Exploring the disparity of Covid-19 with the Crawley BAME Community

West Sussex
(North, South, East)

August 2020

For everyone, for 80 years

We are Citizens Advice

We can all face problems which seem complicated or intimidating. At Citizens Advice, we believe no one should face these problems without good quality independent advice.

Our goal is to provide free, independent, confidential and impartial **advice to everyone** on their rights and responsibilities, so they can move forward and thrive.

We want every voice to be heard and to improve the policies and practices that affect people's lives.

Citizens Advice in West Sussex (North, South, East) is an independent local charity, a member of the Citizens Advice Network.

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"What 3 things will you do to make a difference; in the short, medium and long term?"

Member of the community

We are grateful for the support of Crawley residents in sharing their stories so openly. For the support of local community groups, the District Council, Public Health West Sussex, GP practices and others who helped to facilitate this important piece of community engagement. Including our friends at Diverse Crawley, Gatwick Detainees Welfare Group, Refugees Welcome Crawley and the Sangam Womens Group.

Executive Summary

The coronavirus pandemic has had a devastating impact across society, but the disparity of Covid-19 for the BAME community revisits the upstream links and wider socio economic determinants for health outcomes [i]. This is an opportunity to build on existing work and to achieve real change.

The recent Runnymede Trust report [ii] identified 1 in 20 (5%) BAME people having been hospitalised with the virus, compared with 1 in 100 (1%) white people. It is vital we all work together to find solutions. This piece , funded by Sussex Partnership NHS Foundation, reinforced much of what we know. Through the Crawley BAME community these are framed in a local context with community led solutions which may reduce disparity of Covid-19.

Some members of the BAME community expressed frustration at more research with little evidence of change.

We must all play our part in taking up the challenge set for us to bring about real step change.

Crawley is the most diverse area in West Sussex, with 20.1% of people identifying as non-white. But the BAME population itself is diverse this will present different lived experiences.

Interventions cannot be generic; instead we must recognise what is common across groups while treating people as individuals and finding local solutions.

Early on, the relevance of the local context could be seen. For example, whilst having high Covid-19 incidence for West Sussex, Crawley was still lower than the average in England. This means many people did not have direct experience of Covid-19. Other factors include the proximity of Crawley to London, the impact of Gatwick Airport, and transport choices.

For 18-25 year olds, worry about money and jobs is high, as well as hate crime. Crawley has been identified as at risk of being the most financially impacted area in the country, addressing socio economic factors will be particularly important for Crawley's BAME residents. The Low Commission report on the impact of advice on health outcomes will play an important part in this.

There were positives: in particular for families who found improved quality time; others who identified with a community spirit. People who could find a new structure coped better.

New connections were made, with one community leader explaining attendance at his Temple had increased because of video platforms. However not everyone was aware of the support and activities available. This is a reminder of the importance of ongoing awareness raising, particularly for people who are not a part of established local groups.

There were positive views expressed about the NHS, although different practices can be seen across the District. Improving access to appointments and removing language and communication barriers will bring greater equity.

Emerging needs for newly arrived migrants need to be reflected in future strategies, for example an increase in Arabic as a first language.

The impact of cancelled NHS appointments is an important message for us all. Social distancing has removed connections but not the problems: a number reported ongoing pain and increased worry. Some had life changing events but no access to support, for example two women experienced miscarriage. We must begin the recovery to meet both the needs of the coming months but also the unmet needs as a result of "lock down".

Recommendations:

1. **Engagement must be ongoing, taking existing work and reaching people who don't always engage,** Engagement needs to be part of continuous improvement as well as service and product design. Including reaching second+ generation and people with disabilities. Ensuring the diversity of the BAME community is reflected in interventions, so they work.

2. **Deliverables are needed to build trust with the BAME community so actions are visible and experienced.** Confidence will depend on genuine change as a result of this work. Organisations should create a "road map" with goals and timeframes to be shared and reviewed using quick local actions to demonstrate change.

3. **Interventions and information must be accessible and equitable, tackling both language and communication barriers.** Images, plain language and easy read through a range of channels will help deliver key messages whilst aiding digital and in-person translation. Improved awareness across all ethnicities and cultures will help remove barriers.

4. **Linking interventions and key messages to motivations people will respond to, rather than a one size fits all approach, may be more effective.** Lived experiences influence how a person will respond to key messages. Work should be user-led and informed by the needs and interests of the target audiences.

5. **Developing and sharing the evidence base on downstream causes.** For example the role of Vitamin D or underlying health conditions.

6. **Wider socioeconomic determinants must be addressed to prevent ongoing disparity in Covid-19 and other reduced health outcomes**. Covid-19 has and will continue to have an impact on health, with people's finances driving the level of risk they may be exposed to; for example having to work, use public transport, or not using online shopping. Early support with issues outside of health are needed to prevent widening health and social inequalities.

7. **Lessons should be shared about how people connected, created structure and coped through lockdown.** People will need to continue social distancing for the foreseeable future. New ways of sharing, such as social media and printed leaflets will reach more people, alongside capacity building for organisations, community and faith groups to continue to connect.

This is an opportunity to build on what we know and work underway and address the gaps and try new interventions.

In the words of one member of the community:

"Survey after survey and nothing happens. Then the same survey is regurgitated a few years later. Waste a lot of effort and time, bet nothing will come out of this and there will be a wash and not see any good outcomes from that.

That's my challenge to you."

Methodology

Engagement took place over 4 weeks between July and August 2020 just before lockdown eased, using quantitative and qualitative methods.

The lockdown necessitated digital channels as our primary route, although in person interviews did take place. This created limitations and reduced the capacity to reach high numbers and some who are digitally excluded or people with limited English.

Efforts included using interpreters, using members of the community, and translated printed leaflets. A focus on capturing personal statements from the survey and increased interviews was used to improve validity. A larger response came from working age people and from Asian communities, compared with the 2011 Census. 214 people took part which equates to an approximate 6% of the local BAME population, although taking into account population growth, it is likely the reach is smaller.

It is recommended future engagement use a blended approach and include face to face locations and generic channels.

Quantitative

Online and printed surveys were shared via QR codes, links through the Crawley network, social media, and distributed by hand. Awareness was raised through flyers, word of mouth, digitally and social media, including paid for boosts. Questions were aligned to the other NHS commissioned partners to provide a consistent data comparison.

214 comprehensive surveys

22 semi-structured interviews

8 in-depth interviews

3 Focus groups

Qualitative

1-1 semi-structured interviews using the survey structure with additional free text and exploration of themes. A boost sample was used to improve representation, for example newly arrived migrants.

In-depth interviews taking ethnographical principles, exploring culture and lifestyle, values and experiences in the home setting, via video calling. Demographic profiles identified to represent Crawley's diversity.

Focus Groups to explore and test emerging themes, with one online open style forum.

An advisory group was formed, with professionals working in the area and mixed BAME backgrounds, to provide input and feedback throughout the project and report writing.

Demographics

Crawley is the most diverse area in West Sussex, with 20.1% of the population describing themselves as from a non-White background. Our participant group is reflective but not fully representative of the local demographics, due to the relatively small sample size surveyed: 214 respondents of a BAME population of approximately 3472 (2011 Census).

Figure 1 below compares the proportion of ethnic groups in the 2011 census against this research.

Figure 1 breakdown of ethnicity v. census		
Ethnic Group	2011 census % (of non-white)	Research sample %
Asian	65	62
Black	16	18
Mixed	14	12
Other	5	8

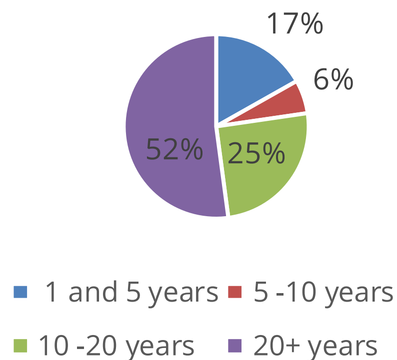


Figure 2

60% of respondents were women compared with 51% overall in Crawley

The average age in Crawley is 37 years, a higher proportion of people over this age answered this survey

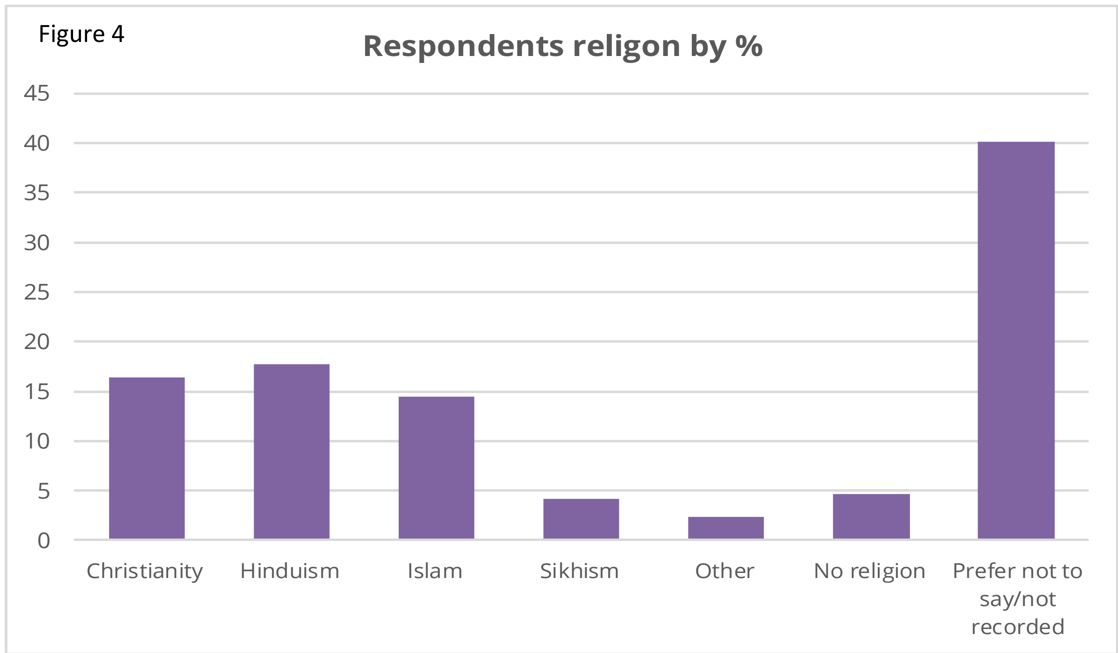
62% of people are from an Asian background compared with 65%

59% of respondents were homeowners: the same as local data for the general population

Almost half of people who recorded their status were born outside of the UK, compared with the 20% recorded in the 2011 Crawley census. This may be influenced by strong participation from established local groups where second generation residents may be better reached through other channels.

Figure 2 shows the breakdown of their length of residence and demonstrates the breadth of lived experiences.

Figure 3 further shows the rich diversity of our BAME community, with a breakdown of ethnicity amongst our participants. This includes Tamil, Ugandan Indian and Mauritian backgrounds. “Other” included Syrian and Kurdish residents, some of whom were newly arrived with Arabic as a first language. Chagossians are under represented in the responses.



Religion has not been compared in Figure 4 as comparative data was unavailable.

However amongst the general population in Crawley, 54.2% of people identify as Christian , 25.5% no religion, 7.2% Muslim, 4.6%Hindu and 0.7%Sikkh. A more even reach across the three main religions was reached, which is likely to be because of engagement through local groups.

Bewbush followed by Broadfield and Langley Green are the most diverse wards in Crawley. In contrast, our engagement had a broader reach across Crawley as shown in figure 5.

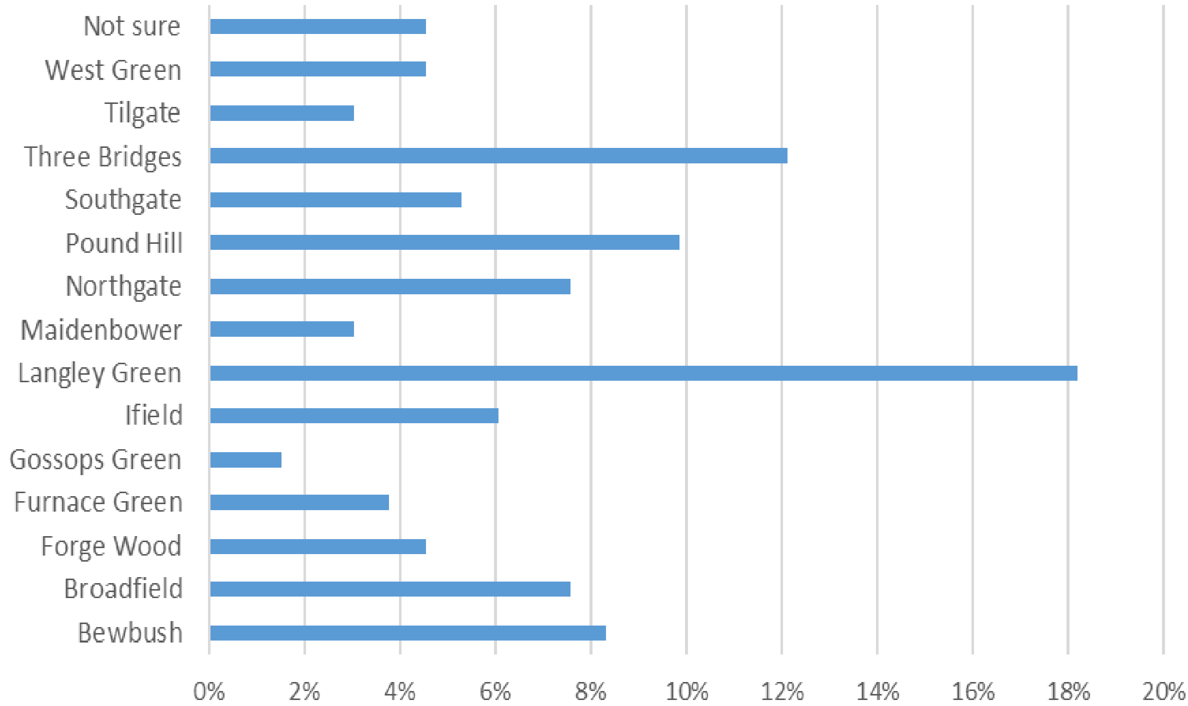
Breakdown of recorded ethnicity

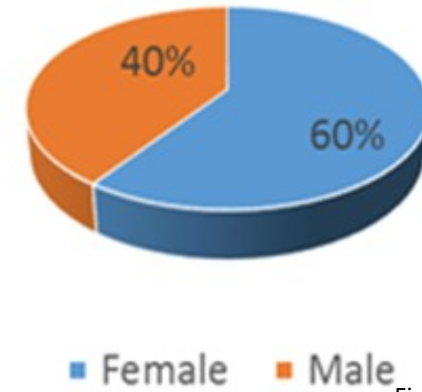
%

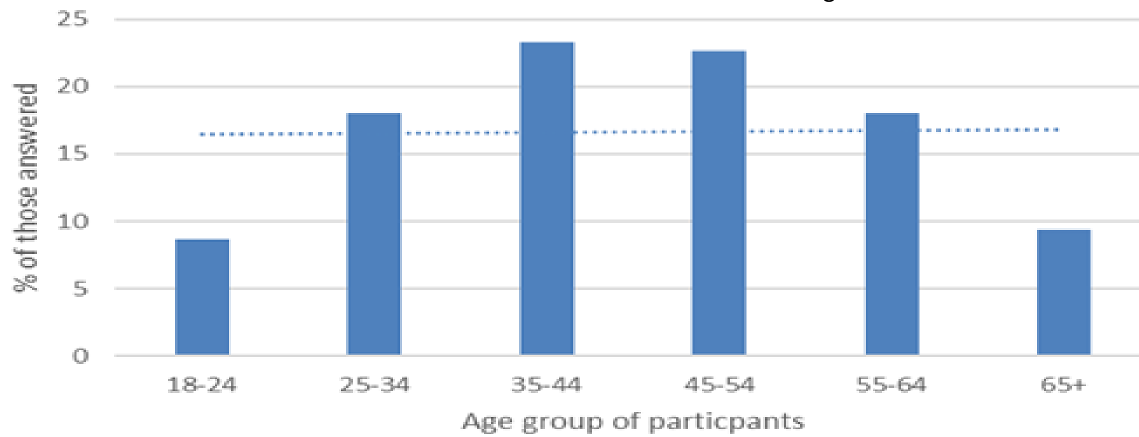
0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

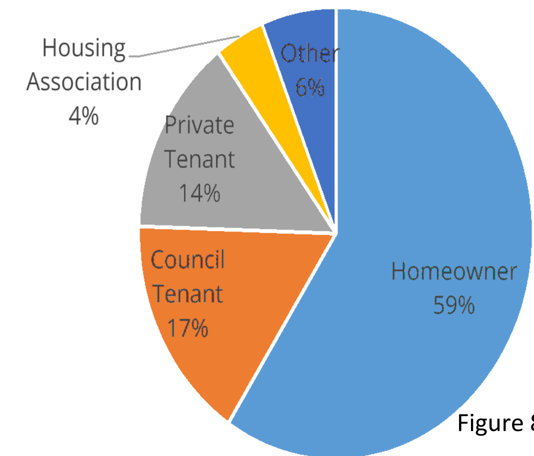
- Asian/British: Indian
- Asian/Asian British: Pakistani
- Asian/British: Tamil
- Asian/Asian British: Chinese
- Asian/Asian British: Ugandan
- Asian/Asian British: Bangladeshi
- Asian/Asian British: Other Asian
- Black/African/Caribbean/Black British: African
- Black/African/Caribbean/Black British: Caribbean
- Black other
- Mixed/multiple ethnic group: White and Black Caribbean
- Mixed/multiple ethnic group: White and Black African
- Mixed/multiple ethnic group: White and Asian
- Mixed/multiple ethnic group: White and Black Caribbean
- Other ethnic group/British other ethnic: Mauritian
- Mixed Other
- Other

Figure 3


Where do you live?
Figure 5
Not sure
West Green
Tilgate
Three Bridges
Southgate
Pound Hill
Northgate
Maidenbower
Langley Green
Ifield
Gossops Green
Furnace Green
Forge Wood
Broadfield
Bewbush
0%
2%
4%
6%
8%
10%
12%
14%
16%
18%
20%


Gender breakdown
40%
60%
Female
Male
Figure 6


Breakdown of ages
Figure 7
% of those answered
25
20
15
10
5
0
18-24
25-34
35-44
45-54
55-64
65+
Age group of particpants


Breakdown housing type by - survey by %
Housing Association 4%
Other 6%
Private Tenant 14%
Council Tenant 17%
Homeowner 59%
Figure 8

Results and Key Themes

A number of themes were explored including experience of the NHS and Covid-19, risks, sources of information, feelings and socio-economic factors.

Experience of Covid-19

Of those surveyed 19% state they had coronavirus, of whom 30% had been tested, which equates to 5% of the sample confirmed to have had Covid-19. Some people did point to the inability to be tested early on which makes it difficult to draw complete conclusions.

Few sought medical advice; for those who did,111 was the most used resource, followed by the GP. Some had sought advice with difficulty. Two fifths said their treatment was good; two fifths average; and 20% dissatisfied due to failures to assess their symptoms fully.

During Interviews, participants discussed the views and actions of others in their community.

They identified :

1. People who are aware of Covid-19 and took measures such as isolating
2. People who believed there was little evidence of Covid-19 and it was exaggerated
3. People who believed they would not be affected by Covid-19.

There are some indications that the greater the interactions with the NHS, the more people were aware of the risks of Covid-19. People in group 3 were more likely to be from an Asian background and have regular interaction with family or friends abroad or follow cultural remedies.

Views on the cause of Covid-19 disparity

Interviewees shared detailed views about why they thought there was disparity in the health impacts of Covid-19 for people from a BAME background.

These are in line with established upstream and downstream causes, summarised as:

- **Socio-economic** – in particular more likely to be a frontline and essential worker with greater likelihood of "viral overload"; more likely to financially need to work; being unable to stop work to self-isolate.
- **Cultural** – varied between groups and ranged from preferences for using own country medical advice or remedies to group-based activities within a community setting.
- **Biological** – reference to diabetes, low vitamin D and obesity, which were identified by interviewees as potential factors.
- **Discrimination** – treated unfairly or believing preferential treatment given to others; language and communication barriers influencing access, diagnosis and treatment; treated worse by employers and society and put in positions of greater harm.

These themes featured throughout focus groups and interviews, demonstrating the importance of influences and motivations in how people receive and use information. For example, one respondent said "**It can be hard to self-isolate and distance in a culture.**"

Targeted messages and examples showing how it can be done could address this. Using role modelled examples people can relate to, personalising the information.

Jameel* is a young adult, he lives with relatives and is a student. He did have a job but was furloughed as a result of Covid-19. His family receive some means tested benefits and he has dyslexia/dyspraxia.

If he was to feel unwell he would ask an experienced relative for help.

He would like information in plan language or easy read and via email.

Jameel had mixed emotions during Covid-19, but he also felt anxious, lonely and isolated.

He would like to have someone to talk to and advice about money.

He is worried about transmission of the disease and is staying indoors to keep well.

Sara* is a young adult, she is self employed. She is an information seeker.

She used Government briefings, social media, WhatsApp, family and friends, community and religious groups, news here and abroad to keep informed on Covid-19.

She would like information from the NHS in plain language, posters, TV and the NHS website. She would speak with a GP, 111 or an experienced family member if she had symptoms of coronavirus, she would also quarantine.

She did not feel she was taking more risks and said: “I'm not gonna take any risk at all.”

Since lockdown she found it difficult “coping with grief and loss for people who have died”. She also felt happy and contented, pleased with a slower pace of life.

She wanted advice on money, energy, loans, keeping fit and up to date with health information on coronavirus.

* Not real name

NHS Experience

Overall, experience of the NHS was positive. Reasons for cancelled appointments were understood and many felt there was little extra the NHS could do regarding coronavirus until a vaccine is available.

" I think they're doing all the right things. I've had a very good experience of the NHS. I rang the NHS Helpline a few months ago as my wife wasn't feeling very well. They gave very good advice and we managed to get a sick note with their assistance. The staff treated me and my family very well on both occasions and were professional and courteous."

It was necessary to separate the responses from NHS key workers. This section focuses on the experiences from a patient perspective.

An area for improvement highlighted was accessing appointments and treatment.

Prior to coronavirus, most people used a range of NHS services, with GPs followed by the hospital and pharmacy the most used. Interviews and community conversations were mostly positive about the NHS, especially staff.

Of respondents who had Covid-19 and received some sort of treatment, two fifths were satisfied with their treatment, two fifths found it average, 20% were dissatisfied. Reasons for dissatisfaction referenced difficulty getting advice and some instances of being wrongly told they did not have symptoms of Covid-19.

Health and Wellbeing Impact

The impact on health and wellbeing in this engagement identified

1) The effect of cancelled appointments
2) The effect of social distancing measures from Covid-19

There was little data to confirm longer term side effects for people who had contracted coronavirus.

Most people recognised and accepted the reason appointments had been cancelled and people who cancelled appointments themselves cited risk of Covid-19 as a reason. However, **all** said it had a negative impact on their health or they were worried it would.

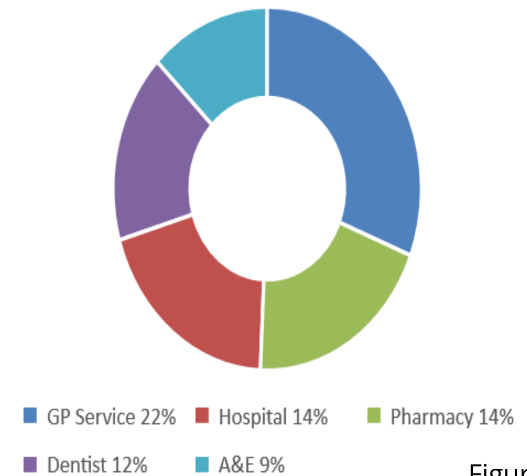


Figure 9

- **16% felt the NHS had done all it could do and had no suggestions to improve it**
- 19% want to be kept informed by the NHS
- **11% raised problems with accessing appointments**
- 6% wanted vaccines and/or improved access to testing and PPE

" The pain clinic cancelled my appointment which left me in a lot of pain. The NHS is important to me and it is good and helpful."

People's concerns following the cancellation of their NHS appointment were :

- Deterioration or fear of a deterioration of their health
- Ongoing pain
- Insufficient Mental Health support

Pain was the most common symptom described.

"Still in pain as no physio available."

The ramifications of cancelled appointments and reduction in accessing health services is not yet known, but there are likely to be long term consequences. This could range from serious health impacts to a loss of trust in the infrastructure. In our survey, two women experienced miscarriages, one of whom had a history of miscarriages and had waited two months for an appointment. Two others are waiting for cancer treatment.

These examples serve as a reminder that there could be a knowledge gap in the health and wellbeing experiences of patients amongst health care professionals where contact has not been maintained.

Respondents being kept informed: this does not have to limit itself to Covid-19 safety information. Receiving follow-up and advice on how to manage their conditions during lockdown may have helped and could apply during ongoing social distancing.

"There were letters early on and text messages from the GP about how to see a doctor, but nothing was ever followed up."

It should be noted that a number of people referenced cancelled physio, optician and dental appointments. In particular, some raised that their children were missing out on appointments too.

"The dentist cancelled the appointments for the children. One of my sons has a broken tooth and it hurts a lot at night.

Several respondents have support from charity or community workers to help with appointments or treatment. This suggests a need for people to use advocates due to language and communication barriers but also help to improve navigating the system. "

40% had an appointment cancelled

10% were dental appointments

4% cancelled themselves due to fear of the virus

51% clearly said it had a negative impact , only 16% stated it did not

Pain is the biggest ongoing symptom

"I have vision problems and the optician has referred me to hospital because of glaucoma. Appointment was cancelled and my vision is getting worse."

"Face to face counselling was cancelled which had a huge effect on my mental health causing me to have to be signed off work as the stress has triggered my fibromyalgia. "

A deterioration in existing mental health conditions was experienced by several respondents. However, many more reported worry and anxiety when reflecting on feelings about Covid-19 and of the future.

This may be in part due to the impact of social distancing.

"I get really depressed staying in all the time. It's like jail, no freedom"

Several people mentioned the importance of structure or routine, either of losing it or finding the benefits of establishing a new one.

"Some days have been harder than others. I find it really difficult to keep motivated when I'm not in a routine. I often felt lost and confused"

Proactive support may have had a positive impact.

Participants reported a range of feelings and emotions during the coronavirus period. A sense of anxiety featured throughout the interviews as well as in the survey which found people felt:

- 46% anxious,
- 33% stressed,
- 26% angry or panicked
- 44% mixed emotions, and
- 26% conflicted or confused.

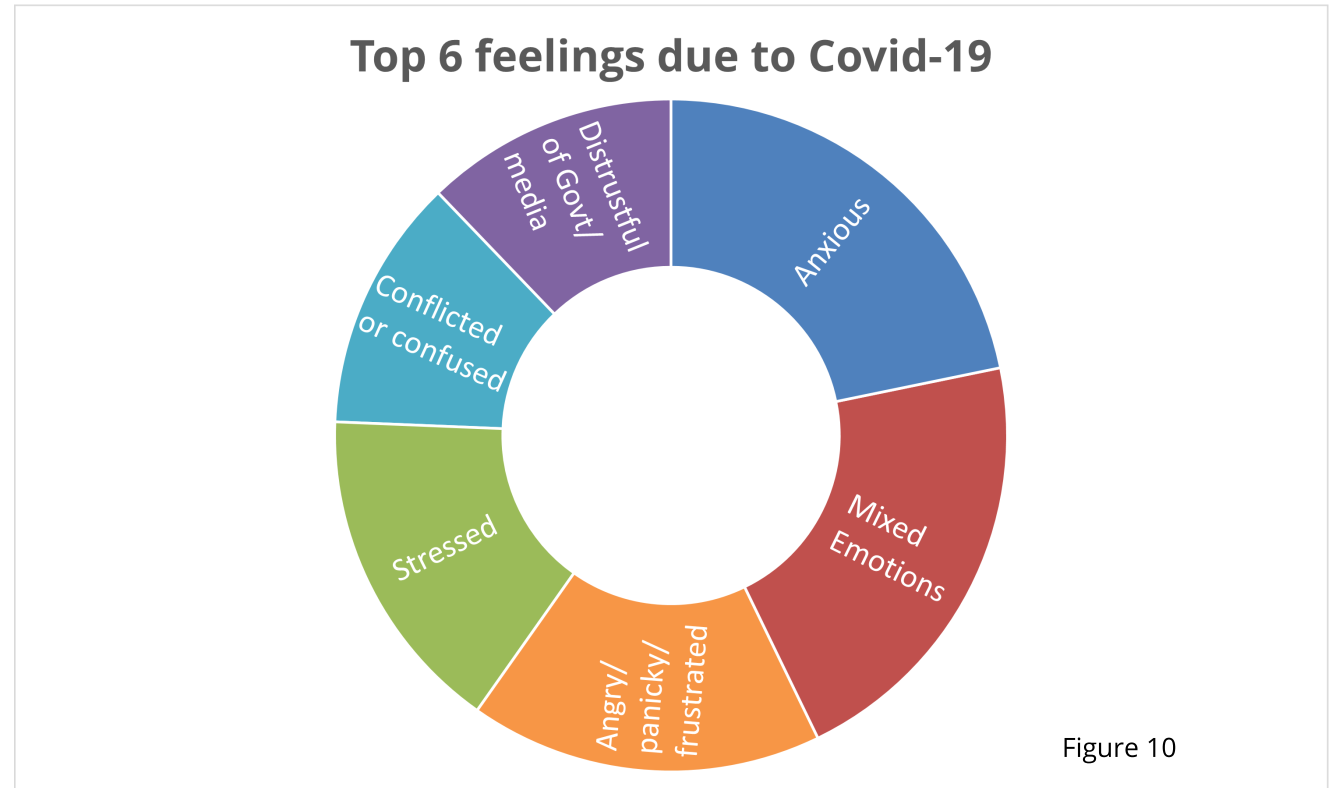


Figure 10

The complexity of feelings can be seen for one respondent in figure 11.

The impact of social distancing on the sense of community was voiced by many, particularly older respondents. This is not a comparable piece of engagement so there is no evidence this is more or less than white communities, or if this is representative of people less connected to local groups. However for those people who participated in this engagement work, that sense of community was often profound and had wide reaching feelings.

"We live like a large family and now everyone is separated and communications are affected"

A sense of community was felt by a number of people and examples of using technology to connect were given. This is an opportunity to build on those new experiences to reduce isolation and support the most vulnerable during ongoing social distancing.

Asian male, 35-44, 1 chlid, worked from home

Anxious

Burnt out from working from home/working alongside other responsibilitie s

Pleased with a slower pace of life

Mixed emotions

Stressed

Increased sense of community

Happy and contented in household

Distrustful of media/govern ment

Figure 11 , Feelings experienced by one respondent

Economic Impact

After health, worry about work and loss of income was the next highest concern.

"Poverty is a problem. Having money to live in a place where you can social distance is key and I would say having financial support and decent accommodation would have helped me." (18-24 year old)

It is well documented people from a BAME are disproportionately affected by socioeconomic downturns. The Runnymede Trust report ii refers to evidence suggesting "*BME households are less able to be financially resilient when they have lost income or jobs, during unexpected times such as Covid-19*."

A worse socio-economic impact may not only add to the cause of the disparity of Covid-19 on the BAME community but also increase the ongoing risk and future health outcomes.

In the context of Covid-19, a lower income makes it harder to afford PPE and safety measures such as online shopping, meaning people are more likely to have to go to public places and use public transport etc. Some respondents asked for access to this to reduce their risks.

Figure 12 shows the work breakdown of respondents. The number furloughed is slightly lower than the overall Crawley statistics iv. This is likely to be because of a higher proportion of keyworkers, including public sector workers, who could not usually be furloughed.

25,000 jobs are linked to Gatwick Airport

Crawley had the highest percentage of workers on furlough in the region

The average age is 37 years in Crawley meaning the emerging recession will have a disproportionate affect on the area

Concentrated areas of ethnicity in West Sussex correlate with the IMD data

Crawley had one of the highest percentage changes in claimant counts in the country

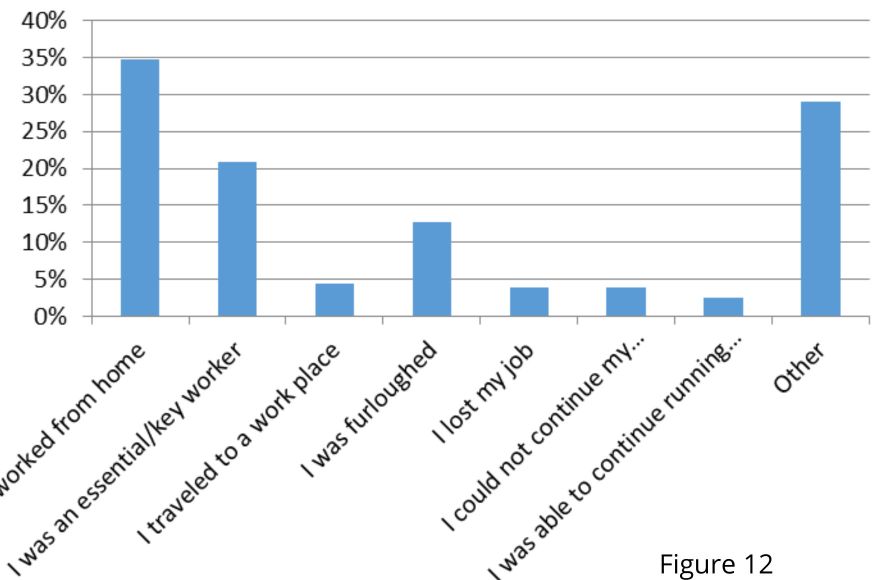


Figure 12

Influencers

Throughout the engagement, trust in the establishment arose across all genders, ethnicities and age groups. Measures to reduce the risk of Covid-19 require information to be received, understood, and used.

Where people access information is not the same as what influences them to act on it.

Previous experiences, both in the UK and abroad, will affect how information from official channels is viewed. Some pointed to a belief that treatment is of a better quality abroad. One community group visited said they didn't believe officials because they hadn't met anyone who had Covid-19. Some pointed to the lack of disparity in other countries and questioning if it was true.

In contrast, people who reported experiences of racism and discrimination tended to agree there was disparity and linked them. For example not being able to access PPE due to racism.

Where people reported positive experiences of the NHS there was no evidence of not trusting the NHS although they may have expressed distrust in the government or media.

The survey found 26% of respondents were distrustful of the Government/ media.

Significantly, several people mentioned suspicion amongst African communities towards a vaccine; feeling like "guinea pigs". One participant gave the example of smallpox vaccination. Another said:

"For the community, the thought of a vaccine is scary. They are worried they will be in the first in line to receive the vaccination and are suspicious of it [in]... the Gambian community there may not be a big take up on the vaccine."

During interviews cultural influences were more prominent. One person gave the example that members of her community believed they would be safe from Covid-19 because they ate hot food. People across a range of ethnic groups mentioned remedies such as ginger and garlic providing protection. Some people drew greater trust from information from friends or family abroad, including receiving medicines.

WhatsApp was used to keep in touch with friends and family abroad. This increases the influence of word of mouth from other countries. Examples included why there is a higher disparity for BAME people in the UK but not abroad, and the socioeconomic impact.

Statements from respondents:

- "Lack of consistency and clarity coming from government messaging leading to confusion."
- "Government strategies prioritising the economy rather than human life."
- "Concerned about a second peak arriving with no proper test and trace in place beforehand."

Nadia* is in her 40s and lives with her husband and three children. She works nights and was furloughed during the lockdown. She is an information seeker, looks for the evidence and finds ways to put it into practice.

Nadia hasn't been ill with coronavirus; at first it was strange being at home with the children because she works so many hours. She got everyone into a new routine with school work and exercise. She keeps up to date from government news and reads up on what she can do to keep her children safe. She is well informed on diet and nutrition but recognises that many in her community eat poor diets. She explained how many also follow traditional practices, including tummy tying after birth. She doesn't feel people question and seek answers the same way she does, instead they follow what their parents or others tell them.

Nadia supports her community and says the impact of social distancing has been hard for families, increasing the stress of being under one roof and putting pressure on relationships.

Nadia explained that many people don't go to the doctor when they are very poorly because they think their treatment will not be as good as for white people. Instead, they would rather travel abroad. Nadia explained that many people struggle to communicate with the reception staff and health care professionals. They struggle to explain at the beginning and may not get an appointment. If they do speak with a doctor, they cannot always explain the symptoms with many phrases not translating. She searches the right terminology so she can communicate better with her doctor and supports others to do the same.

Nadia thinks that a combination of perception, and language cause people to delay going to the doctor so when they do attend, their health is worse. This reinforces that they are given worse treatment because their outcomes are worse. Nadia was made redundant and had to fight to get her job back. She is worried for the future and providing for her children .

* Not real name

Discrimination

In both the surveys and the qualitative engagement, discrimination was raised as part of the cause as well as impacting on solutions to the disparity of Covid-19 for the BAME community.

According to the NPCC report "Policing the Pandemic" , BAME people were 1.6 times more likely to receive a fixed penalty notice for breaching social distancing than a white person, whilst there is no evidence of any greater prevalence in the BAME communities of not following rules.

This ranged from views that white patients are treated more favourably to expectations on front line workers. Interestingly, the concerns from frontline workers were predominantly from those who worked in the Health and Social Care sector.

Several interviewees pointed to the impact discrimination has on people's health: from having to work when ill, to poverty, access to diagnosis and treatment.

People sought to understand causes of the disparity by drawing on the experiences of friends and family in Africa or Asia which at the time had lower incidence rates. Some highlighted the impact daily racism has on stress levels and the effect this has on physical health. Lower diversity in West Sussex may mean people experience increased differences which may not be as reflective in some other parts of the country.

For example, a number of respondents felt they were treated poorly by white Health Care staff due to their ethnicity.

One interviewee gave an example of black staff who worked night shifts and white staff and managers worked the day shifts; the managers didn't leave a key to access PPE when stocks were low, potentially putting them at greater risk.

Feeling ignored and not noticed in a range of situations from public transport to talking to doctors was raised.

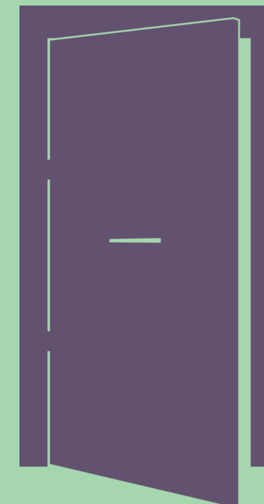
"BAME [are] treated even worse. On the bus you are treated differently. Feel people don't see you and start stereotyping. If you get angry, you're an 'angry black person."

These examples influence not only treatment received but also how and when someone from a BAME background interacts with the health service. For example, several people gave examples of people they knew who didn't want to go to the hospital because they felt they wouldn't be treated or would be placed at risk.

Two respondents who were in a Home Office detention centre explained feeling scared and unable to follow social distancing.

For people to respond to information and access services there must be trust. As one respondent said :

"Trust is also affected by racism [...] data shows that 18-34 year old BAME are twice as likely to be fined for breaking the rules [...] even in a pandemic we are treated worse."



Accessing and using information

The survey found 74% of people accessed their information from government briefings, with 24% of that group indicating their distrust of government and media.

A number of people expressed a desire to access English classes and computer classes to empower them to research information independently.

The importance of information being accessible to avoid the need for translation was identified. This could be through images but plain English or Easy Read were identified and make translations easier.

Exploration of technology solutions would support this, ensuring information is accessible and easily translated.

Formats which can be shared digitally may improve the reach of good information.

Whilst there is a place for written or visual communications, a lot of people were influenced by conversations, for example friends and family. Organisations should work together to engage, including with grassroots groups. However it must be noted that some people do not identify as being part of a BAME community and should be reached through generic channels.

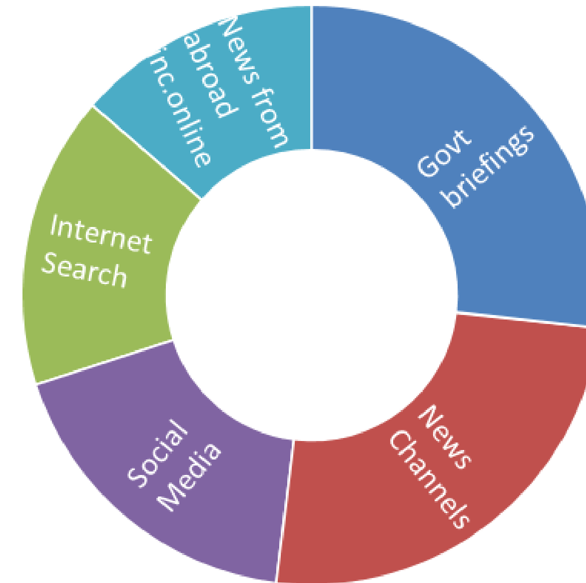


Figure 13

Figure 14

Language and Communication barriers

The majority of people who took part in the engagement spoke English; this is consistent with the profile of Crawley. Despite this, many people expressed a desire for information in accessible formats.

A lack of access to language support can affect the experience of patients as well as informing consent.

"My experience of birth was badly affected by having no interpreter available to explain to me what was happening at key moments, especially when my consent was needed"

From the perspective of Covid-19, language can influence how symptoms such as "dry cough" are understood.

Where language support is provided, it is essential it is in the right dialect, particularly for Arabic speakers. Where support is provided, patients report better experiences.

"The NHS has been very good for my family and me. The GP uses a phone interpreter or I speak to my keyworker"

Language and communication support need to be flexible and at each touchpoint of the patient's interaction with services.:

"The main problem with using the NHS is that getting an interpreter takes time, for example on 999. We had to wait a long time on the phone to get the interpreter to help with the 999 call. Also with phone appointments, if a GP calls on the phone without an interpreter, it is impossible to make progress with solving the problem and the GP needs to call again."

Communication needs to be recognised as separate to language. Where English is the first language or a person is fluent, there may still be communication barriers, for example the choice of words, tone or actions. Some reported that it is harder to communicate through the phone because of being unable to read body language with the doctor and vice versa .

There is a wealth of existing marketing and communications evidence which should be used to support making resources accessible. This ranges from clear key messages : "Online information in simple short form like the form of an advert."

Another said of the existing information :

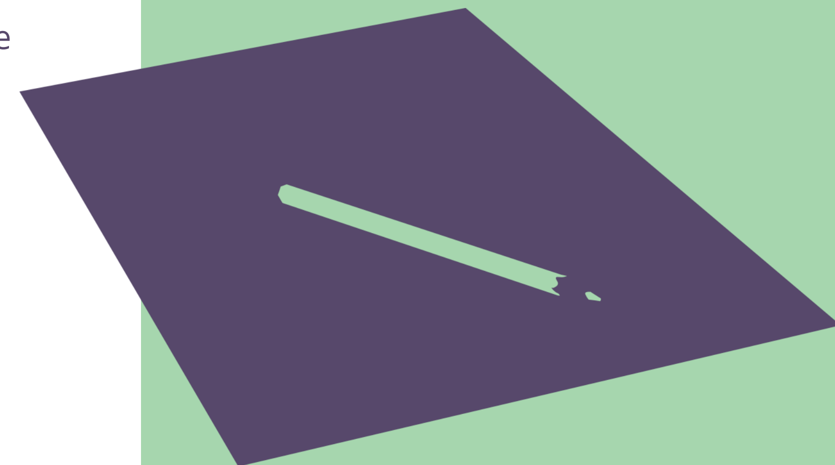
"Offer video calls every other week or so. Other people in our community felt that not all information was accessible. A lot of translation."

A small number of people who replied to the survey want help with English classes. They were predominantly new to the UK and several were Kurdish or Syrian.

They pointed to this empowering them to be independent, demonstrating the benefits of inclusive strategies.

People will move between support resources; the clearer the message, the easier it is to be independent and empowered.

"I use Google Translate on my phone and the dentist uses a phone interpreter if necessary [....] I also speak to my keyworker to help me understand what I need to do. I am lucky my doctor speaks Arabic."



* not real name

Cascia* is in her 50s and lives alone, she stopped working and owns her home. She has number of health conditions including visual impairment, poor mental health, mobility and dexterity problems. She is an information seeker but has struggled to access information and is influenced by friends.

She would call 111 if she had symptoms which she identified as respiratory problems, high fever and coughing. She would like to access the library.

“I did not think that the NHS knew what it was doing e.g. how to safeguard. There seemed to be a lot of controversy, such as with levels of PPE. So I felt I had to rely on my own instincts to keep safe.”

I feel: Anxious, Distrustful of the Government/media, Happy and contented in household.

“I have many concerns about coronavirus. I'm happy to be at home but I felt some tension and apprehensive - especially at first. Then I felt ok once I got used to it and started a new routine. I did not feel strange as I'm used to being on my own. I got a lot accomplished while being at home, e.g. de-cluttering. I was worried about going out but then I discovered many online zoom courses and found I could stay in more. The library could have come to some arrangement about borrowing books. It would have helped me a lot to have access to the library. Also I found it difficult to get information about online classes, as well as how to access them. I would have liked more interaction with other people through zoom.”

“I keep fit by going for walks, talking to friends on Zoom and WhatsApp. Some of my friends have told me that as a woman on my own it's not safe to walk by myself in places like big parks and woods, so I try to go to more populated places if I'm on my own. It's not easy because coronavirus means you have to stay away from people but if you go to isolate places there are other safety risks if you are a woman on your own.”

“All my appointments were cancelled due to Covid-19. So far, they have not been re-scheduled. I have had very good experiences with the NHS, the staff were always polite to me. But there were long waits for appointments, sometimes 2-4 weeks if I wanted to see the same GP.

“Negative impacts especially my physiotherapy and eye appointments and worrying about when regular appointments would be scheduled again.”

Conclusions and suggestions

The BAME community in Crawley is itself diverse. The survey sample was small which made it difficult to segment data, however there were patterns and themes across all groups. For example, needing advice on rights and money, accessibility, and the range of information sources people use.

This engagement reinforced previous studies on disparity but the community also highlighted the role of lifestyle, diet, culture and biology. Although views on the cause of the disparity of Covid-19 were split and influenced by individual experiences. These could be grouped as:

- **Diet, biology, lifestyle and culture** – e.g. low vitamin D levels, diabetes, communal gatherings.
- **Informed** – e.g. not understanding or following up to date guidance, doubts about the seriousness or prevalence of Covid-19.
- **Socio-economic** – greater exposure to Covid-19 situations, e.g. frontline work, the impact of a low income and racism, discrimination and bias.

People from an Asian background were more likely to mention the first and second causes, whereas people from a Black or mixed heritage background were more likely to mention the third.

Understanding experiences and views will be vital in communicating information as we adapt to "living with Covid-19".

The influence of people's socio economic situation was the strongest theme emerging, ranging from having to work despite concerns, the effects of discrimination on health and access to treatment.

There were high levels of anxiety about the future, job security and money across the adult working age population. Some people already had or were at risk of losing work.

The existing evidence of the impact of debt on mental health, plus deprivation on health, wellbeing and children's education outcomes are echoed in the concerns of the community. There is a desire to receive help now.

Early advice on money, employment and housing will reduce the economic impact on the community. We need to work together to tackle the discrimination and bias felt by the BAME community to address the disparity in health outcomes and wider socio economic determinants.

Overall feedback on the NHS was positive, increasing the more a person used the services. However access to appointments and a belief of preferential treatment for white patients spanned all ethnic groups.

For people with additional languages, access to appointments and challenges with communication extended to treatment . There can be an over emphasis on language, e.g. interpreters, but communication is also relevant.

People's experiences of the NHS will influence how and when they use it but increased accessibility, addressing unconscious bias and cultural views may improve health outcomes.

Concerns about additional risks came mostly from health and social care frontline workers. Others worked from home or socially distanced work. Many felt able to reduce their risk but using public transport and shopping raised concerns.

As well as supporting employers to communicate with staff about risk and protective measures, further consideration could be given to local measures reduce the risk associated with public transport and shopping.

Engaging during Covid-19 lockdown meant engaging primarily through digital meaning people less confident with English or digitally excluded may not have participated as actively. People who do not connect to community groups were harder to reach.

It would be helpful to continue engagement by testing solutions with different people including those who do not actively participate in engagement work.

People tended to keep up to date from official channels . However this does mean it was always understood or followed. Interviews suggested the influence of friends and family in the UK and abroad may have been stronger. This may not be unique to the BAME community.

Using known communication practice will improve access not only for languages but disabilities and more.

Some people reported feeling confused and suspicious with the level of information. Messages need to cut through personal experience and views.

Accessible and clear key messages work better in places people go and share, but they should be targeted with clear objectives.

Influences and motivations which effect change emerged during in-depth interviews. Examples included living and working in the UK, often long and hard hours, was linked to improving their children's prospects . This powerful motivation can be used to inform interventions.

Exploring this theme discovered opportunities to use existing information and touch points One Mum talked about using the pregnancy book she received ten years ago to keep her family healthy during coronavirus.

Influencing changes in lifestyle can be effective when it is driven by motivations.

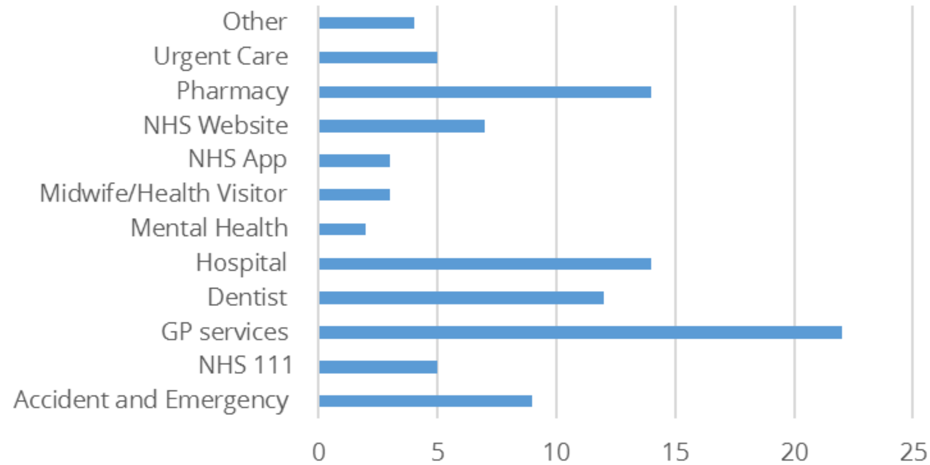
Interventions could include :

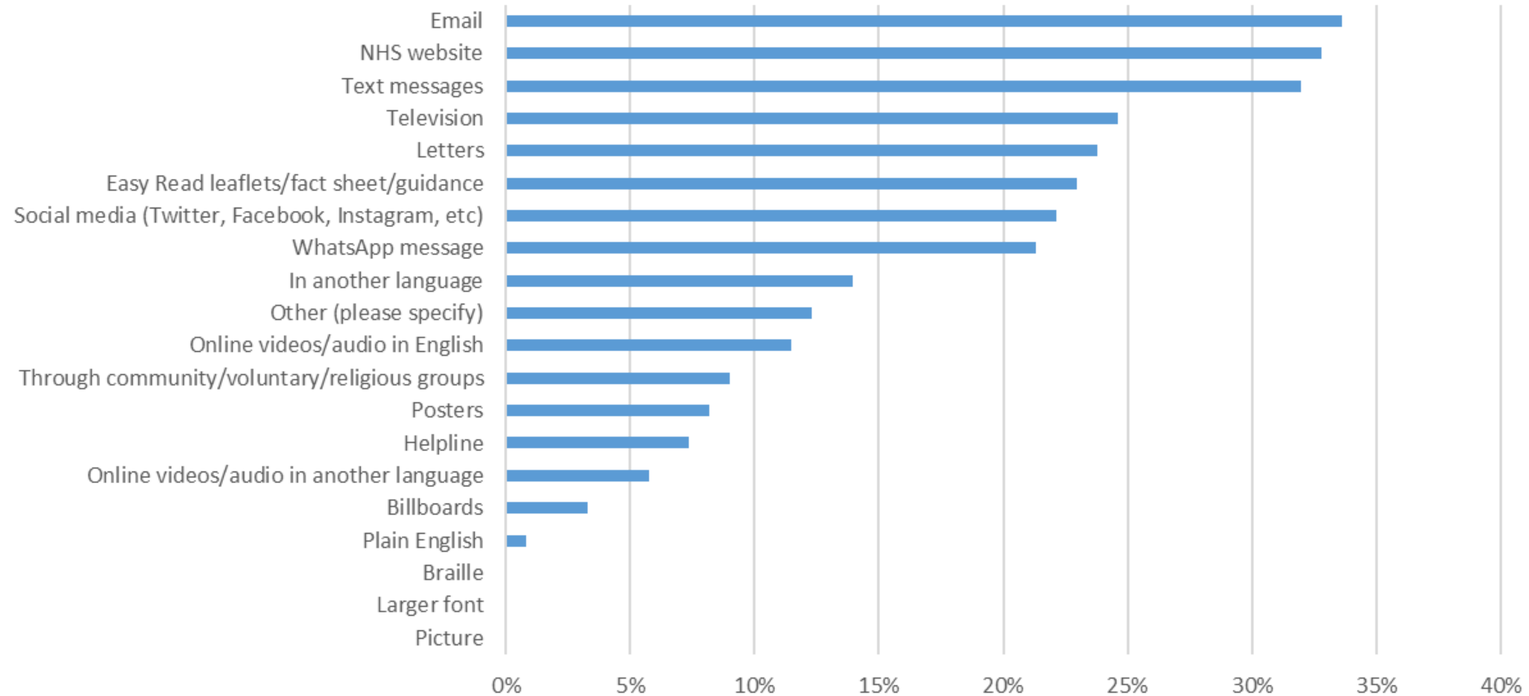
- **Translated Covid-19 information resources using plain English and Easy Read** tested with different people and digital translation, so key messages are understood, e.g. accurate translation of "dry, persistent cough".
- **Easier access to interpreters at the outset** e.g. built into switchboard options, proactive use amongst healthcare professional.
- **Visible communicate plans** to catch up on cancelled appointments; providing guidance on managing conditions , using Easy Read and in multiple languages.
- **Ensure access to protective support** especially for people on a low income; e.g. PPE, thermometers, online or local shopping and alternatives to public transport.
- **Use a blended approach to messaging** videos and champions and not rely on written communication.
- **Share examples of good practice and coping mechanisms** across the community via video, radio or stories
- **Have honest discussions about bias** and a lack of cultural awareness across all ethnic groups.

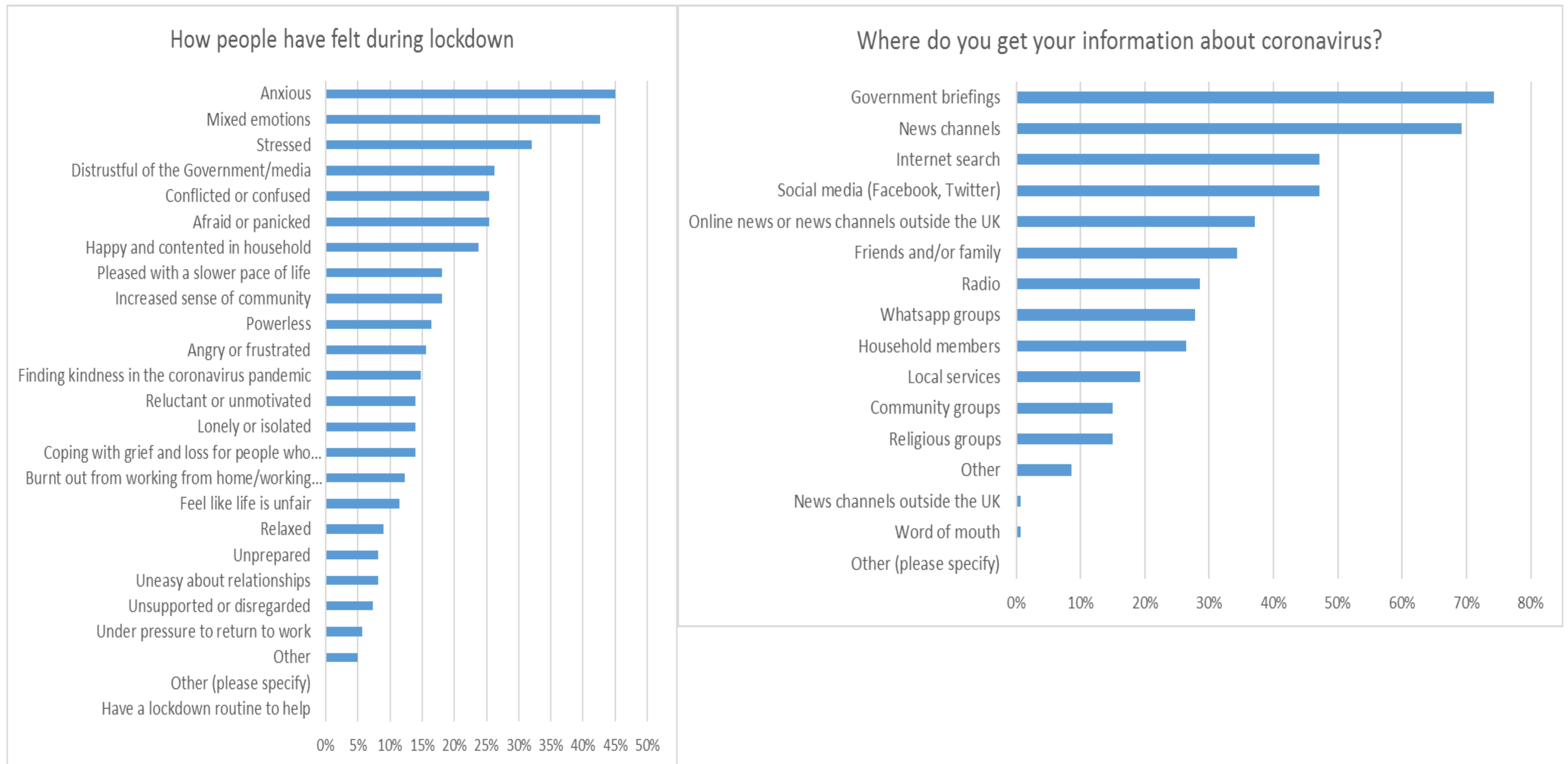
These engagement activities have given a platform to take this work further. To not only address the impact of Covid-19 but support people as we learn to live with it. Measures taken will likely improve wider health outcomes.

Together this could be the change needed to reduce inequalities and make a real difference.

Appendix 1—Breakdown of Survey data







Endnotes

I Independent SAGE Report 6 : Disparities in the impact of COVID-19 July 2020

Ii Runnymede Trust: Over-Exposed and Under-Protected: the Devastating Impact of COVID-19 on Black and Minority Ethnic Communities in Great Britain (2020)

Iii https://jsna.westsussex.gov.uk/assets/core/Black-Asian-and-Minority-Ethnic-Communites-Needs-Assessment-2016.pdf

Iv https://www.centreforcities.org/blog/may-unemployment-count-economic-crisis/

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