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The Community-Led Momentum in Gloucestershire to Tackle Healthcare Inequalities

**Through the Strategic Rebuilding of the
Black and Minoritised Voluntary Sector**

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This research project was undertaken by Chiara Lodi, Senior Researcher at BSWN. Data collection was aided through fieldwork carried on by Verona Vidal, Associate Researcher at BSWN. This report was designed by Kat Garoës-Hill, Creative Communications Officer at BSWN.

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Acknowledgements

This research project started with humble but clear objectives and developed into something significantly bigger than originally intended. It grew together, and to some extent, fed into the community-led momentum that sparked in Gloucestershire over the last two years. I was the lucky person tasked with capturing this wave of innovative and galvanised bottom-up energy and in doing so I spoke to several individuals from various communities who were kind enough to give their time and share their honest experiences with the researchers on this project. A huge thank you to you all who participated, you are the heart of this report.

The project delivery was also met with many obstacles, stemming both from a professional and a personal ground. The BSWN research team managed to overcome these obstacles thanks to the constant support of the expert but also flexible individuals who sat on the Steering group. For this reason, a warm thank you goes to Joanna Underwood, Diana Billingham, Matt Lennard and Elaine Pearson Scott for their constant support and work on this piece.

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Chiara Lodi, Senior Researcher

Terminology

BSWN moved away from the acronym "B.A.M.E." in early 2020 as communities across the South West and nationally deemed it inadequate and limiting in identifying the variety of identities and cultures facing racial discrimination. Therefore, BME or BAME will only be present in this report where it is an integral part of a direct quote from participants which we do not have permission to edit.

BSWN believes that each community has the right to decide the terminology that is the most appropriate for referring to its members. Therefore, in this report the researcher will utilise 'racially minoritised' communities which was selected to be used by the Gloucester City Commission to Review Race Relations in their 2021 report, and 'Black and Minoritised' communities which was selected to be used by the newly founded Gloucestershire Race Equality Action Group (GREAG).

More specifically, 'racially minoritised' and 'Black and Minoritised' individuals here will be synonym to 'individuals who are racialised as a non-White minority in the UK society' and therefore it can refer to persons from African, Asian, and Middle Eastern backgrounds, heritage and/or descents, including mixed-race individuals.

BSWN is also committed to use specific terminology for each group whenever possible. Whilst representative data will be provided whenever possible, please understand that individual participants have the freedom to request for all identifiable information to be removed from the report and select the highest level of anonymity. Within a limited sample, any demographic information – including ethnicity – can be considered identifiable information.

Please also understand that the terminology and data capturing discussions are always evolving and there is currently no fixed term accepted equally by all communities who experience racial discrimination. BSWN will keep engaging with the discussion led by communities and operate to ensure our terminology and data-capturing is developed as the discussion evolves.

Acronyms	
BSWN	Black South West Network
GCC	Gloucestershire County Council
GREAG	Gloucestershire Race Equality Action Group
ICSs	Integrated Care Systems
NHS GCCG	National Health Service Gloucestershire Clinical Commissioning Group
VCS	Voluntary and Community Sector

Introduction

Context

In many ways, this is a historic moment in Gloucestershire, full of opportunities to nurture and achieve systemic change. A wave of transformative action is spanning across different sectors, ranging from the formalisation of Integrated Care Systems (ICSs) in the cross-sectoral healthcare partnership 'One Gloucestershire' to the actionable recommendations provided by the 2021 Gloucester City Commission to Review Race Relations report, and the community-led setting up of the Gloucestershire Race Equality Action Group (GREAG); all key stakeholders in the county are contributing to a meaningful transformation.

Whilst it is undeniable that COVID-19 and Black Lives Matter have provided drive for change on a global scale, many other locations have failed to materialise real outcomes out of the revolutionary impetus. In the case of Gloucestershire, the merit goes to the pioneering approach of its public and health authorities, and to the leadership demonstrated by its communities.

In fact, this project begins in early 2021, when the Gloucestershire Voluntary and Community Sector (VCS) Alliance identified a gap in the VCS representation for Black and Minoritised people in the county. The Black South West Network (BSWN) was therefore commissioned by the NHS Gloucestershire Clinical Commissioning Group (NHS GCCG) to undertake a piece of scoping work on the capacity and capability of the Black and Minoritised VCS voice within ICSs, also in partnership with Gloucestershire County Council (GCC).

For the entirety of its delivery, the research piece was overseen by a strategic Steering group including representation from its funder, the county council, the VCS Alliance and the Black and Minoritised VCS in Gloucestershire.

This mapping research provided a route for dialogue, and its preliminary findings supported and accompanied the development of meaningful Black and Minoritised community-led action in the county. This report aims to capture both the challenges and opportunities given by the current Gloucestershire community-led momentum to tackle racial healthcare inequalities.

Objectives

To better respond to the changing landscape and truly capture the breath of the community-led action that is currently taking place in Gloucestershire, this research project has significantly shifted its objectives and design throughout its delivery.

The objectives on the original research proposal intended to:

1. Map out the Black and Minoritised VCS sector in Gloucestershire ICSs to produce a comprehensive picture of the sector with in-depth information on its make-up, its geographical distribution, its modus operandi and the issues and challenges hindering its development.
2. Scope existing channels of engagement and influence and identifying opportunities to amplify the sector's voice in decision-making mechanisms.
3. Produce recommendations to support and improve the Black and Minoritised sector's development, capacity, and capability within the Gloucestershire ICSs.

Whilst these objectives remain in place, and the report will dedicate space to provide answers to them, it will also aim to build on recently published findings.

In this sense, it will:

- Build on the findings of the 2020 Director of Public Health Report to provide culturally nuanced context to the causes of racial systemic healthcare inequalities, providing lived experiences as examples to understand exactly where racially minoritised individuals' needs mismatch with the current mainstream health and care services.
- Provide context to the community-led momentum in Gloucestershire through bringing the voices of Black and Minoritised communities to the centre and build a narrative that accurately portrays their perspective, as well as offer examples of good practices implemented by the Black and Minoritised VCS sector in response to racial systemic healthcare inequalities.

- Illustrate the current state of the Black and Minoritised VCS sector in Gloucestershire, highlighting areas for investment to rebuild the sector strategically and equitably, and examine the current levels of engagement between the Black and Minoritised VCS sector and mainstream health and public bodies.
- Expand on the first recommendation proposed by the 2021 Commission to Review Race Relations report focused on setting up a 'Legacy Institution', particularly in relation to its advocacy role.
- And lastly, provide evidence of the potential that ICSs might have in improving racially minoritised communities' healthcare outcomes as well as on the role that the Black and Minoritised VCS sector can play within ICSs.

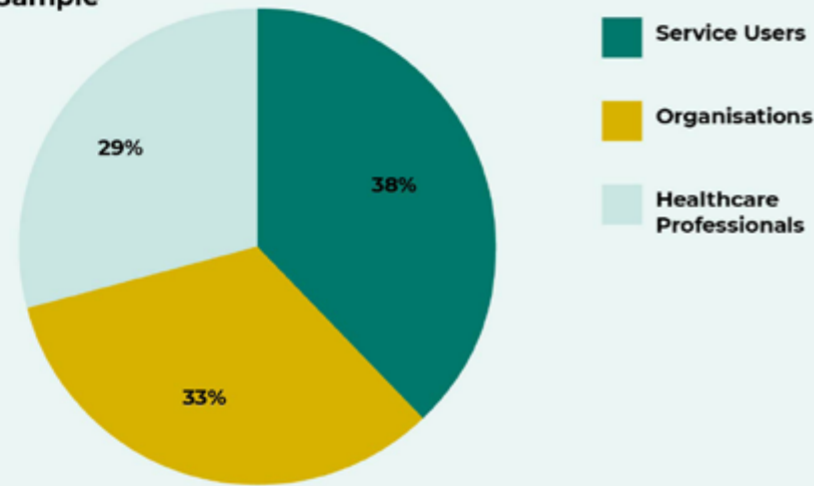
Methodology

This project's methodology included both qualitative and quantitative primary data collection across a varied demographic sample, which was intended to be diverse not only in terms of ethnic and cultural representation but also in terms of ages, gender, socio-economic backgrounds, and professional and personal history.

More specifically, the project collected primary data through the following:

- A visioning session hosted virtually on the 28th of April 2021 in partnership with the VCS Alliance to introduce the project and its objectives to the Black and Minoritised VCS sector in Gloucestershire. The session included 29 participants – a mixture of VCS representatives, racially minoritised residents and representatives from the public sector and the wider stakeholders' network - contributing to the inception and design of the project.

Figure 1 - Make-up of Survey Sample



- As shown in figure 1, a survey was designed to capture perspectives from three different groups.
- 14 representatives from the Black and Minoritised VCS Sector.
- 16 racially minoritised health and care services users.
- 12 racially minoritised health and care professionals.

The survey was disseminated both online through key networks and snowballing techniques as well in person through fieldwork, which was carried on by a local Research Associate to increase the outreach.

- A series of 9 interviews undertaken between the 22nd of March 2022 and the 22nd of October with key individuals in Gloucestershire who are strategically placed to have extensive knowledge on the Black and Minoritised VCS sector history, as well as racially minoritised people who have shared their personal experience as health and care professionals or service users.
- The qualitative collection also included a focus group on the 21st of January 2022, facilitated virtually by Gloucester FM with 10 Black and Minoritised people sharing their experiences with health and care mainstream services in Gloucestershire.
- Lastly, the project also engaged strategic stakeholders across many dimensions of health and social care to build a momentum that would set up the ground for actionable recommendations to follow the research.
- Overall, the total number of engagements that produced data was **103**, of which:

- 18 were strategic stakeholders in Gloucestershire.
 - 14 were Black and Minoritised organisations.
 - The remaining 71 were racially minoritised individuals.
- Out of these 71:
- 42 were individuals from African Caribbean and/or African backgrounds or descents.
 - 12 were individuals from South Asian backgrounds or descent.
 - 6 were individuals from East Asian backgrounds or descent.
 - And the remaining 11 participants explicitly requested for their ethnicity not to be recorded in the report.

Disclaimer

It is important to share in this context that the data collection of this report came with significant challenges caused by:

- The **historical distrust** that racially minoritised communities have in research and systems, which manifested particularly strongly in the Gloucestershire area. This is due to systemic issues of power imbalances that have permeated research-production for decades, where community members would provide their experiences to researchers and then would not be able to see any practical outcomes coming out of their contribution. Over the years, this has resulted in communities losing faith in the transformative power of research.

To overcome this obstacle, a significant project-restructuring was done along the

way to accommodate the extra time needed to rebuild the trust and engagement of communities. Furthermore, this project was community-led to ensure that all participation was equitable and devoid of power-dynamics.

- The second reason for the slow process of data collection was given by the **delicate subject matter**. Participants were requested to share extremely personal experiences where the healthcare systems had failed to respond to their needs or the needs of their loved ones. This was not only a painful experience for some, but it also came with a general fear of openly critiquing the system. For these reasons, many individuals approached decided not to contribute to the piece even when they had something to input.

To overcome this problem, the highest level of anonymity was provided to everyone who requested it (11 participants) and different other levels of anonymity according to the conditions that would make the participants more comfortable. Extreme flexibility to the engagement model was also provided and implemented with an active listening approach rather than a traditional research questionnaire approach, with signposting to support services whenever appropriate.

- Another challenge was the unequal engagement in terms of the multitude of communities and groups that the project intended to involve. As shown above, the sample's representation of African Caribbean and African groups is stronger than that of the other groups engaged. However, the overall sample is still nuanced enough to allow for the identification of systemic trends. In this sense, it is important to note that this report does not aim to provide a comprehensive account of all possible experiences from racially minoritised communities and related cultures at all levels of health and care as this type of record would require exponentially bigger resources than what was made available for this project. On the contrary, this report rather aims to identify the most recurrent systemic failures in responding to racially minoritised communities' needs. In other words, it looks at trends and gaps in the system and provides understanding to tackle systemic challenges.

Whilst the challenges were significant, the project was enabled to succeed and overcome the widespread research fatigue thanks to the flexible approach that the Steering group leadership provided. There was an explicit intention from this report's funder and its strategic partners to give leadership to the Black-led sector, to give space to communities, to give autonomy to the people who had lived experiences to tell their own stories, and ultimately to build a momentum oriented towards action.

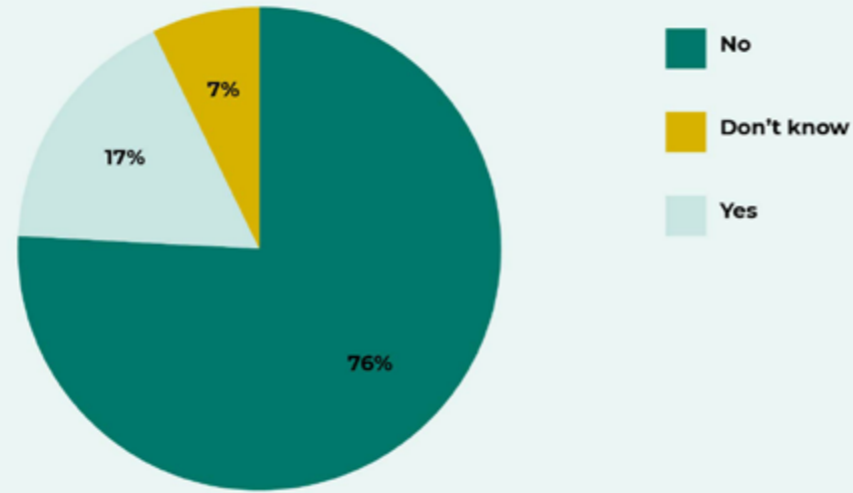


Racial Healthcare Inequalities

Are The Health Care Needs Being Met?

When asked the question, "Are the health care needs of your communities being met?", a striking 76% (32) of survey respondents answered "No", whilst 17% (7) selected "Yes", and the remaining 7% (3) of the sample stated that they did not know or did not have enough information to respond [see Figure 2].

Figure 2 - Are The Health Care Needs Being Met?



Only two respondents out of the 7 who stated that the health needs are being met gave further explanation. One stated that they are satisfied with their current GP surgery because it provides competent interpreting services, whilst the other is a community worker who praised the flexibility of services of their local hospital.

COVID-19 Impact & the Digital Divide

After a closer analysis of the open comments shared by respondents who do not believe that their communities' health needs are being met, the impact of COVID-19 on the NHS capacity is unsurprisingly one of the most cited problems (7 mentions). Details on the disproportionate impact that COVID-19 has had on racially minoritised communities in healthcare can be found in the 2020 Report of the Director of Public Health. As there is plenty of evidence already available, this report will not explore this theme in-depth.

However, it is important to note that the extreme strain the pandemic has put on mainstream services is still significantly affecting people,

particularly in underserved areas of the county. Multiple respondents shared that they had to wait over 3 weeks to get an appointment at the GP practice; and two respondents had to wait over a year to get appointments at the hospital, with one person specifically suffering from epilepsy and the other having serious complications due to severe asthma.

A related and similarly unsurprising theme is the problem of the digital divide (3 mentions) increasing due to Covid-19 safety measures. This has systemically lowered access to services for digitally excluded people. An example was given of an older person having to submit pictures of their skin concern online and being unable to do so due to not having access to a smartphone nor a laptop.

Intercultural Communication Failure

The problems mentioned above are tightly linked into the wider issue of a systemic communication failure (15 mentions) between older people from Black and Minoritised communities and mainstream healthcare services that has been

occurring for years and significantly worsened during the pandemic. Whilst the 'language problem' has been cited consistently in previous reports and more recently identified as a key issue in the Commission to Review Race Relations Report (2021), the evidence collated for this project provides a more in-depth understanding of its causes and shows that there are cultural nuances to it that go beyond the occasional lack of access to competent interpreters.

One example is offered by the Jamaican participants to our focus group, interviews, and survey, consistently explaining how healthcare professionals often misdiagnose their elders due to miscommunication based on the assumption that Jamaican Patois is the exact same language as British English. In reality, what sounds to an inexperienced ear as broken English, is effectively an English-based creole language with West African influences which utilises different terminology when referring to body parts compared to British English.

“Even though Patois, and in Jamaica that’s what it is called, would be spoken, it’s broken English. It stems from slavery as broken English. We weren’t looked at, and when I say ‘we’ I’m talking about my parents coming from Jamaica. So, if somebody said my hand is hurting, they meant their whole arm or top of their arm. The interpretation wasn’t there so they would give them the wrong treatment or something like that because there was not that understanding. That’s where the breakdown of communication happened with a lot of the elders now.”

– Interviewee #5

“We had the older Jamaican with broken English, I know a lot of people have to accompany their elders because otherwise they will probably end up on the hospital table being cut in the wrong place, because when the uncle says his stomach, but would tap his chest, he means his chest. We don't need interpreters because Jamaican speak English but it's broken English, so you can still get a misunderstanding and the wrong diagnosis because of the example I gave.”

– Participant to the focus group #1

Another cultural assumption that is often made when providing aid for intercultural communication is that any interpreter who is fluent in the required language will be able to accurately translate specific medical terminology, without having received training in the medical field. Layers of complexity are added when there is no exact translation between two languages due to one concept being non-existent in another cultural context. A common case is that of mental health and mental illnesses that are often not directly translatable to Asian languages.

“And the other issue is people who do translation/ interpretation services not having appropriate training and awareness of medical terminology. Especially when working within mental health services, where commonly heard and understood conditions in English have no equivalent words/phrases in languages such as Gujrati and Hindi. For example, there is no word for depression in Gujrati & Hindi, therefore, if you are working with a person from one of these communities how do you get the message across to the person and provide treatment going forward?”

– Interviewee #9

Incorrect Diagnosis and Treatment

Cultural misunderstandings leading to wrong diagnosis have also been linked to the healthcare practitioners being unaware of the cultural background of service users. This is a pattern that has been mentioned 7 times across the entire sample among different medical fields. One of the most striking examples is cited below, where a Jamaican person was misdiagnosed with mental illness for exercising a recurrent culinary practice in Jamaican culture that is seen as uncommon in the UK.

“My mother was wrongly diagnosed with depression, I believe. She was wrongly diagnosed, and she had a cocktail of different medicines. [...] One of the things in Jamaican or different traditions, we wash the starch off our rice and everything. [...] She was just picking out the bad bits before she cooked the actual rice. Because of the lack of understanding of different cultures they didn’t understand that she’s picking out this rice and then just going to wash it. They actually put a diagnosis saying that she’s counting rice so she must be mad as we don’t count rice.”

– Interviewee #5

In many other instances, participants have mentioned situations where medical practitioners were unable to recognise symptoms on Black or Asian people’s bodies and/or unaware of the higher-than-average rates of diseases such as diabetes, blood pressure and prostate cancer for Black and Minoritised demographics. This denotes a lack of preparation that is evidence of systemic racial biases in the wider healthcare system.

“The systems used are for White people, there isn't recognition of appropriate care for Black people. For example, our skin does not blanch, so the staff is unable to detect if older people leave hospital with pressure sores.”

– Respondent to the survey #9

“Someone fit went into hospital, he had pressure sores on the bottom, the staff was not using proper equipment and the person almost lost a foot.”

– Organisation responding to the survey #9

“The GP was trying to put him off from requesting prostate check, but he fits the criteria, over 50 and from community with additional needs. He had to argue the case because he was told he did not need it. They need more training on awareness around minoritised communities.”

– Organisation responding to the survey #11

The lack of specialised expertise when treating patients who are from racially minoritised communities in combination with the ‘language problem’ or better yet the systemic intercultural communication failure described above, and the overall racial systemic biases present in the medical system are all causing an increase of distrust in mainstream healthcare services, especially for older Black and Minoritised people.

This results in racially minoritised people being extremely reluctant to turn to mainstream services for support, which in turn causes an increase in numbers of people who are fundamentally excluded from early prevention and monitoring programmes. This overall communication breakdown has severe consequences on the communities’ quality of life. A few instances have been mentioned where older people have been given long-term medication without reviews for decades, resulting in huge damage to their bodies.



Lived Experience

Incorrect Medical Treatment

A lived experience was shared by an interviewee whose mother suffers from chronic debilitating rheumatoid arthritis and osteoporosis. Despite being in acute pain for months, the patient was admitted into three different hospitals and had to wait for several months before an x-ray was undertaken. When a fracture was found, a doctor ultimately checked the patient's record and found evidence of an incorrect medical treatment that had been ongoing for over 15 years.

"The colleague said to my mum's rheumatologist 'You've had this lady on bisphosphonates for 20 years and she's only supposed to be on them for five.' The reason why her bones are so bad is because she was given bisphosphonates for 20 years when she should have only been given them for five because that's what the NICE regulations say. Now I come across medical practitioners that say they have never seen anybody in such a bad state as my mum ever. In all the years, one of the consultants said, 'I've never seen such bad bones in all my life in all my medical experience.'"

- South Asian interviewee

Maternity Services Under Capacity

According to the data released in the 2021 confidential inquiry into maternal deaths, Black people in England are four times more likely to die in pregnancy or within the first six weeks of childbirth than their White counterparts (MBRRACE-UK, 2021). In this context, it is not surprising that one of the most discussed types of service in the research is maternity services, with four participants specifically mentioning them due to their extreme lack of capacity that results in women not receiving appropriate care and being rushed into and out of care too quickly for their own safety.

“[A member of community] went to the hospital and had to wait in pain for hours. No one should be asked to give birth like that.”

– Organisation responding to the survey #14

“Looking at maternity services we all know the situation is when you go into the hospital if you are not screaming the place down, you will be told to go and come back. I have seen young women go into labour and being told go away and come back, ‘You can’t be in until the latest stages of labour and you are probably not there yet’. No examination, just go away. And then when they go in, the baby is rushed and you know there’s poor outcomes for the baby and the mother, so that’s happened, and it was happening before, and it was even worse during Covid-19.”

- Participant to the focus group #9

Racism and Stereotypical Assumptions

In three distinct instances, participants shared experiences of open racism in the way that Black and Chinese women and their new-born babies were treated during their childbirth stay in the hospital. One example was given about an interracial couple receiving a different set of questions compared to White couples, where the questions have implicit racist undertones.

Another experience, shared by three women in the sample, is in relation to the Mongolian blue spots that typically appear on new-born babies and are not associated with any dangerous conditions or illnesses. The nurse practitioner, unable to recognise the birthmarks on diverse skin colours, raised an unnecessary safeguarding concern with the doctor.

In addition to this, another issue directly related to stereotypical assumptions is the lack of discharge planning (7 mentions) based on the assumption that Asian and more generally Black and Minoritised individuals will have supporting family members available to take on caring responsibilities. This results in discharging delays that cost time and resources both to the service user and the system.

“A colleague of mine was pregnant at the same time as my daughter-in-law. My daughter-in-law is White, but her partner is Black, so some things occurred during the assessment and some things were said, that I thought no that can’t be right. So, I checked it out with my White colleague, and she didn’t have the same experience. She wasn’t asked ‘did you go to prison?’ or ‘did you take drugs?’ Is that a normal question? Because the White couple didn’t get asked those questions, but the mixed couple did.”

- Participant to the focus group #9

“I had the experience with my daughter, I could see that they were looking at my daughter and wondered ‘what is that?’ And I said, ‘it’s a Mongolian birthmark.’ And she obviously didn’t know and then she got the doctor, and I thought here we go... I know about safeguarding, so I am strong enough to challenge, but people who are not strong enough to challenge, this is where you know... we all have these experiences.”

- Participant to the focus group #8

“Just about the time when they are about to be discharged when they ask about their social... how they are going to be looked after when they are at home. It’s at the last minute that they realise that no, that person doesn’t have anybody at home. They need to be assessed early so they don’t all end up in hospital beds for months, while they could have gone home if the assessment was done early.”

- Participant to the focus group #7

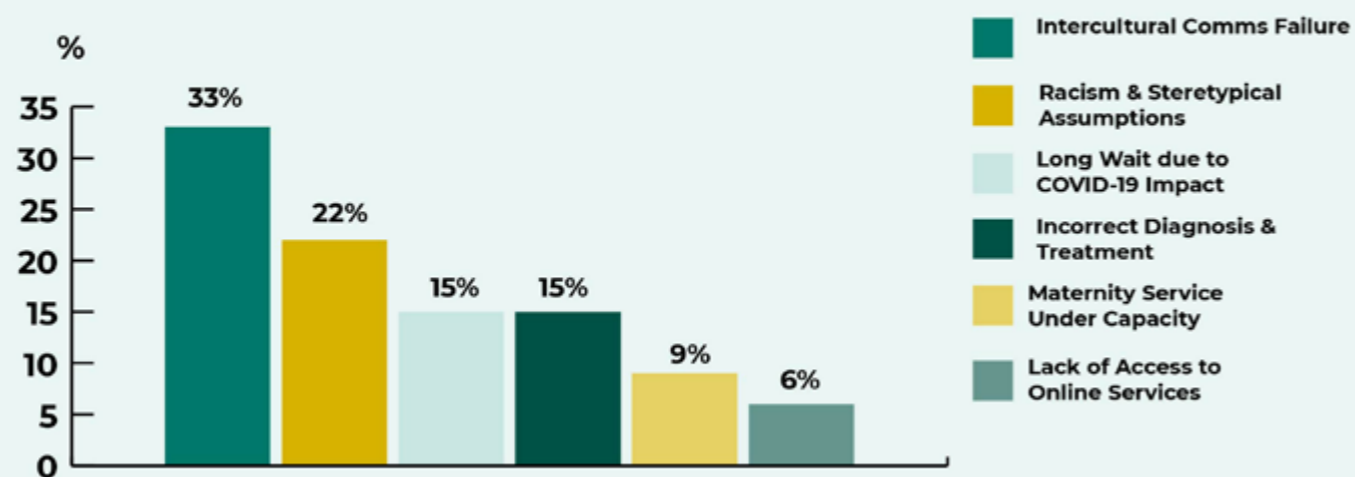
“Very often when you come from a culture like Black and Asian community you have people who know you, neighbours, friends who will come in and visit you and there is almost a biased professional assumption that you are going to be looked after when you go home, but nobody has that discharge planning in the early stages. And then when you are about to be discharged, it's identified that actually there isn't anybody at home. There shouldn't be an assumption that there is a care package already in place.”

– Participant to the focus group #3

“There is always this stereotype about how the Asians look after their own, the Chinese look after their own. That's alright in India, Pakistan, and those countries is like that. In England, they have to go out to work. The men are working all the hours that God sends. The women have little part-time jobs now. That's how they make things meet. They can't always be at home to look after their ageing mother and father. Some of them do work.”

- Interviewee #1

Figure 3 - Most Frequently Mentioned Issues in Health Care



As summarised in figure 3, from the evidence provided by the sample of people participating into this research, the health needs of Black and Minoritised communities in Gloucestershire are not being met primarily due to the following:

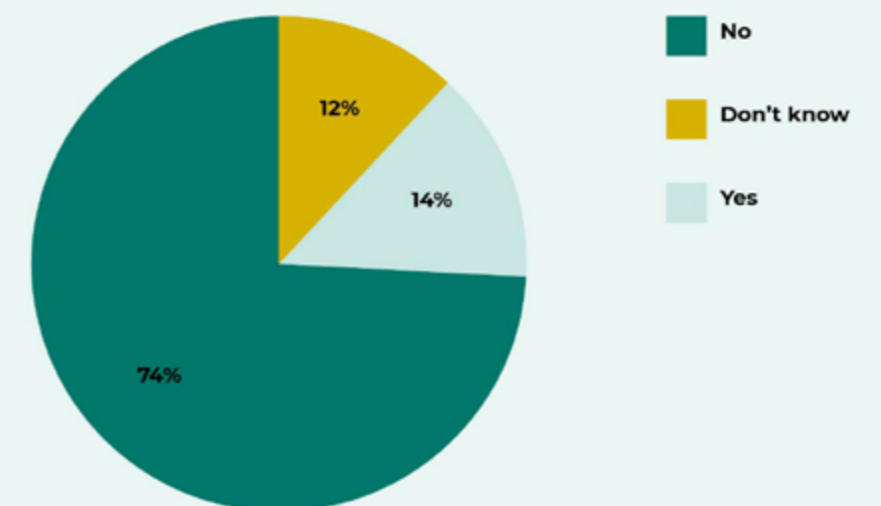
1. A systemic **intercultural communication failure** caused not only by the lack of access to competent interpreters, but more broadly by the system's failure to adapt to the diverse cultural backgrounds of service users.
2. Racism and **stereotypical assumptions** have been experienced across the sample by all communities engaged and resulted in growing distrust and lack of the sense of safety that should come with healthcare services.
3. Extremely long waits due to the **COVID-19 impact** on NHS services.
4. **Incorrect diagnosis and treatments** caused by the lack of specialised training and equipment to cater to Black and Minoritised individuals' needs.
5. Maternity services being extremely **under-capacitated** and therefore not delivering appropriate healthcare during Black and Asian women's childbirth stay in the hospital.
6. A **lack of access** to online services, particularly impacting older Black and Minoritised people.

Are the Social Care Needs Being Met?

When posed the question "Are the social care needs of your communities being met?", the vast majority 74% (31) of survey respondents stated "No"; 14% (6) replied "Yes", and the remaining 12% (5) ticked the "Don't know" option [see figure 4].

At a closer look, the situation is effectively worse than shown in the graph, out of the 6 people who answered that the social care needs are being met, only one person stated that they get the support they need from mainstream services, specifically through a sheltered scheme for disabled people. One person wrote that they get the social care support they need only because their family works in the social care sector and another two shared that they get appropriate support from community nurses and through community centres; the remaining two did not share any further comments.

Figure 4 - Are the Social Care Needs of Your Communities Being Met?



Intersectional Mental Health Support for Young People

Out of the 31 respondents who stated that their social care community needs are not being met, almost a third (10) has mentioned mental health as a priority area where the support is extremely delayed, it is often inadequate or not provided at all.

“The Gloucester counselling service has a waiting list that is too long. The initial assessment took two days but waiting for a caseworker took months. I was then offered an online service which was not suitable. I asked for bereavement counselling and - since they do not provide it, I was taken off the list. Counselling and advice support is just not being provided.”

- Respondent to the survey #2

It is important to note that 5 of the 10 mental health-related mentions are specifically regarding Black and Minoritised children and young people. Respondents found that considering the growing evidence that racially minoritised children are more likely to develop mental illnesses due to the pressure and trauma given by systemic racial inequalities (Abdi, F. M. and Sanders, M., 2022), the approach the public sector has to their mental health lacks early intervention and is not proactive enough.

Beyond mental health support, still in relation to the inadequate addressing of Black and Minoritised children’s needs are the experiences of two respondents who were looking for intersectional support for families with Black disabled children and stated that they have experienced lower access and quality of support services compared to White families.

“The information, advice, and support for people with disabled children is not provided. More specifically, it's hard to find support for Black families with children on the Autism spectrum. My son is big, and he has been stereotyped. The carers want to get him out of the room as quickly as possible. [...] having talked to other mothers I realise that White families are getting a different service. I almost feel like I have to use my son to forge improvements for other Black boys.”

- Respondent to the survey #5

“From personal experience, my son is on the autistic spectrum and was let down by the system. [...] In my son’s class there were 3 other children on the spectrum, and he was the only one excluded. Black children do not have access to the same care packages as White children. Having access to care plans, OT reports, diagnoses, I can see the difference between options given to young people from minoritised communities.”

- Respondent to the survey #22



Culturally Appropriate Social Care

The second most frequent theme (9 mentions) is the lack of culturally appropriate social care in nursing homes, hospitals, and residential care for older people from African Caribbean, Chinese and South Asian cultural backgrounds. The example cited more often is the lack of provision of culturally appropriate food, followed by the lack of specific training for carers to support personal hygiene routines (e.g., knowing how to correctly use products to wash a Black person's hair).

“The social care needs of our African Caribbean communities are not met, due to wrong matching between care and patients. Carers do not understand the cultural needs of African Caribbean individuals i.e., how to wash their hair or how to take care of their hygiene.”

- Respondent to the survey #3

“I have seen a Black resident in a care home unable to comb her hair and the staff are unable or unwilling to help.”

- Respondent to the survey #21

“When Black people are in nursing homes there is lack of cultural foods, the chef unable to cook culturally diverse food and personal care is a slap dash.”

- Respondent to the survey #11

This results in families having to take on caring responsibilities and tasks at extra financial costs such as making food daily and bringing it to the residential care homes or nursing homes.

An additional barrier cited multiple times in the sample are the logistics-related complications given by the family members often being hospitalised too far away from home, which puts additional pressure on the supporting network.

“People from our community... they put them in these hospitals which are miles away and many are not able to get transport to get there, so that's something that needs to be looked into.”

- Participant to the focus group #5

“Family members [were] sent to Cirencester and the family [was] unable to visit.”

- Respondent to the survey #16

The same problem was present in the qualitative sample when it comes to Muslim communities, with participants sharing how the nursing homes and hospitals were not equipped to prepare halal food and therefore the family had to take on the task of preparing meals and bringing them in daily.

“When he realised that he was being fed pork, he stopped eating. He completely stopped eating the food so it meant that every single day we would have to take his food in for him from home. It's a 60-mile road trip day in day out every single day weeks while he was being rehabilitated.”

- Interviewee #4





Lived Experience

Lack of Culturally Appropriate Food in Residential Care

“When my father was in residential care, we wanted him to have Caribbean meals and they couldn't sort it. I said the hospital can do it, why can't you buy off the hospital? Or better still why don't you send somebody to buy it from Caribbean shops?”

We were all working at the time, and we couldn't just do it [bringing in the Caribbean food] every day, even though weekends were fine. We found that if we made it and asked them to freeze it or put it in the fridge and warm it up, the next day it would be overheated in the microwave, it wasn't edible. There was a whole problem, they couldn't do it. They couldn't get it from the hospital because they couldn't commission it, and they couldn't send someone up to buy it.

But I kept pressing and pressing in the end they found a way to order it, but to be honest it was such poor quality, it was unhealthy, and he couldn't have it. If you know to advocate and push you will eventually get something, but the quality was poor, and they were so reluctant to change their system to accommodate. Unless we were willing to go every day in with the food, it was too much trouble to accommodate his cultural needs when their admission policies clearly said they will.”

- African Caribbean participant to the focus group

Quality of Life

Overall, there is a strong cross-cutting theme across social care and healthcare dimensions that mainstream services are failing to provide the necessary support to achieve a good quality of life for Black and racialised communities (7 mentions).

There were a couple of instances where end-of-life treatment was refused and there is a distinct conviction across the sample that the support for the growing number of people with dementia is severely lacking and not culturally appropriate.

Numerous are also the respondents who stated that they are not being given appropriate checks and treatments to achieve a healthy ageing process but simply being prescribed painkillers to keep the chronic pain at bay. It is important to note that this was also a key finding in the Commission to Review Race Relations report.

“And one of the things is the doctors don't listen to what the patients are saying, they were just giving him pain killers and the pain killers wasn't helping and when the pain killers stopped, he was still in this pain and they sent him home with a lot of pain, and then we found out that the pain killers had built up in his body and caused a blockage and he had to be readmitted in the hospital to have that sorted out.”

- Participant to the focus group #5

“How can we age healthily? For example, the diabetes treatment, how are you managing your diet if you got diabetes? Because all the information is generally towards White Europeans and their diet, and I know some places are starting to look at that, doing work around other dietary requirements for communities.”

- Participant to the focus group #9

Weakened Community Infrastructure

A second cross-cutting theme across social care and healthcare is the idea that racially minoritised communities' awareness around what the social and healthcare services have to offer is extremely low due to the weakened state of community infrastructure and networks that are no longer able to facilitate the dissemination of knowledge and information (6 mentions).

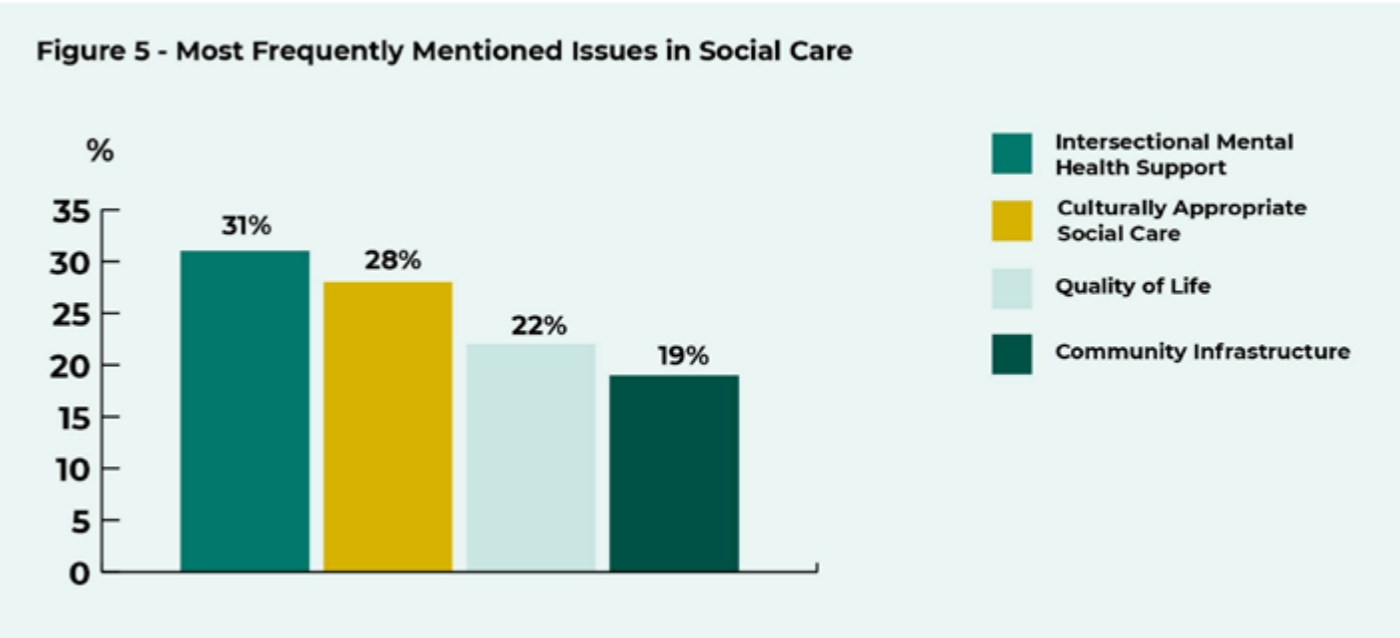
Historically, racially minoritised communities have relied on the presence of strong communities' networks and the voluntary sector to access opportunities and share knowledge. After the 2010 austerity policy, the anchor organisations, and key points of contact within the mainstream system – such as Linking Communities, the Community Development Team, the Black Mental Health Team and more – have either ceased their work or have been weakened significantly by funding cuts.

“If you know the language and you know who to contact you can access a service, if you don't know the language and you don't happen to be in a network when you can access somebody who knows how to negotiate themselves around the service, you don't get that service.”

- Participant to the focus group #3

“I think that's very clear, in the health and social care arena you need to know who and what to go to, and if you don't know that, then you can also be at disadvantage.”

- Participant to the focus group #4



It is safe to conclude that the participants providing evidence to this report strongly believe that the social care needs of racially minoritised communities in Gloucestershire are currently not being met by mainstream services.

This is mainly due to the following:

- 1. Intersectional mental health support** is severely lacking whilst being one of the priority needs within the Black and Minoritised communities, especially for young people and children.

- 2. Culturally appropriate social care** is needed to cater to the needs of racially minoritised older people and reduce the pressure on informal supporting networks and family members who are lacking capacity.

- 3. The quality of life** of Black and Minoritised communities in Gloucestershire could be significantly improved if social care services were providing more support for people with dementia and enhance access to end-of-life care.

4. **Infrastructure** in Gloucestershire specifically targeted to support racially minoritised people has been **weakened** by austerity funding cuts resulting in communities' reduced access to information and opportunities.

Demanding Action as a Collective Voice

Whilst the data provided on the current needs being unmet paints a grim picture of racial healthcare disparities in Gloucestershire, the same people who shared dissatisfactory – and sometimes traumatic - experiences with the current services have also ended their contribution on a hopeful note, recognising that there is a cultural shift happening in the county.

Partly driven by the Black Lives Matter movement and partly by the impact of COVID-19 exacerbating socio-economic and racial structural inequalities, the public sector and healthcare authorities in Gloucestershire have taken action to work together with the voluntary sector and Black and Minoritised communities to understand what transformative action would look like to truly address healthcare inequalities.

“There's something that we have to do ourselves and take the responsibility to drive that forward. I will continue to do the work to drive that forward. [...] Part of it, we have to take responsibility is about us coming together.”

- Participant to the focus group #9

“Recently, I've noticed a bit of a shift to be honest, a little bit of a shift very recently because of Black Lives Matter and we've had COVID. The impact of COVID has been massive on Black minority ethnic communities and I've lost loved ones and family members through COVID as well. It shone a really bad spotlight on just how bad things really are. [...] I do think also that I feel for the first time in I don't know how many years that there seems to be some genuine efforts being made now to try and improve and close these gaps and try to address some of these inequalities.”

- Interviewee #4

There was a strong recognition across all communities involved in the research, as well as representatives of the voluntary sector, and representatives from the healthcare authorities and the public sector authorities' sitting on the Steering group for this project that a **transformative and effective Gloucestershire's response to healthcare inequalities needs to be community-led.**

“Lot of that is our own responsibility as well – we have to stand up and say that we're not going to take it anymore – that we have to be proud of who we are, and stand up for what we've given, and seek the opportunities for ourselves as well.”

- Interviewee #2

“Together we will have a stronger voice.”

- Participant to the focus group #8

To achieve a space where Black and Minoritised communities can genuinely be enabled to take on action, the previously cited issue of a weakened community infrastructure needs to be addressed.

Therefore, the following section of the report will focus on the Black and Minoritised Voluntary and Community Sector (VCS) in Gloucestershire. It will provide examples of good practices and case studies that are currently happening within the voluntary space - despite its current very limited capacity - to demonstrate its potential in reducing racial healthcare systemic inequalities.

Furthermore, it will capture an overview of the sector's state, highlighting the areas where investment and capacity-building are needed for a strategic rebuilding of the sector to fully meet the healthcare needs of its communities.



About the Black & Minoritised VCS Sector

Solutions from the Sector

In the previous section of the report, evidence was shown that the healthcare and social care needs of Black and Minoritised communities in Gloucestershire are not being met due to a series of systemic barriers hindering communication and healthy engagement with mainstream services.

However, the evidence brought by this project shows that there was a model in the past that allowed for Black and Minoritised communities' specific needs to be catered for through the intermediary role of the Black and Minoritised VCS sector, bringing its specialised expertise to the table and bridging the gap between individuals and the system. Despite the reduced capacity, the sector is still playing this role to an extent as demonstrated by the following case studies.

Cross-Sectoral Expertise-Sharing to Bridge the Communication Divide

Being aware of the difficulties that older Jamaican individuals are facing when explaining their symptoms to the medical practitioners in Jamaican Patois rather than in British English, Ebony Community Carers hosted a session specifically to improve community members' communication skills and knowledge of body parts in British English.

This level of cultural specialisation in the support delivery is only possible when the members of communities who are directly affected by the issue step forward to design and customise the type of support. In this sense, the Black and Minoritised VCS Sector has a central role in providing the infrastructure and connections needed for the delivery to be successful, but also in providing a safe space for community members to discuss their cultural needs.

The expertise-sharing role of the sector follows a two-pronged approach where the knowledge is not simply disseminated among communities, but also vice versa from communities to the health and social care authorities.

“We did a training session with an ex-nurse at Ebony. Language and vocabulary are another issue. It’s not about being able to speak English but being able to speak the vocabulary of the health authority. This particular training session was about understanding their vocabulary so when we say, ‘doctor, this is hurting or that is hurting, I’ve got a pain here, this isn’t right’, we could say to them what the actual area was. If we say we’ve got a pain in our belly. As you know, the belly is split into two places, the abdomen, and the stomach, so which part is it? That’s what it was about.”

- Interviewee #1

A few VCS representatives have shared clear evidence of the effectiveness of this model, for example sharing instances where medical practitioners have demonstrated to have absorbed the knowledge and implemented it in their practices with racially minoritised people, and even one case of a successful system-change from culturally biased practices to a more inclusive approach to assess dementia in Black and Minoritised communities.

“We’ve set up a Walk in my Shoes (WIMS) programme to work with the directors of the NHS to help. The question to you for what you’ve asked is that there is still a breakdown or ignorance in the sense of communication with cultures, I think it is still there. We are working on that.”

- Interviewee #5

“You’re constantly working with new social workers who don’t know [about Black and Minoritised people’s needs], you’re constantly training them. [...] You could see in his face: ‘I don’t know what the point of this meeting is, but we’ll go along with it’ and by the end of the meeting he said, ‘oh this is quite useful, I’ve learned quite a lot this morning, maybe we should do this more often’.

- Interviewee #6

“They asked me to deliver training to wider managing memory services. So, I deliver training to dementia leads and people working within memory services on how to improve working within cultural competence and working with patients and carers from Black minority ethnic communities. [...]”

- Interviewee #4





Case Study

Fixing Cultural Biases in Dementia Screening Assessment

“As a result of experiences that I’ve had that I’ve shared with colleagues we’ve been able to change the way in which assessments were undertaken for people that experience memory problems.”

What was happening was that again there were quite high levels of dementia within Black minority ethnic communities but the screening tools that were being used by professionals were not picking this up. People were presenting to GPs, because that is the first point of call, with experiencing memory problems and the dementia screening that they were doing was very Eurocentric and it wasn’t working. The memory assessment testing that they were doing and talking to people about things that would be part of normal life within an English family or somebody living

in England, these questions were being rolled out and being asked of people from Black minority ethnic communities and they just weren’t working.

We have successfully managed to change the way in which screening is done in the county and another tool has been launched and it is used widely now which means that people are going to be able to be screened more effectively at a much earlier stage. That has been a really positive outcome of some of the work that I’ve been able to do. It’s not just myself but my team as well. It’s something that I’ve been really passionate about.”

- Community-led activist group

Culturally Appropriate, Flexible and Personalised Support

The smaller and flexible structure of VCS organisations is a point of strength when providing to people who are at higher risk of developing long-term conditions and complex needs. Thanks to its flexibility, the VCS Sector also provides the best type of infrastructure support and channels when there is need of developing quick responses to emergencies. This was shown across the South West region and more specifically in Gloucestershire during the COVID-19 response.

“We shouldn’t forget that actually [during COVID-19 emergency response] you did better with the small organisations who were in the neighbourhoods and working with their own communities – that worked. And that Gloucestershire was able to respond very quickly and get support out really quickly rather than waiting for government to tell you what to do. So, I think that’s one of the absolute strengths and I’d like to see that encouraged and continue.”

- Interviewee 6

Whilst we approach an uncertain future that is likely to bring more and more emergencies due to climate change and global socio-economic and political instability, the VCS Sector and grassroots community groups - which have the quickest ways to mobilise fast and effective responses to communities' needs - become even more valuable.

The same flexibility is shown by the VCS Sector also when offering personalised support to the communities. The many elements that make up each individual's identity, their personal situation and their complex needs are often overlooked at least in part by the mainstream services that don't have capacity to customise approaches to the individual due to being the central point of support for millions of people across the country. On the contrary, community organisations are born out of a specific grassroot purpose and develop around it, bringing to the table a different but complementary model.

“[The mainstream service] wouldn’t work with us because they have very strict rules in the sense of you have to have a diagnosis of dementia before you can join. We’ve got somebody who has got a head injury. He hasn’t got dementia, but he has a head injury and therefore causes some memory problem, some memory loss. Another lady, she has epilepsy. Every time you have an epilepsy fit some bits of your brain cells deteriorate so we welcome people like this and anybody that was just concerned about their memory. We would say you haven’t got a diagnosis but come.”

- Interviewee 7

Finally, there is no denying that the culturally appropriate support delivered by the Black and Minoritised community organisations is better positioned to navigate through intercultural barriers and potentially break through culture-related obstacles (e.g., the stigma and/or lower levels of awareness around mental health).

“I have come across so many people with dementia. As a result of that, I did some training and a group of us had to volunteer really to support people with dementia, because there was nothing out there to support people, because what they failed to understand that people don't even know what dementia is in the community or mental health, they don't understand it. So, there should be some training on awareness on how people understand these illnesses and I believe it deeply when they speak somebody from the community, they need to listen to what they are saying, understand them and not just prescribing medication for them.”

- Participant to the focus group #6

Providing a Safe Space for Cultural Expression & Feedback

By virtue of playing its role between communities and the public authorities, the VCS Sector is in the best strategic position to enable the monitoring and correction of biased practices.

It directly responds to the central need raised in the original visioning session discussion that kickstarted this project; a need for safe spaces for cultural expression and for openly discussing diverse cultural health and care needs.

Strengthening this type of infrastructure will automatically strengthen the power of communities' voices by providing safe platforms to speak. This is true for all members of community including Black and Minoritised practitioners who are often witnessing the consequences of racial systemic bias within their workplace but are not confident enough to voice their concerns for fear of retribution.

"The Black people within the NHS, need to stand up and say, 'no, this won't work in our community', but they must be able to do it from a point where they have no fear of retaliation.”

- Interviewee #1



Case Study

Gloucester FM, A Safe Platform for Information-Exchange

“What we try and do is get councillors in and doctors, nurses, public health people to give information. But at the same time, you can ring in, text in, email in and ask a question and you don’t have to give your name.

So, they’ve got that feeling of safety, that they can ask what they want if they want. But at the other side of it, we’re getting information out to people even the benefits, what benefits are there? So, that’s where GFM comes into it, and we are also highlighting what voluntary groups are out there.”

- Gloucester FM Representative

Rebuilding the Sector

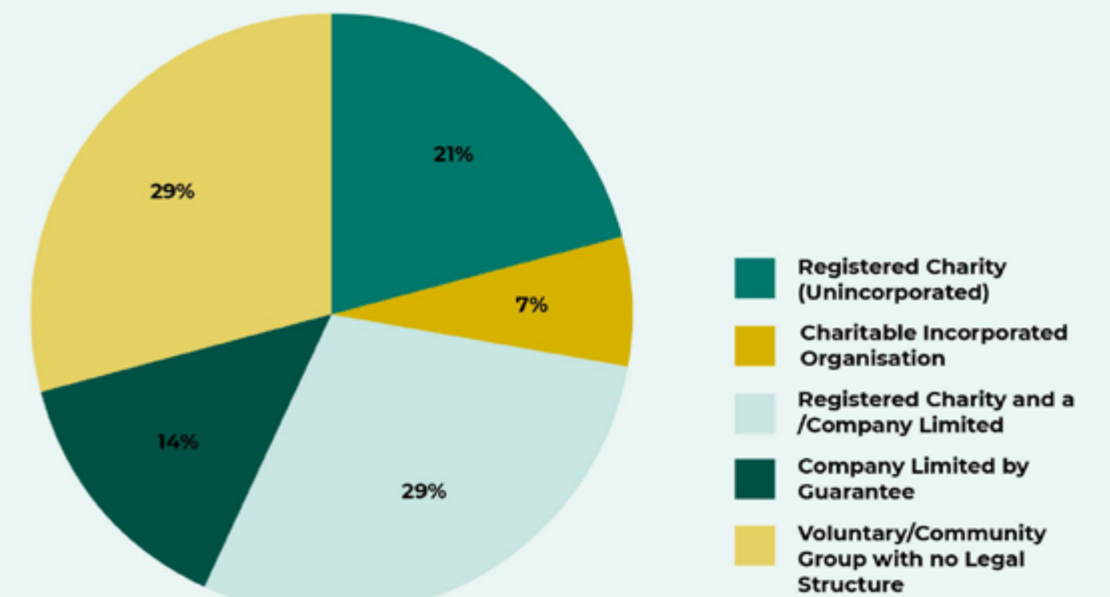
“What we have to do is rebuild from within. So, we have to take the opportunity and go, ‘Actually, what is it that we want?’ and we have to build that for ourselves regardless of the external kind of pressures that are coming in, so we need the time and space to be able to do that, and the ‘Interact’ and say, ‘Well, actually, this is what it looks like, and this is what’s missing, and this is what we need.’”

- Interviewee #2

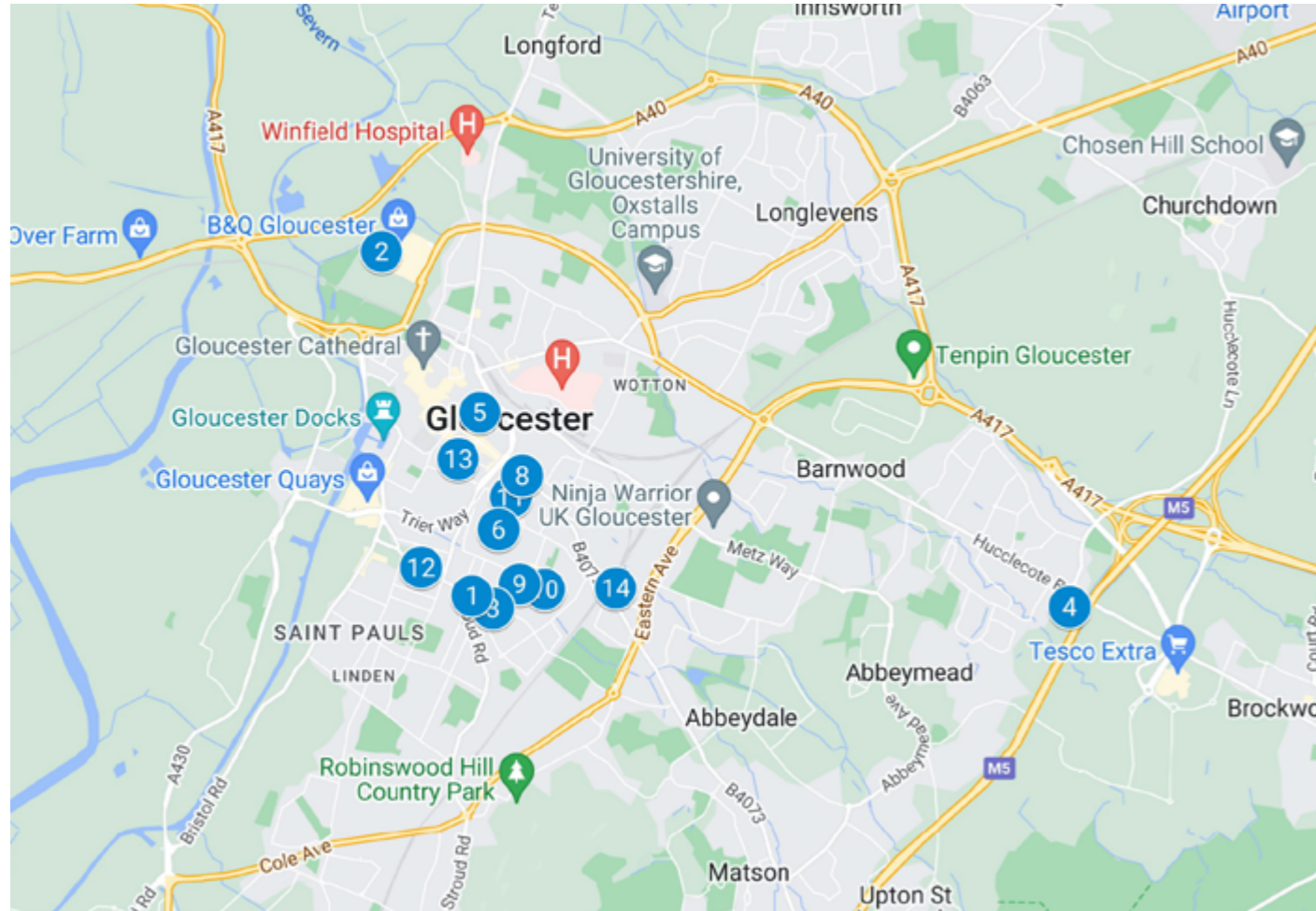
Make-up of the Sample, Outreach & Representation

Out of the 14 voluntary and community organisations that responded to the survey, the majority are either registered charities and a company limited by guarantee (29%) or voluntary and/or community groups with no legal structure (29%). 21% of the sample are registered as charities but unincorporated and 14% are legally registered as companies limited by guarantee. The remaining 7% are charitable incorporated organisations [see figure 6].

Figure 6 - VCS Sector Make-up by Legal Structure

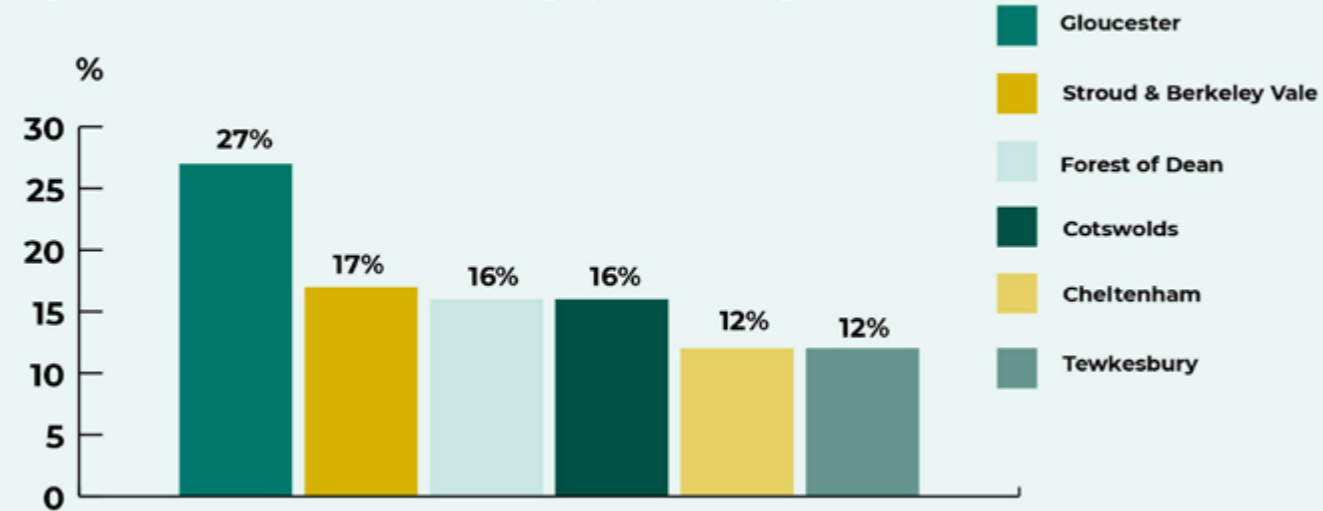


Looking at the geographic distribution of the sample, most respondents are physically based in Gloucester. It is important to note that the representation in this sample is not comprehensive of the entire VCS sector in Gloucestershire. The data collected by the survey is affected by the limited capacity of the project. The qualitative sample includes mentions of further unincorporated Black and Minoritised community groups who are active across the Forest of Dean and Cheltenham, and possibly more areas. However, it is safe to say that the most active ward remains Gloucester.



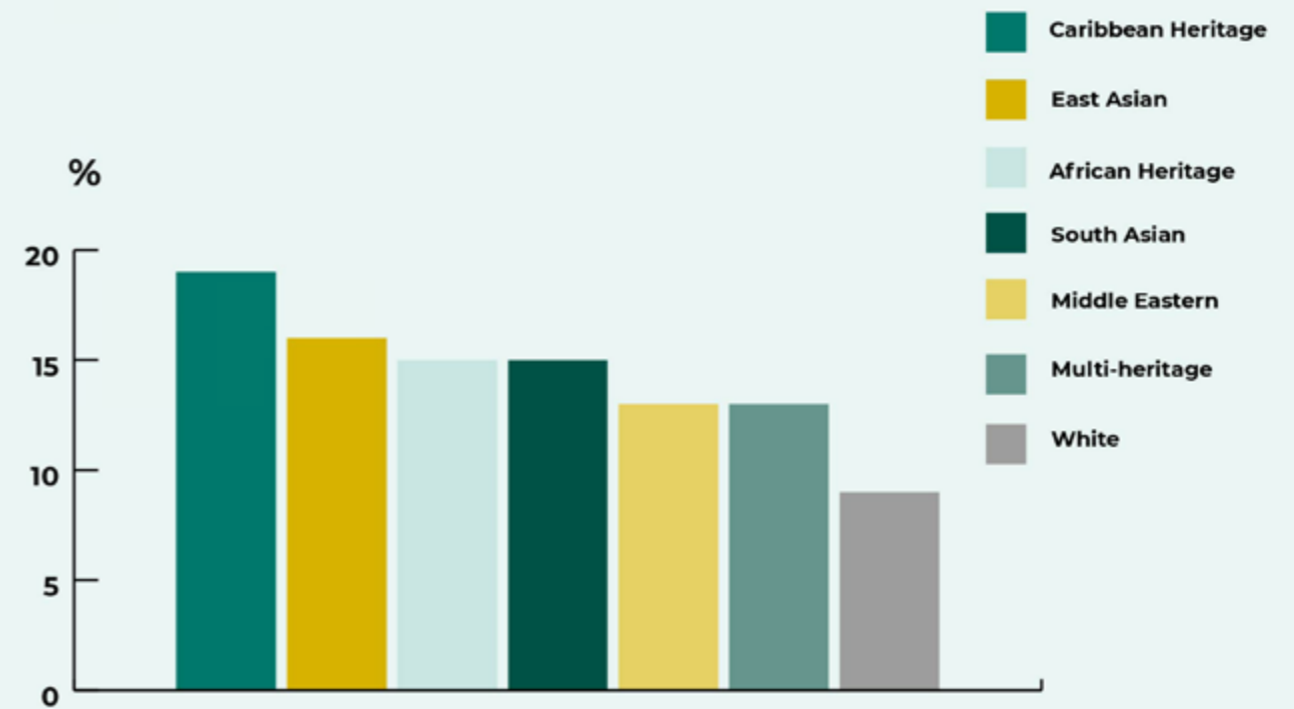
Unsurprisingly, the geographical outreach of the sample is slightly unbalanced with a better coverage in Gloucester (27%) and the worst coverage levels in Cheltenham (12%) and Tewkesbury (12%) [figure 7]. More specifically, 5 organisations out of 14 have a county-wide outreach when it comes to their services, 3 have shared that they cover two or more wards, and one has a worldwide outreach thanks to its online delivery. The remaining 5 are only working in Gloucester.

Figure 7 - What is the VCS Sector Geographical Coverage?



When looking at their coverage by ethnic communities, there is a noticeable predominance of focus on serving African Caribbean communities (19%). Right after, East Asians (16%) are the second most served community by this sample. Logically, the least served ethnic group is White people (9%), given by the fact that this project actively focused on targeting organisations that provide for Black and Minoritised communities [Figure 8]. Still, 6 organisations – half of which are faith-led groups - stated that their services are open to all communities. 3 have stated that their only focus is on African Caribbean individuals, 1 only focuses on Chinese, 3 deliver for all racially minoritised people, and the last one has a mixed focus on African Caribbean, all Asian groups, and Polish people.

Figure 8 - What is the VCS Sector Coverage by Ethnic Communities?

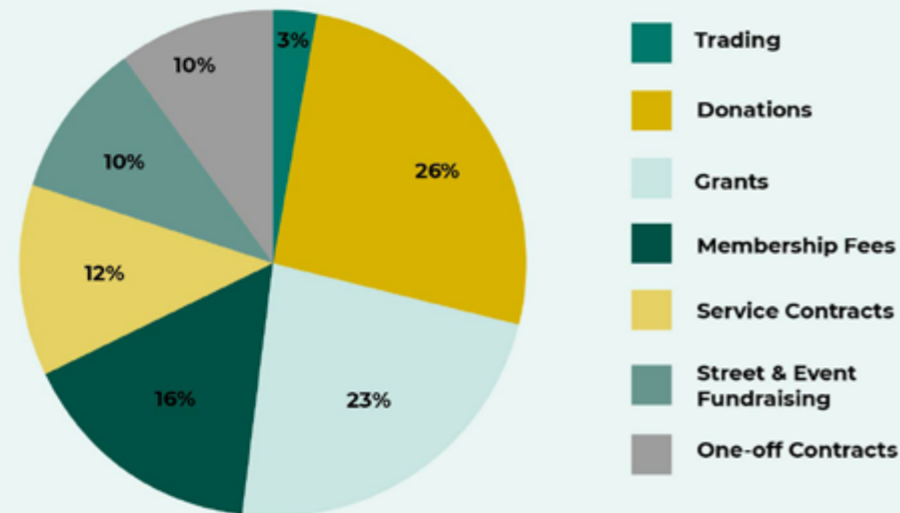


The sample shows a clear imbalance in terms of leadership, with 6 organisations being led by African Caribbean groups; another 6 being led by a combination of all communities, 1 led by East Asian people and 1 led by various minoritised communities. Once again, it is important to note that there are multiple active groups in the county that the survey has failed to engage. The research team actively tried to target South Asian led organisations to contribute to the survey. However, due to lack of capacity most groups contacted were unable to engage. Fortunately, the qualitative sample has good South Asian representation for this project, making up in part for the imbalances present in the survey.

Financial Sustainability & Long-term Capacity

As evident from figure 9, the sample's sources of income are varied, ranging from membership fees (16%) to service contracts (12%), one-off contracts (10%) and street and event fundraising (10%). However, the organisations surveyed still shows **low levels of financial sustainability** given by their high reliance on donations (26%) and grants (23%) and the extremely low percentage of trading (3%). To some extent, these results are to be expected considering the high number of churches and faith-led groups in the sample.

Figure 9 - How is the VCS Sector Funded?

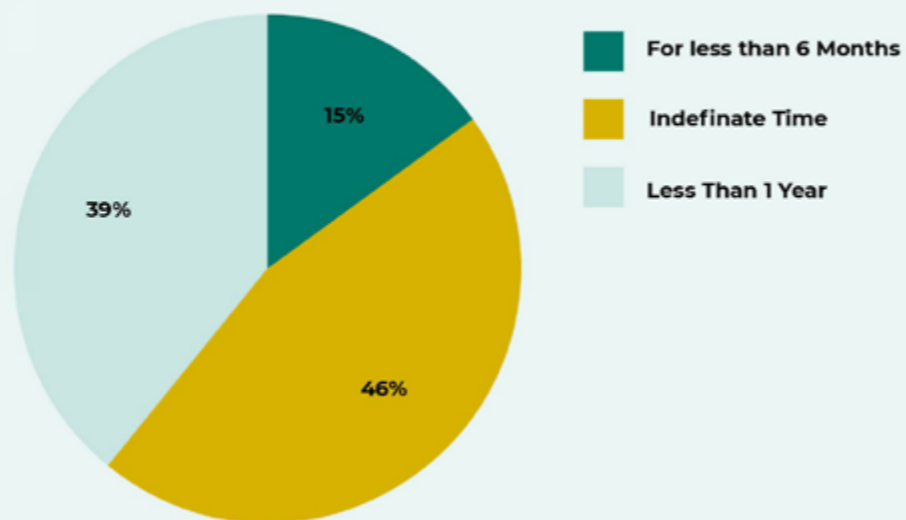


When questioned about the most common barriers in applying for funding, the complexity of funding applications was mentioned 4 times, with one respondent specifically mentioning that they lack expertise on writing funding bids. A general lack of capacity was also stated as common cause for not applying. This is not surprising considering that **50% (7) of the sample does not employ paid staff** at all and therefore would have to rely on volunteers to manage their funds.

There is an overall tendency to apply for smaller amount of funds, because they are perceived are more attainable. However, two people expressed their **frustration with short-term funding** that does not leave room to plan for the longer term. 3 people also mentioned that they face challenges in accessing information on funding sources and 3 more have stated that there is not enough funding targeting their specific areas of work.

When selecting options for average annual income, **almost half (43%)** of the organisations stated that they are **earning below £15,000**. None of the organisations owns assets apart from the churches. However, on a positive note, 93% have reserves or savings to fall back on.

Figure 10 - VCS Sector Financial Stability



Lastly, when posed the question; "In your current financial situation, for how long can you keep operating?", only 46% (6) replied that they will be able to work indefinitely – therefore implying that they are fully financially sustainable -, whilst 39% (5) stated that they will be able to continue for less than a year and 15% (2) selected 'for less than 6 months' [Figure 10].

Engagement with Mainstream Health & Social Care Services

The final objective of the survey was to assess the level of engagement that the Black and Minoritised VCS sector has with the county authorities and mainstream health services. 57% (8) of sample respondents successfully engaged with mainstream services. More specifically, out of these 8, 4 organisations were satisfied with their engagement with Gloucestershire County Council and 4 others were happy with their engagement with the NHS. However, one of them mentioned that the time invested to build a proper relationship with the system was over 10 year-long.

“It took a long time, over 10 years, to build up credibility and proof of service enough to be able to engage successfully with the system.”

– Organisation responding to the survey #6

2 organisations have not tried to engage so far as they do not see the necessity to do so.

The remaining 4 have had less satisfactory experiences. 2 of them tried to engage and have been asked to contribute more by local authorities. However, they are unable to comply due to lack of capacity; in terms of financial resources and time.

“Working with health authority and Council but not delivering services. They are asking for more input but difficult currently without the resources. Lacking capacity.”

– Organisation responding to the survey #8

A third organisation was unhappy with the small pots of one-off funding that are not enough to build organisations' capacity, and specifically criticised institutions' lack of awareness when working with racially minoritised communities, citing power imbalances during the engagement.

“Institutions don’t have enough awareness to work with minoritised communities, they tell us rather than asking.”

– Organisation responding to the survey #3

The final organisation did not provide any explanation for their discontent.

The data provided by the survey is also supported by the qualitative evidence of this project in demonstrating that the sector is in high need of an equitable and strategic rebuilding across three fundamental priority areas:

1. Financial Sustainability & Capacity-Building (e.g., core funding, owning assets, paid staff etc.)

“Voluntary organisations need the support of the local authority from the core funding element, so they can say, ‘Right, we can at least fund one part-time assistant,’ knowing that person will be there to answer the phone, do the basics, write application forms – and, in Gloucester, it was seen as almost paramount to their moving forward.”

– Interviewee #3

“They say over and over again, ‘we just barely get through the day just surviving. We do not have the capacity to take on anything else.’ At the same, we all know that there is a huge need so how do we work through this?”

- Interviewee #4

“All in all, there wasn’t that many [Black and Minoritised voluntary organisations] but because of capacity issues, they required initial, I would say, serious funding. [...] All those groups needed major funding just to get them started, just to be able to buy the expertise to support themselves.”

- Interviewee #1

2) Community Infrastructure Building (i.e., enhancing each racially minoritised community's access to accessible information, and culturally appropriate and tailored support.)

“When it comes to meeting the needs of people that come from minority communities, what commissioners tend to do is they commission services that are for the majority population, and anything in relation to minority communities tends to be an add-on a bolt-on, which invariably is inappropriate.”

- Interviewee #9

“There are now conversations around perhaps putting together community research, like a participatory project, so people in the communities undertake their own research. So, I facilitated a meeting last week with the community group to see whether it is something that the groups want to do, but unfortunately in Gloucester in particular we have really poor infrastructure.”

- Interviewee #4

“We’ve had years and years of neglect and no effort has been made to join up communities, join up the resources, to empower the communities, to invest in the communities. [What is already available] doesn’t really represent Black and minority ethnic communities.”

- Interviewee #5

3) Building Mechanisms to Channel Black and Minoritised Communities’ Voices for Advocacy Purposes (i.e., improving opportunities for communities’ voices to be meaningfully included by the system, and contribute to the design of services.)

Since one of the sub-objectives of this research project was to investigate how to enhance the Black and Minoritised voluntary sector and communities’ leverage across mainstream decision-making spaces, the third point will be explored more in-depth in the following section.

More specifically, the next part will focus on the recommendation proposed in the Commission to Review Race Relations report of “establishing an independent, permanent, funded, and high-profile legacy institution for Gloucestershire.” (2021). According to the Commission report, this organisation’s functions should include:

1. The development of a dynamic, diverse, independent, and strong, Black-led VCS and civil society sector.
2. Monitoring the implementation of equalities policies and commitments, including the Calls to Action of the Race Commission, and of public bodies.
3. Providing advice, information, and advocacy.
4. Contributing to public sector policy development and the commissioning of services.
5. Providing a strong voice for, and raising the profile of, diversity through communication and celebration to ensure that racially minoritised communities feel ‘at home’ in their City and County.
6. Leading on the development of a shared terminology across Gloucestershire

It is important to note that most of these points have already been explored and vastly supported by the evidence collected in this research.

The report's mid-section is entirely dedicated to offering evidence of a necessary rebuilding of the Black and Minoritised VCS sector's and racially minoritised community-led infrastructure across the county.

The third point was also discussed in the first section of the report, as it is evident that racially minoritised communities do not have equitable access to appropriate advice and information on what is currently available for them.

In relation to point 4, in the "Solutions from the Sector" section, evidence was provided on how the VCS sector is already spontaneously contributing to improving the inclusivity of systems.

The report will now take the space to expand on the remaining points which focus on the advocacy function and the connecting role of the legacy institution, being the channel through which the strong voices of racially minoritised communities come together to demand systemic change.

What Would the 'Legacy Institution' Look Like?

The researcher included a direct question in its qualitative questionnaire to collect opinions and perspectives on the Legacy Institution. Across the varied sample of participants, there was unanimous agreement that a central interconnecting organisation is needed. Many mentioned previously existing organisations that were successful in the past, providing examples of what had worked.

"It's needed because you need an organisation that is at the centre."

- Interviewee #3

"Yes, there is a need for a qualitative organisation like Linking Communities that can address the race issues and can address the young people issues."

- Interviewee #1

"Yes, it is definitely needed. I think reflecting on what was there before and looking at what was achieved and putting all the positives together and putting that together would be nice [...]. You would definitely need something, so that there is more support out there."

- Interviewee #5

More specifically, the request was for a central hub-type organisation that has specialised expertise in racial systemic inequality and connects different racially minoritised communities in need. However, at the same time, it supports the setting up of new single community-focused organisations, because it understands the value in diversified and culturally appropriate provision.

For this model to work – having a central organisation that the other specific community-focused organisations can use for pivotal reference – the make-up of the organisation's leadership should be representative of all the local racially minoritised communities and implement a distinctive community-led approach to its modus operandi. One example was given by a participant who worked for Linking Communities who expanded on why their representation model worked in making many racially minoritised communities feel like they belonged to the organisation's space.

"I think this kind of structure would have to be definitely like you said, community-led, and it has to be bottom-up approach. That would then open a few more doors for people to feel comfortable in coming forward."

- Interviewee #5

"Our board was made up from the community, so we had a percentage of Asian, we only had one Chinese lady and then the rest were Afro-Caribbean. I think at the time our board was about 23. It was quite a big board. [...] When we had our AGMs, we always used to have some sort of a cultural activity. We always had food representation from the three main communities, always. That was our principle. They were very well attended."

- Interviewee #1

Another recurring point in order to build a truly representative and inclusive organisation, was the intentional approach to include the contribution of faith-based communities, (i.e., churches and mosques).

"And it can work really well, especially if we involve say, places of worship for example the three local mosques in the city, they are places that are frequented by worshippers."

- Interviewee #9

"I think we need to maybe pay a bit more attention to the 'Black' churches, there's a lot of expertise there, there's possibility of funding there, and there's connectivity there."

- Interviewee #3

The role of the centralised organisation is not limited to supporting the development of the Black and Minoritised VCS sector and its communities' strong collective voice, but it is also a mechanism to channel their voices towards mainstream institutions' decision-making spaces. In this sense, it connects Black and Minoritised people with the system, by disseminating information on how to navigate the system, but also celebrating diversity and promoting the Black and Minoritised VCS sector's successes to mainstream spaces, and finally for advocacy purposes.

The model described by participants for setting up a successful 'legacy institution' can be represented figuratively as a tree, where the roots are compared to the frontline organisations and grassroots community groups reaching individual communities with diversified and culturally appropriate provision. The trunk is the legacy Institution bringing the different parts of the roots together into one strong collective voice, which ultimately feeds into the branches where the public and health authorities are, influencing their work and contributing to the codesign of policy and services. As this imagery shows, there is no "flourishing" of good service provision without strong roots stabilising the tree within communities.



Lastly, the 'Legacy Institution' will need to show leadership and provide coordination for communities to come together and remain focused on achieving transformative change.

“You’re the drive, that’s the thing, isn’t it? You’re the drive that keeps bringing it, there’s got to be somebody that’s got the energy to keep bringing people back to the same room and it’s that person [or organisation] I believe.”

– Interviewee #7



**Case Study
The Gloucestershire Race Equality Action Group (GREAG)**

A long-standing gap in Gloucestershire’s VCS representation of Black and Minoritised communities has been recognised by communities, the voluntary sector, infrastructure bodies and institutional stakeholders.

In order to address the systemic challenges of structural racism, lack of capacity and under-investment – which have been exacerbated by Covid-19 and the global economic and energy crises – the Gloucestershire Race Equality Action Group (GREAG) has emerged.

GREAG is born out of a community-led effort in which the Black and minoritised-led sector can authentically create a meaningful space for local organisations to organise, engage and develop strategies for racial justice. It is also a platform through which to engage with stakeholders, including policy makers, decision-makers, and funders amongst them.

The Potential of Integrated Care Systems

Part of the project's objectives was to understand what potential Integrated Care Systems (ICSs) could have in improving health and social care outcomes for racially minoritised communities. And additionally, what role could the Black and Minoritised sector play within the ICSs partnership.

The NHS England website provides the definition for 'Integrated Care' as follows:

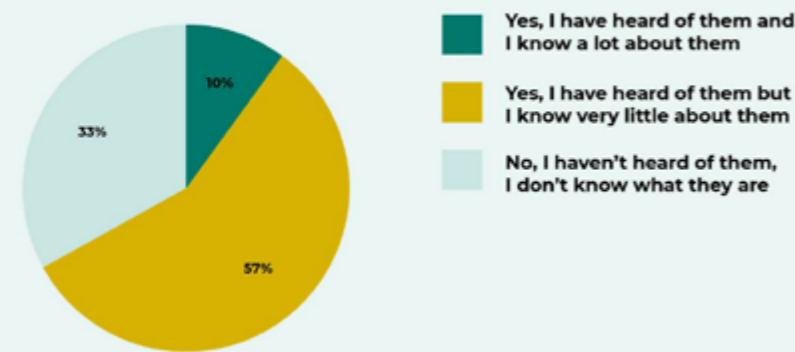
"Integrated care is about giving people the support they need, joined up across local councils, the NHS, and other partners. It removes traditional divisions between hospitals and family doctors, between physical and mental health, and between NHS and council services. In the past, these divisions have meant that too many people experienced disjointed care."

'Integrated Care Systems' (ICSs) therefore are defined as:

"... new partnerships between the organisations that meet health and care needs across an area, to coordinate services and to plan in a way that improves population health and reduces inequalities between different groups."

Overall, integrated care is deemed successful if it contributes to better care experiences; improves care outcomes; delivers more cost-effective care; and reaches groups facing systemic care inequalities. In this sense, it would seem logical to conclude that this is an approach with great potential for Black and Minoritised communities who face the consequences of disproportionate levels of racial systemic healthcare inequalities and – as evidenced earlier in the report – are more likely to need holistic, personalised care. However, the research has also provided evidence of potential barriers as well as potential benefits of an ICSs implementation.

Figure 11 - Awareness of Intergrated Care Systems



The first barrier identified is the low levels of awareness around ICSs. In fact, only 10% (4) of the entire survey sample felt confident that they knew what ICSs were and did not need any further information on them. 33% (14) stated that they had never heard of them and do not know what they are at all.

The remaining 24 people – which equals to more than half of the sample (57%) – stated that they have heard of ICSs, however they knew very little about them [Figure 11].

An interesting detail to point out, is that all respondents from the VCS sector sample replied that they somehow knew about ICSs, except three respondents who were representatives of churches. The level of awareness among people engaging with the VCS sector is noticeably higher when compared to the rest of the sample. In this sense, it is fair to say that the Black and Minoritised VCS sector is already playing a role in increasing awareness among communities.

When looking at the qualitative sample, there is a similar pattern, where people who are engaging with health and public bodies either through their profession or through organisations have a much higher level of awareness compared to the average community member. However, the most common answer by far, remains:

"I have heard of it, but I don't know a lot."
 - Respondent to the survey #5

Another barrier identified, was the concerns of community members around privacy issues that might stem from sharing access to medical records across different bodies.

"I believe there is a discussion around privacy."
 - Respondent to the survey #3

Another concern is in relation to the standardisation process required for such a system to be put in place, as Black and Minoritised communities have historically suffered from having to 'fit into boxes' provided by the system and therefore not accessing services that are appropriate for them.

"Not sure it covers people from different backgrounds."
 - Organisation responding to the survey #10

"They can't pigeonhole people."
 - Organisation responding to the survey #3

Regarding positives, among the people who were confident in knowing what ICSs is, there was a general sentiment of hopefulness and positivity around the potential that ICSs might have in increasing inclusivity and access of health and social care services for racially minoritised communities.

"Lots of potential in terms of vision, implementation, and Inclusivity." – Organisation responding to the survey #5

“There is a lot of potential.”

– Respondent to the survey #17

In addition, a few people have mentioned that ICSs might be successful not only in increasing access but also in providing better quality of care through the higher degree of personalisation of services, and they were supportive of the idea that ICSs would be designed to centre people’s needs at the heart of delivery.

“Good idea, if it works because joint working will be more effective in terms of personalisation.”

– Respondent to the survey #23

“We really need to rethink social care to be designed around people's needs.”

– Respondent to the survey #3

Finally, another positive aspect mentioned was directly in relation to the Black and Minoritised VCS voluntary sector and the impact that ICSs might have on it, decreasing competition and silo work, as well as improving the overall ecosystem by ameliorating information-sharing across different bodies. Overall, there is agreement that the Black and Minoritised VCS sector has a central role to play in ensuring that the ICSs implementation is equitable and inclusive.



Recommendations

As evidenced by this report, the recommended way forward is:

1. To meaningfully invest in the capacity-building of the Black and Minoritised VCS sector with particular attention to its financial sustainability, i.e., long-term types of funding and investment to cover the organisations' core costs.
2. To build viable mechanisms to channel Black and Minoritised communities' voices for advocacy purposes. For instance, by supporting the establishment of a central organisation (or 'legacy institution) that will:
 - i. Be a central point of support for developing old and new Black and Minoritised organisations to fill in the gaps in the current infrastructure and ensure that all communities are accessing tailored and culturally appropriate support.
 - ii. Be a central point of contact for increasing Black and Minoritised communities' access to information on how to navigate the system and access opportunities
 - iii. Channel the strong voices of racially minoritised communities and individuals towards mainstream decision-making spaces, influencing policy and services design.
3. To build communities' capacity and willingness to take on community-led opportunities in healthcare research, evaluation & monitoring programmes, by implementing participatory methodology, which compensates adequately the members of community for their input into Research & Innovation and involves them in all stages of knowledge-production, and especially in the practical outcomes of the research.
4. To directly challenge the hyper-localised predominant cultural narrative in Gloucestershire that hinders both individuals' expression and the development of wider community cohesion. This can be achieved by creating safe spaces for individuals to express their cultural diversity and openly discuss their cultural needs, as well as openly promoting and celebrating the value of the county's diversity.
5. To locate the Black and Minoritised VCS sector at the centre of ICSs implementation and design.

Several participants shared a sense of fear at the idea that this momentum to tackle racial healthcare inequalities might fade like it happened many other times before, and the actions implemented would not bring any real system-change.

What differentiates the actions undertaken in recent times from previous instances is that genuine Black and minoritised community leadership is driving the current approach. In this unique landscape, Gloucestershire has a real opportunity to test new dynamics for a bottom-up rebuilding of social fabric; it has a real opportunity to truly bring transformative change to the system. As one of the participants would say, Gloucestershire has all the tools in place now to start a 'revolution'.

“We need a revolution. We’ve tried the evolution process, which hasn't worked, we need a revolution now.”

– Interviewee #9

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