ACKNOWLEDGEMENTS

I would like to give my heartfelt thanks to all respondents who willingly took part in face-to-face interviews and focus groups. Without their willingness and meaningful participation, the community participatory action research (CPAR) project work would not have been completed successfully. I am thankful to Herjeet Randhawa at Reading Voluntary Action (RVA) who encouraged me to engage in CPAR work as a local researcher and provided support as and when deemed necessary in its initial phase.

Similarly, I am very grateful to Dr Andrew Paterson from Scottish Community Development Centre (SCDC) for providing necessary training, mentoring and report development support. I am very proud of having such a wonderful facilitator, Dr Esther Oenga, RVA who continually encouraged me to progress the research work according to the planned timeline, and ensured access to audio recording equipment in order to carry out interviews. Her role in supporting the development of this research report cannot be ignored, and I would therefore like to express my deepest appreciation to her. Also, I am grateful to Dr Sally Lloyd-Evans, University of Reading who shared the CPAR creative methods with the community researchers prior to commencement of the interviews and focus groups. I found the tips and methods that she provided helpful.

I enjoyed attending shared meetings as part of the CPAR project and working together with the other participating community researchers. In general, the support provided by Michelle Berry and Nisa Unis from Reading Borough Council (RBC) was helpful and I am thankful to both of them. Finally, I would like to recognise the support provided by all others those directly or indirectly connected to this piece of work to get the research to where it is now.

Profiles and reflections: community researchers and partners

EVANGELINE KARANJA, COMMUNITY RESEARCHER

I am a mother to twin girls, with a passion for community work and service. I am a Master's graduate from the University of Reading and previously worked as a Mortgage Advisor at NatWest. During the pandemic, I volunteered my time with grassroots community organisations ACRE and Utulivu Women's group. Volunteering offers me the opportunity to extend my knowledge base, network with other professionals, work meaningfully in the community, and most importantly, have a positive impact now and on the next generation.

I believe that community-based research empowers local communities creating a constructive relationship between communities and the institutions. Community engagement is necessary, and viable, as it is likely to lead to more equitable, sustainable public decisions and improve the liveability of local communities. The research was an opportunity to pursue an in-depth study on access to maternal services for ethnic minority English-speaking women and midwives in Reading, Berkshire.

Through this research, I learned to use qualitative research methods and data analysis. This helped me gain sound technical knowledge, perfect my soft skills, and gain confidence and credibility to make a good professional impact. I hope the recommendations in the report can be used and adapted to make a change to maternal healthcare and access. I feel confident and empowered to carry out more community research in the future.

DONNA MA, COMMUNITY RESEARCHER

During my 24 years in England, after moving from Hong Kong, I have always had a mission to serve ethnic minority communities particularly Chinese immigrants. The opportunity came in April 2021 through RCLC which is one of the three charity organisations in this CPAR project. Becoming a CPAR researcher has enabled me to go beyond the religious, social and educational sectors.

My working experience as a qualified ESOL tutor has given me knowledge about different ethnic minority cultures. The trust and respect that I have gained from ethnic minorities helped the respondents feel more comfortable to share their views and life experiences. When I started my first online training session in April 2021, I was anxious and not sure whether I would be able to do a good job. The support which I have received in this CPAR programme has provided me the skills to design the questionnaire, do the data entry and data analysis as well as compiling the final report. After taking part actively in this programme for a year I am feeling empowered and confident. Working with a colleague and other people in this project, I have learnt to be more patient and open-minded and also picked up some IT skills.

I am glad that through this research the women respondents had the chance to speak their mind in spite of language barriers and lack of IT knowledge and social contacts. The findings of this research will inform future communication plans for all health and wellbeing issues within Reading's diverse communities, and facilitate the development of accessible health care services.

I also participated in the Town Centre Strategy Community Engagement led by Reading Voluntary Action and hosted a focus group online. I would like to continue my learning journey to become a competent community researcher and contribute more to the ethnic minority community.

HEMAMALINI SUNDHARARAJAN, COMMUNITY RESEARCHER

With a deep sense of commitment to do something for society, I have taken up different voluntary and paid roles at Reading Community Learning Centre (RCLC) over the last 8 years. This has enabled close interactions with ethnic minority women.

As an Outreach Support Worker, I was able to establish a level of trust with ethnic minority women, wherein open conversations could be had about their day-to-day challenges. Some of these challenges were generic and systemic in nature, especially regarding education and healthcare support, with deeper impacts due to Covid.

When the CPAR research initiative was talked about at RCLC, I enrolled as CPAR Researcher. Even though I had no prior experience of conducting research, the CPAR programme team ensured that appropriate guidance was provided through all the phases of the research. This research provided me the opportunity to take a structured approach in summarising the challenges faced by ethnic minority women and formulating an action plan for implementation. Personally, this has helped me to improve my social and IT skills and my research skills, including formulating questions, data collection, data analysis and reporting.

The eagerness with which the research team, RCLC and 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 community development. The research findings and recommendations have highlighted the need for additional focus on education and steps to improve the reach of healthcare services. I hope that the research findings would be looked at as the voice of Reading Ethnic Minority Women and the recommendations taken in earnest for their improvement.

I am thankful for this opportunity and look forward to more such engagements to contribute to the society.

TARIQ GOMMA, COMMUNITY RESEARCHER

This CPAR research has been a great wake-up call for me during Covid-19 and lockdowns. It has opened doors and provided great opportunities for me to discover myself and my potential. It started when Victor Koroma at ACRE gave me the opportunity to be a part of this research. At first, I was very nervous and many questions went through my head such as: was I the right person to do this research? what am I going to investigate? how am I going to do that? and can I really do that? There were many questions and worries, but the biggest worry was that I wasn't equipped enough with knowledge to do this. My self-esteem was quite low, my confidence was zero, my motivation and self-belief were not there due to what I had gone through during the pandemic.

One day, hope came along from someone believing in me, who told me that everything is possible and nothing impossible under the sun. That person is Dr Esther Oenga the CPAR Advisor and facilitator, who motivated me to take the first step, she reassured me that support and guidance was available throughout the research process. That was a big step for me. Then Dr Andrew Paterson, the CPAR mentor, stepped in alongside Esther in the mission to guide me along the way. They were the real driving force and the brains behind it all. These two wonderful people made it very easy for me, guided me, advised me, lifted me up and motivated me along the way. They helped me from the beginning until the end, from designing the questionnaire to writing this report. Their support at each stage gave me more confidence to move on to the next step.

I cannot describe the magnitude of experience I gained from doing this research. It taught me so many things and important lessons in life, including working according to your values and objectives. It taught me to always look ahead not back, look up not down, feel positive not negative. Nothing is 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 learn more about the subject of mental health and the need to create awareness of mental health in BAME communities.

CPAR research gave me all the confidence I needed, and I decided to join West Lancashire College's online course, Mental Health and First Aid. I have learned so much that people in my community have started getting advice from me about the subject. For example, a friend of mine is so inspired by me doing the research, he decided that he will be more involved with volunteering with ACRE. Furthermore, a woman at a local café which I regularly visit told me she had been through a tough time and had recently experienced depression. When I had a chat with her regarding mental health research, she was touched by my experience and the useful information I shared. She decided to take the flyer that was developed during the CPAR research and put it in the staff room to encourage other staff members to learn and seek help when needed. Finally, a group of Sudanese asylum seekers started feeling better and confident when I introduced them to the Mental Health Hub sessions that are taking place at ACRE's office every Tuesday.

CPAR research has made me realize the value of self-motivation and I'm hungry to learn more about mental health to be a better person for myself, my community and people in need. There is no shame in seeking help and it's never too late to take action. Small positive steps may change your life or someone's life.

KRISHNA NEUPANE, COMMUNITY RESEARCHER

Krishna has a Master's degree in Forestry from the University of the Philippines and a Bachelor's degree in Agriculture from India. Krishna is trained in development-oriented research in agriculture, instructional development foundations, project management and programme administration in developing countries. He has worked in the technical and vocational training institute managed by the Council for Technical Education and Vocational Training in Nepal and as Senior Programme Manager for the Nepal Agroforestry Foundation he conducted various field research projects and coordinated externally-funded projects such as AusAid watershed projects, a Danish-funded private forestry project and a University of Reading funded livestock livelihood project.

Krishna entered the UK in 2005 under the highly-skilled migrant programme scheme. He worked as a chair of trustees for Greater Reading Nepalese Community Association and during his tenure launched various programmes and activities with funding and support from Berkshire West Clinical Commissioning Group and RBC.

In 2016, he founded the Integrated Research and Development Centre (IRDC), Berkshire, UK CIC, which aims to contribute to reducing poverty and inequality (one of the strategic plans of Reading Borough Council), and supporting primarily south Asian BAME community groups by providing training in basic IT and computers, English conversation, gardening, and health, wellbeing and nutrition.

For the last few years, Krishna has been actively engaged in community research works such as community needs assessments, community surveys and community participatory action research initiatives.

DR DEMELZA HOOKWAY, RVA COMMUNICATIONS MANAGER

The CPAR project has been inspiring to work on in so many respects. From an RVA perspective, it has built on previous participatory action research with community partners and the University and highlighted once again the importance of foregrounding community voices. One of the highlights has been Eva, Donna, Hema, Krishna and Tariq presenting their findings at regional and national showcases and seeing their research become part of the evidence base for all stakeholders committed to reducing health inequalities in Reading. As well as the community researchers' findings, this report aims to document the collective effort it has taken to accomplish the CPAR project by people who are committed to listening, learning and taking social action. Sally, Esther and Aisha write so eloquently about the vital importance of funding and resourcing this work properly, so that we can hang on to the 'action' in participatory action research.

DR ESTHER OENGA, PROJECT FACILITATOR

Community participatory action research (CPAR)-Reading is described by many stakeholders as a unique and successful research project conducted between February 2021 and May 2022. Five CPAR-Reading researchers were among the 41 community researchers recruited by Health Education England, South East (HEE SE) to undertake research. The aims of the programme were to equip community researchers from Black, Asian and Minority Ethnic (BAME) communities without research skills to undertake research within their communities.

A great achievement of the CPAR project was the ownership taken by the CPAR researchers for the duration of the project and participation from the beginning until the end. They engaged in the research processes, decided the research topics in consultation with their communities and prepared a final report sharing their findings in different showcasing events. This achievement was inconceivable to the researchers at the offset because they had little or no prior research experience, they were nervous, fearful and not ready to engage in research. A significant contributor to their success was the existing relationship and trust they had within their communities.

It was evident that, the additional research projects, the Town Centre and Southcote digital research projects provided practical experiences for the researchers in terms of engaging the communities in meaningful conversations and presenting the research progress in different showcase events. This further enhanced their confidence. One researcher, who was initially nervous to take part in the research project said, ***"I am now a competent researcher, I now have full appetite for research and want to turn my research career upside down. We have been supported and nurtured every step of the process by our mentor".*** The researchers have been empowered and become great assets in the Reading community.

The CPAR partners tirelessly supported the research project all through up to the end, with the researchers being grateful to the community partners for their commitment and sacrifices. In an informal meeting, the researchers had the following to say about the community partners: ***"the community partners have been fantastic, they provided solutions to all the research challenges such as transcribing recorded interviews, translating questionnaires into different languages, they provided recorders, laptops, and even the use of physical space where we have met real people in a real room with snacks away from the Zoom screen".***

One noticeable success factor of CPAR-Reading as noted by all the stakeholders was the role of a part time CPAR facilitator to support the researchers, partners and wider collaborations. The facilitator role was unique to CPAR Reading and no project within the South-East region had a similar role supporting their research projects. The stakeholders said, "the role was unique, essential, and a great asset as it was most needed in the CPAR research". The CPAR partners regarded the facilitator as a "bridge", "glue", "connector" that supported the smooth running of the CPAR project. In addition, the local support provided by Michelle Berry, Nisa Unis from RBC, and Lorna Zischka and Sonia Duval from the University of Reading was highly appreciated by the researchers.

A key aspect highlighted during the CPAR project was the required time and need for the stakeholders to be flexible. The part-time facilitator had to be flexible to accommodate the researchers needs, often working on off days beyond the contracted hours. The facilitator went far and beyond her role not only to support the local project but also support the South East region research as a whole. In addition, many CPAR partners and researchers worked more hours beyond the initial hours allocated to the project. The facilitator observed great commitment from different researchers. **At one time, one researcher attended a physical meeting during his work break while another researcher made a zoom presentation while on a break at work.** These are really sacrifices, commitments and efforts that go unnoticed but contribute to overall success of the project.

The success of the CPAR-Reading project was as a result of strong partnerships with the five partners that depended on existing relationship and collaborations. The five partners: Reading Community Learning Centre (RCLC), Reading Borough Council (RBC), Alliance for Cohesion and Racial Equality (ACRE), Reading Voluntary Action (RVA) and University of Reading Participation Lab worked as a team and supported the project passionately. Each partner contributed uniquely beyond their initial commitments. The CPAR-Reading project partners created several opportunities for the researchers to showcase the many benefits their research produced. This enhanced the researcher's confidence, presentations skills, and widened networks locally, nationally and internationally.

At the end of the CPAR-Reading project, events were organised to present the researcher's work. This was carried out both online and in person with the objective of presenting the research findings and recommendations. The events enhanced the relationship the researchers had with the partners and created a broader trust within the community as they felt valued. It is hoped that this CPAR report will not only be shared widely to different organisations but also to the diverse communities represented in the research undertaken. One community participant in the final showcase event asked ***"CPAR recommendations, what next?".*** Such questions were shared with organisations, policy makers and service providers tasked with taking forward the CPAR project recommendations and address the **ACTION** points in order to make the necessary interventions. **As the CPAR projects comes to an end, there is need to support the researchers post research. This will be different for all researchers. In the short term, this includes their emotional wellbeing, as they may have become more vulnerable during the research process. Additionally, there are practical needs relating to any further community work they undertake that will need support, including making presentations without adequate resources.**

It is important to note that two other CPAR projects were conducted in Reading by Jacquah Foundation who focused on Covid-hesitancy and Utulivu Women's Group that focused on mental health among young people. Their reports will be published independently.

CPAR project is a great model, however, there is a need for researchers to be recognised, valued and rewarded. Partnership and collaboration are key to addressing the local issues identified and the coordination of any efforts made is essential and most needed. This utilises the underlying strength when the community works together. In order to achieve good outcomes, adequate time allocation and funding are required. The implementation of recommendations at the actions stage needs to be taken seriously, or else, relationships built over time are broken. Finally, despite the CPAR project being conducted during the pandemic, I can truly say that participating in research that focused on a bottom up approach and equal partnership has been remarkable in all ways.

AISHA MALIK, CENTRE MANAGER, READING COMMUNITY LEARNING CENTRE

It has been widely reported that the COVID-19 pandemic has disproportionately impacted Black and Ethnic Minority (BAME) communities across the UK, which have suffered higher rates of hospitalisation and mortality. While the causes of this outsized impact are yet to be fully untangled, it is consistent with longstanding disparities in health outcomes and access to medical treatment between BAME communities and the white majority. The pandemic has, in effect, brought pre-existing health inequities to the fore.

Reading Community Learning Centre (RCLC) has over 20 years of experience in delivering services to support traditionally 'hard-to-reach' refugee and migrant ethnic minority women. Our mission is to empower and support refugee and migrant women by creating a space for learning, and advocating for equal treatment, equal rights, and a life free from violence and discrimination. When the opportunity arose for us to be involved in a project which would not only investigate and assess why some of these disparities exist within the ethnic minority groups locally but also train and support women from the community to undertake this research, we were thrilled to be part of it. Especially as it meant that this would increase the diversity of community researchers locally.

The role of RCLC was to work collaboratively in partnership with RBC, Reading Voluntary Action, the University of Reading Participation Lab and ACRE (Alliance for Cohesion and Racial Equality) to recruit, train and produce a research report for CPAR funded by SCDC and HEE. A key strength of this project has been in bringing together the skills from each of these organisations culminating in research which has engaged with a much richer and diverse group of ethnic minorities. Another great strength has been the funding provided by RBC to employ a facilitator to oversee the project and bring it all together. Without this funding for the role, it would have been extremely difficult to coordinate the four research projects, complete them within the time frame but also provide much needed support to the five community researchers on this project. The facilitator was crucial in spreading the word about the project and was invited to speak at various steering groups to talk about the project.

Due to the Covid-19 pandemic although the project was due to start in April 2021, we were not able to really get the ball rolling until June 2021. We were always adamant that our research must be completed in person as we had already experienced 3 lockdowns with the women we supported and knew that we would not be able to get the detailed research and information unless it was in person with the interviewees in their first language. This in person contact was also vital to build trust and support so that women could feel safe and free to express their experiences of accessing healthcare in their first language during the pandemic and how it affected them at their own pace.

RCLC recruited two female community bilingual researchers from the centre, who between them had lived experience of coming to this country as a migrant, a background in teaching ESOL, volunteering and providing outreach support to migrant and refugee women in Reading. Our researchers were passionate and excited to be part of this research but also to have the opportunity to receive mentoring and training.

RCLC would like to thank SCDC for the mentoring and training which equipped and prepared the researchers with research techniques as well provided an opportunity to meet other researchers, share and reflect on their work. Our project benefitted hugely from having the expertise and support from the University especially in the collection of data, data analysis and the inputting stages. The facilitator who also had experience in carrying out research was also a great strength during these stages to support the community researchers who were doing this for the first time. This additional support helped to give the community researchers confidence in their research, build their research skills at their own pace and have a support network.

Another great strength of this research project was that we were able to investigate and research the topics and areas which mattered to each of the partner organisations rather than being dictated by funding. Moreover, the existing links, trusted relationships, and connections the partners had to each of the diverse ethnic minority families and communities meant that the project was able to engage with, identify and question those communities who are often overlooked or not included in this type of research.

This research was incredibly important to us in not only making the voices of the women we were talking to heard but also in using this research to bring about changes and improvements. As a charity we pooled all our resources and connections which were not funded by the project such as translation, volunteer support, administration and management and outreach support.

An important recommendation for me for any research which engages with communities who don't have English as a first language is to include a budget for translation work but also to budget in the real time costs for the additional support mechanisms to see this project come to fruition, such as the management time, outreach work, translation support and volunteer costs. The cost of the project was far more than just the few paid hours for the researchers for their time in attending trainings. I would advise that for future projects a realistic budget which includes these elements is budgeted for.

Being a part of this CPAR Project has truly been a great experience not only for us as a partner organisation but also for the researchers. Not only were we able to carry out research in an area that was hugely important locally and nationally, but it has also equipped the community researchers with new skills which they could utilise in working in this field in the future. The fact that we as a small grass roots charity can use this funding and platform to carry out research and hopefully bring change to the forefront is immensely rewarding and exciting. I hope that there is more funding for this type of research empowering communities to be active, vocal participants in brining local change by getting the decision makers to listen and take note. RCLC are really proud of all the researchers and looking forward to seeing the social changes the report will influence.

REFERENCES

Disparities in the risk and outcomes of COVID-19, Public Health England, 2020

Evandrou M, Falkingham J, Feng Z, et al. *Ethnic inequalities in limiting health and self-reported health in later life revisited.* Journal of Epidemiology and Community Health 2016; 70: 653-662

DAYNA WHITE, NEIGHBOURHOOD AND PARTNERSHIPS MANAGER AT READING BOROUGH COUNCIL

The CPAR project has been an incredible opportunity to build a strong partnership between Reading Borough Council, University of Reading Participation Lab and the community organisations hosting and supporting the community researchers – Reading Voluntary Action, Alliance for Cohesion and Racial Equality and Reading Community Learning Centre. The project has enabled us to build this partnership, supporting members of the community to upskill as researchers and provide a supportive platform for this vital research to take place.

The community researchers have been able to collect such valuable insights from communities that so often go unheard, by exploring the experiences of these groups around these important topics and collating them into formal research the project has amplified these voices and experiences in such a crucial way. The interest from wider partners in this research shows how much this work is needed and how significant the work of the community researchers and all the organisations involved is. As a local authority we really see the value in using the community researcher approach and this is something we're keen to explore moving forwards.

The support from the partners involved and the work of the researchers themselves is what has made this project so successful. The support from the CPAR facilitator both to the researchers, but also to the partners has been impeccable and a key foundational block to the realisation of the project. The role of facilitator has been a vital one and is something to consider when thinking about community research projects like this. The resourcing of the project is an area to consider moving forwards as much of the success has been a result of unpaid hours worked and goodwill given by partners and researchers – this work must be properly resourced moving forwards to create a sustainable and ethically sound approach. Locally we will be looking, as a partnership, at potential routes to do this.

The final reports and recommendations from the community researchers are essential reading and something we as a local authority are taking forward via a task and finish group. We're also keen to continue to develop the strong partnership of the CPAR project group and together, find a sustainable way to build on the success of the project.

VICTOR KOROMA, CHIEF EXECUTIVE, ACRE

Alliance for cohesion and racial equality (ACRE) in its previous and present establishments has been advocating on issues affecting, and supporting ethnic minority communities in Reading for over 50 years. The incidence of Covid-19 took everyone by surprise and the rate at which it impacted particularly people from minoritised communities was devastating. Investigative reports which summarised the effect of the pandemic on BAMER communities only served to confuse people further. However, what was clear was that at the heart of the problem was poor access to health services, leading to equally poor health outcomes.

ACRE and our community support partners in Reading, including Utulivu Women's Group, have in recent times been highlighting the fact that health services were not meeting the needs of ethnic minority communities. Said services were designed on a one-size-fits-all model, and when it came to ethnic minority groups, it further compounded their unequal access to services leading to many who deserved to be helped not getting the help they needed.

The CPAR project was a welcome opportunity for us to put some of the questions we had to the test. Our two researchers, Tariq Gomma and Eva Karanja investigated areas of Men's Mental Health, and access to Maternity Services respectively and the results speak for themselves. However, taken in context of the other researchers' reports is easy to surmise that there are many more areas of glaring health inequalities experienced by people from minoritised communities. This type of work should not be a one off.

The other challenges this piece of work brings are: how are we going to meet the expectations raised within the various communities that were investigated; what service development approaches would the NHS/Health Education England and local public health planners take to address issues raised in this report; and what help and support would be provided to voluntary sector organisations [Reading CPAR Partners] to enable us to carry out further investigations on health inequalities in Reading.

That said, sincere thanks to NHS/HEE & SCDC for the opportunity; to all our CPAR partners, especially Dr Esther Oenga for the support provided to all the researchers; Dr Sally Lloyd- Evans for her support and especial thanks and gratitude to Eva and Tariq for their commitment to the task.

DR ANDREW PATERSON, POLICY AND RESEARCH OFFICER, SCOTTISH COMMUNITY DEVELOPMENT CENTRE

CPAR was an amazing learning experience for me. I think it's important to say this, since my role was to offer mentoring support to the community researchers, guiding them through the different stages of their research with their communities. But even though the community researchers were having to learn a lot, I felt that I was also learning a huge amount in my mentoring role. In part, this was because there was a lot that was new for me – I'm relatively new to supporting people to do research as my normal job is more traditional policy and research work, and I've only recently started supporting groups to do their own research, although this is something SCDC has been doing for many years. The Covid-19 pandemic and lockdown meant we had to support people online rather than face-to-face, so everyone had to adapt quickly.

But the main learning for me was to see how much enthusiasm, bravery, insight and commitment the community researchers have in taking forward their research. Leading on your own research can of course appear extremely daunting, and I don't mind admitting that the thought of supporting numerous community research projects from start to finish seemed like it would be a huge undertaking for me too. And in many ways, it was a huge undertaking for everyone, but importantly, it was achievable. Donna, Eva, Hema, Krishna and Tariq showed that, given the right support, people who have little or no experience of research can design, carry out and take forward their own research that benefits them as individuals and has valuable insights for improving services for their communities. I've learned a huge amount about what 'right support' means – including the role of peers and making sure emotional and mental wellbeing is considered carefully. Having someone as dedicated and as dexterous as Esther in a local support role has been invaluable, and it's fair to say the success of the Reading CPAR project has a lot to do with her.

It's good to think that, one year on since the programme began, CPAR will have a lasting legacy for local services as well as everyone involved in the programme.

CPAR Acknowledgements

The idea for the CPAR project came from Public Health England's report that recommended a bottom-up approach to support local community researchers to investigate the issues that mattered to the community as a result of the impact of Covid-19. The project took over a year: to design the research, for the data to be collected, for analysis to be done and for the final report to be written. The whole process was a journey of dedication and commitment from many different people and organisations.

Thanks to Public Health England for first recognising and recommending the engagement of community researchers without which the community researchers will have not gotten the opportunity. Thanks to the Health Education England team and especially Joanne McEwan for working so hard until the end with the showcase event that celebrated the researchers. To all our partners in the South East region. We are deeply grateful for your support. We are grateful to the Scottish Community Development Centre especially Dr Andrew Paterson for supporting the researchers and giving valuable feedback on their reports.

Thanks to the Reading Borough Council team who supported the CPAR research: Unis Nisa who designed and printed the researchers' ID badges, Amanda Nyeke for supporting the project in many ways, and Michelle Berry for making the grant application and seeing the project take off, and providing the researchers opportunities to showcase the research at RBC meetings. Thanks to RBC for funding the part-time facilitator role and the researchers' laptops. Thanks to Dayna White for her support towards the end of the project and for spearheading the CPAR recommendations.

Thanks to the University of Reading Participation Lab for all the support in creative research methods, and for recording devices, transcribing services, conference costs, and additional contributions from Dr Lorna Zischka and Sonia Duval with quantitative analysis. To Dr Sally-Lloyd-Evans, thanks for being there for the researchers, facilitator, and other partners with all your advice and guidance. Thanks to Professor Adrian Bell for participating in the showcase event at MERL and presenting the certificates to the researchers.

Our gratitude goes to Reading Voluntary Action for its enormous contributions including conference rooms and covering printing and costs for flyers and the final report. Thanks to Rachel Spencer who worked tirelessly for the project to succeed, to Herjeet Randhawa for her supervisions and close monitoring, Dr Demelza Hookway, working powerfully behind the scene editing the final report and to William Westwood who supported the CPAR research from day one.

We are thankful to RCLC for supporting the researchers throughout, facilitating payments, solving issues and to Aisha Malik for attending partner's meetings and ensuring CPAR was a success. Thanks to the Alliance for Cohesion for Racial Equality for working with the researchers and other partners directly to ensure that research processes went on smoothly. Thanks to Victor Koroma for all the hard work and the We Men group who assisted with data collection. Thanks to the facilitator, Dr Esther Oenga for being flexible and working beyond her hours to support the researchers.

Thanks to the diverse Reading COMMUNITIES that participated in the research in different ways without which no research will have been accomplished. Last, but not least, thanks to the community researchers for successfully participating in the research from start to the end. A considerable amount of time was invested in this research and we want to say thanks to ALL that contributed in one way or the other.

Notes

Notes

FOR FURTHER INFORMATION, PLEASE CONTACT:

RVA
0118 9372273
info@rva.org.uk

ACRE
0118 9510279
info@acre-reading.org

University of Reading
s.lloyd-evans@reading.ac.uk

RCLC
0118 9595455
rclcinfo@yahoo.co.uk