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

Krishna Neupane

Integrated Research and Development Centre (IRDC), Berkshire, UK CIC[1]

May 2022

[1] IRDC is a registered non-profit community interests company came into being in Reading, UK since 2013.

Contents

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.

1. Background to the research

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.

2. Research focus

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

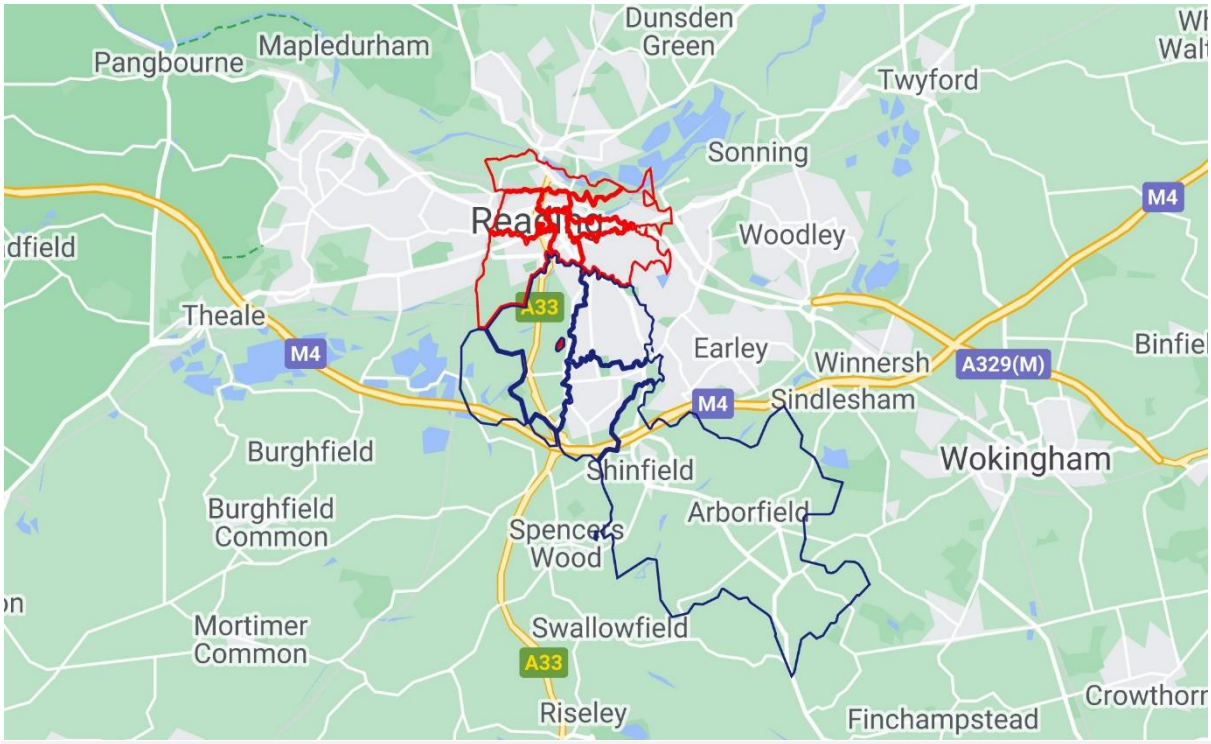
2.i. What factors have contributed to the disproportionate impact of Covid-19 on BAME communities, specifically among Nepalese community groups residing at east and south Reading locations?

2.ii. What improvements to services can be recommended in order to address these factors and potentially improve health and wellbeing outcomes for these groups?

3. Study area selection

Map of RG1 and RG2 postcodes

Key: Red boundaries show RG1 postcode district; blue boundaries show RG2



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.

4. Research Processes and Methods:

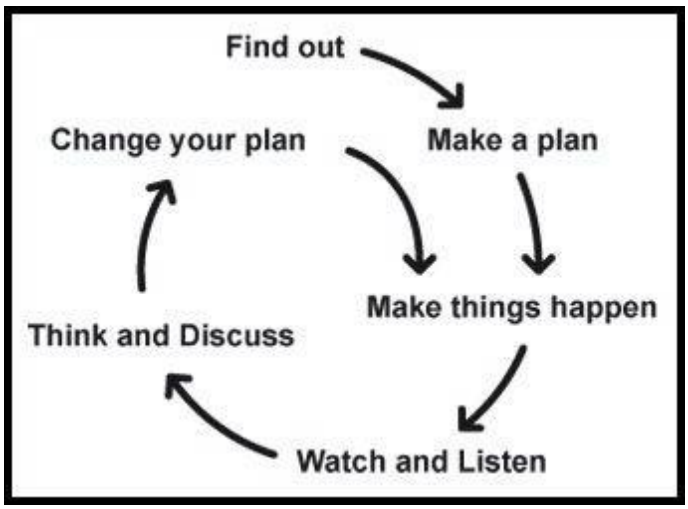
Training and support:

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: SDRC 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.

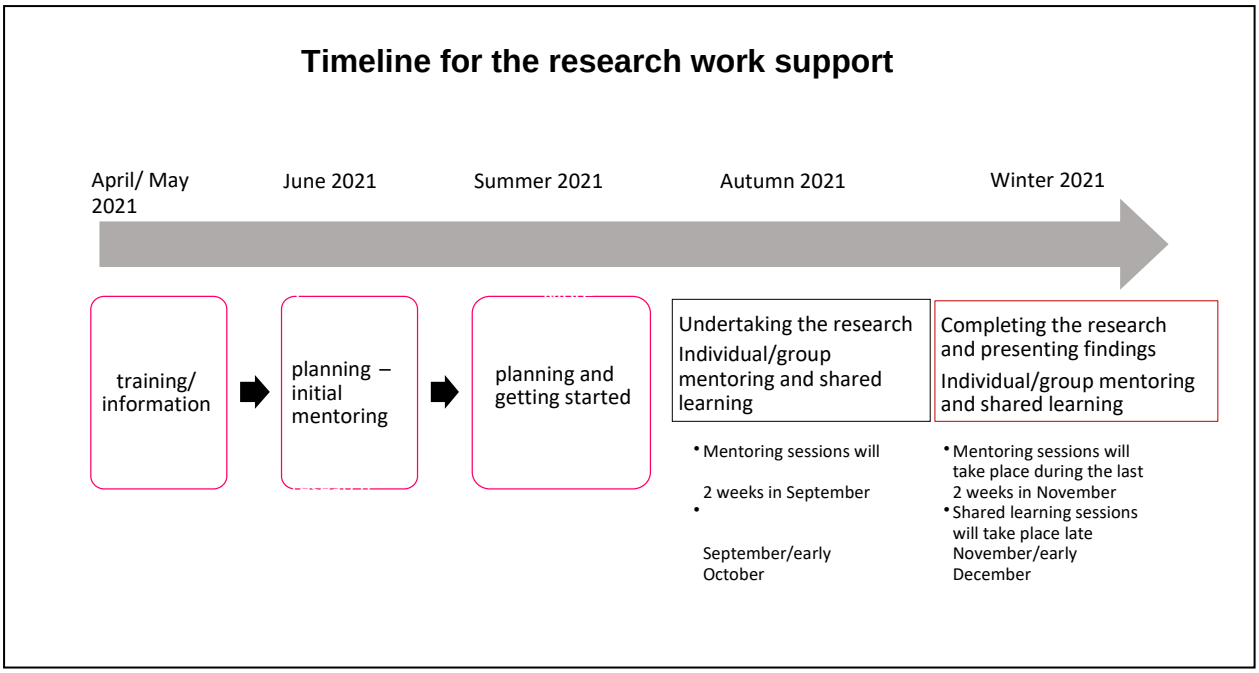
- A virtual session on creative research methods was provided by Dr Sally Lloyd-Evans, University of Reading. This gave an insight into a range of community participatory research tools before commencing the research work with community groups.

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 222. 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 (Annex 1: 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.

5. 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 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 put 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 flue and that we should not worry much about it. Some other people were 'vaccine hesitant' due to believing that negative side effects included infertility and becoming more vulnerable to other diseases.

Other beliefs which came through in the research included 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."

6. Recommendations

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.

7.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.

Appendix A: Abbreviations:

BAME: Black, Asian and Minority Ethnic
CPAR: Community Participatory Action Research
RBC: Reading Borough Council
RVA: Reading Voluntary Action
SCDC: Scottish Community Development Centre