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What care and support did Birmingham citizens need during the Covid-19 lockdown?

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Introduction

Healthwatch Birmingham exists to put patients and the public at the heart of care. Our purpose became both more important and more challenging during the Covid-19 lockdown. People's care was disrupted as health and social care services responded to increased and unprecedented pressure, while social distancing restrictions made it impossible to gather feedback from the public face-to-face.

This report shows the important role Healthwatch Birmingham played in directing members of the public towards essential information and emergency support during that often confusing and troubling time. We also tried to bridge gaps between patients and services by informing providers about grey areas and capacity gaps within their response to the Covid-19 challenge.

We engaged and involved people by listening to their experiences in order to identify where help was needed. This report describes some of those experiences and how these were shared with health and social care services during the lockdown. Examples of difficulties experienced included:

- carers trying to cope without support or PPE
- patients who needed to obtain medication for ongoing medical conditions
- people obtaining supplies when self-isolating
- vulnerable people who were not sent a shielding letter
- vulnerable and elderly African-Caribbean people lacking good access to services.

We shared feedback with health and social care services, as well as third sector organisations, through a number of channels. These included: direct emails to relevant professionals, responses to consultations, presentations and our regular quarterly feedback reports to commissioners and regulators. We also shared feedback with Healthwatch England and this formed part of their evidence report for the Parliamentary Health and Social Care Committee.

We hope that health and social care services in Birmingham will learn from the successes and difficulties described in this report to redesign the support they provide, and prepare for future public health emergencies. We also want to reassure the public that services are listening to and acting upon their concerns. A very different health and social care sector will emerge following lockdown. Everyone must have equal opportunities to access the best possible care for them.

How did we hear from Birmingham residents?

Our key role during the lockdown was to link Birmingham residents to sources of support such as supplies (including food), medical care, social care, emotional support and Covid-19 related information. In total we heard feedback about health and social care services from 974 Birmingham residents between April and June 2020.

Our standard channels for hearing feedback include the online feedback centre, our information and signposting service, our research projects and community engagement. People who had requested information or signposting were provided this through email or telephone. We also updated our website with information pages about local sources of support, which were viewed over 1,600 times between April and June.

In addition to these standard channels, we asked people to complete an online questionnaire to tell us about their needs and those of friends or family members. Social media helped us reach more people. Health and social care providers and commissioners, as well as non-profit organisations, also shared the questionnaire with service users and members.

Between April and June 2020, 792 people completed the questionnaire; 577 of these were Birmingham residents. Their status at the time of answering the questionnaire can be seen in Figure 1. Of these, 152 were currently self-isolating/shielding, 345 were social distancing, 29 had previously self-isolated/shielded, and 51 did not provide this information.

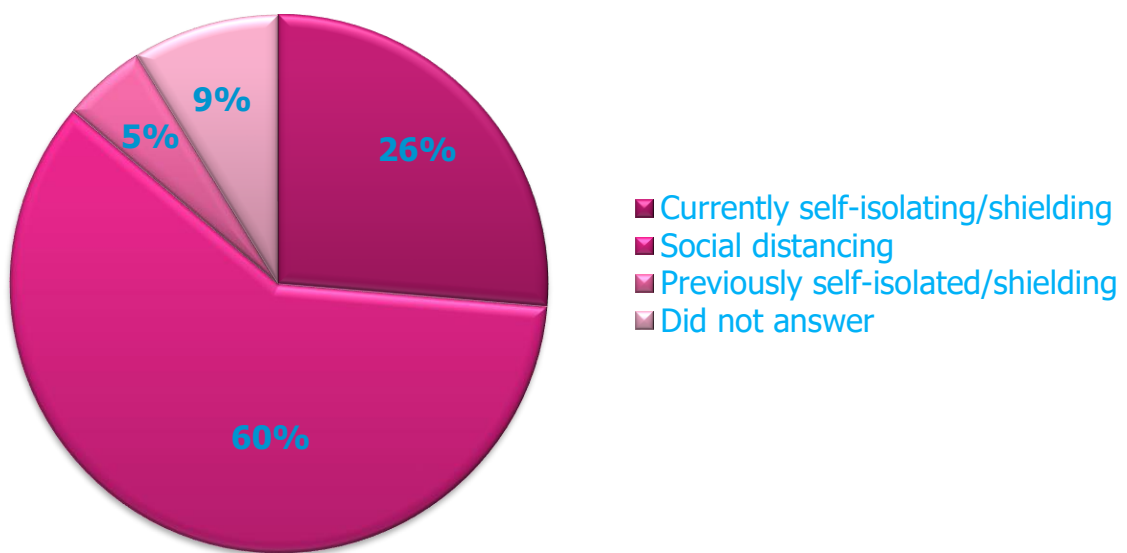


Figure 1. Self-isolation/shielding status

Working with health and social care services to direct people to support

On most occasions, we were able to provide people with information or direct them towards sources of support. Occasionally this was not possible because we did not have up-to-date information about how certain services had adapted to the lockdown. In those cases, we directly contacted health and social care providers and commissioners to ask them for this information, which we then passed to service users.

This process worked well, as the following examples demonstrate:

1. Support for people caring for adults without help or PPE

Carers contacted us who were exhausted as, due to lockdown, day care centres were closed, and they often had to look after their loved ones 24/7. One person told us:

Due to day services, clubs, 1 to 1 support not happening I am now caring for an adult with autism and a learning disability, who is naturally anxious due to so much change ... without help - 24 hours a day, 7 days a week. I am exhausted.'

Added to these difficulties was a fear of spreading the virus within the family due to lack of PPE.

My sister is my full-time carer and she cannot get any masks or gloves. She has to buy her own when she can get them as she's trying to protect me and herself. They should be helping non-paid carers to do this and I get no help even when you asked for it. No protection garments gloves and masks.'



We contacted Birmingham City Council to share our concerns and request support for carers. The council quickly responded, requesting the details of carers who were struggling (with the person's consent). Also, the Commissioning Manager (Prevention/Complex) in the Adult Social Care and Health Directorate provided his mobile number for people to contact him directly to resolve any difficulties or discuss their needs. He also provided the email address for individual requests for PPE stock. We shared this information with callers.



2. Information for people finding it difficult to obtain medications

We heard from people who were unable to obtain their medication during lockdown. Examples included a parent whose son has had a liver transplant and the necessary medication had run out of stock. Another person had made three visits to the pharmacy to try and get supplies of anticonvulsants. We asked the Birmingham and Solihull Local Pharmaceutical Committee (BSoL LPC) about the best course of action for patients who could not obtain their medication, and what was being done to address medication shortages in Birmingham.

They told us that the issue was far wider than Birmingham. There had been some medicine shortages for a while; either short term - where there is supply in the system just not in

the right place – and longer-term issues where the medicine had not been available for some time.


BSoL LPC told us that it was best if patients stayed with their original pharmacy. They needed to inform the pharmacist how much medication they had left at home and how long it would last. The pharmacist would then discuss options with the prescriber to design a pathway for the patients. However, if there was widespread lack of stock, alternatives may need to be agreed.

They explained that the Covid-19 emergency meant GPs were controlling access to premises and both GPs and pharmacies were overwhelmed with telephone calls. This meant a longer time to find a good solution.

We provided this information to service users to help them work out the best way to obtain the medication they needed during lockdown.

3. Support for families needing hot meals

A young mother told us that she needed:


 *Hot meals, as when ill and on your own with two children it would have been nice to have a hot meal made for the children.'*

We spoke to [The Active Wellbeing Society](#), who suggested that (with the person's permission) we send them contact details of anyone in need of hot meals.


Praise for individual services


The questionnaire also asked people about the services that had been particularly helpful during lockdown. They named specific primary care services (e.g. general practices, pharmacies, dentists, community services etc.) and hospitals. All positive feedback heard was put onto our [online feedback centre](#) and we emailed the service to invite them to respond to the positive feedback. We also celebrated some of these successes on social media.


People were particularly appreciative of general practices and pharmacies working well together to support their patients.

 *Ashfield surgery contacted to adjust meds which was done promptly without an appointment and they sent script to Walmley pharmacy, which was delivered the same day. Excellent.'*

We also heard praise for district nurses conducting home visits, gratitude for care homes that went the extra mile for their residents and their families during lockdown and appreciation for food deliveries from Birmingham City Council.

 *Community nurse phoned to arrange visit for catheter change and explained how they are still visiting essential patients.'*

 *In honour of the seventy-fifth anniversary of VE Day, I had the pleasure of attending the celebrations at the Perry Trees Care Home in Kingstanding. It was a socially-distanced commemorative event ... The car park was utilised, families remained in their vehicles at all times and drove around the one-way system, stopping intermittently to wave and speak to the residents and staff through their car windows. It was a wonderful atmosphere; the residents sang along to Vera Lynn's iconic WW2 song "We'll Meet Again" to mark the occasion. A special thank you to the Manager for his creativity and vision for Perry Trees. He continues to find ways of bringing families together through this difficult time, which was demonstrated through the joyous VE Day celebrations. Well done Perry Trees!'*

 *Government registration enabled access to online food delivery. This also meant that a telephone call was received from Birmingham City Council offering help and the offer of a food parcel and assistance to collect medicine. Regular emails have also been received from local councillor with excellent up to date information.'*

What needs to change if there is another lockdown?

The NHS and Birmingham City Council should prepare to be able to quickly respond to people's needs, including access to food supplies, medication and treatment for ongoing conditions, during any future lockdown. We signposted people who contacted us to appropriate sources of support, and contacted services directly about individual cases, if necessary. Examples of issues we heard about from Birmingham residents include:

Supplies


Over a fifth of people who completed the survey (114 out of 547) told us that they needed more supplies. They found it difficult to find fresh food at local shops; particularly important for people with medical conditions such as diabetes. These people, when self-isolating or shielding, needed food parcels that were not full of sugary food.

We were contacted by an individual patient who was wheelchair bound with numerous medical conditions (including asthma, osteoarthritis, rheumatoid arthritis, underactive thyroid and nutritional blackouts), who could only use one hand and had suffered blackouts and falls in the past. He was self-isolating and unable to get enough supplies, telling us he needed food but had not received any food parcels. He said that some days he only had one meal, all his medical appointments had been postponed and he had not had his B12 injection. He was feeling tired and was having blackouts.


Shielding letters

Two people contacted us because a family member or friend had not received a shielding letter. One contacted us because his friend, who has diabetes and asthma and falls under the extremely vulnerable category, had not received a shielding letter. He was self-isolating and could not leave the house to get his insulin and other medication. The caller was also concerned because his friend was self-employed and could not claim any benefits without the letter. He had tried contacting his GP, but the GP had said that they couldn't help him.

Another caller said:

 *I have not heard anything from Birmingham City Council and as over 70s have been told to stay in and not to shop I would have thought some query as to whether we needed help would have been useful. I would also have thought my husband's heart condition made him vulnerable but he has not had a letter telling him so.'*

Other vulnerable people felt they needed more support:

 *I am never contacted by health services. I am totally locked up alone, no family in the Midlands. I have no idea what will happen after my 12 weeks, now week 7. A regularly updated contact, say weekly or fortnightly, would be enormously helpful. I feel deserted and neglected. I am 77 living on my own!!'*

Access to medication, treatment and appointments

Approximately a third of people (121/328) that had needed medication, treatment or appointments said they had not received the medical care they needed. Forty-two percent (14/33) of people receiving social care said they needed more support during lockdown. For example:

All my appointments have been cancelled and I am in pain with stone in my kidney, doctor has given me painkillers but I feel sick when I take them. The doctor said if I am in a lot of pain, I should go to the hospital but I can't because of the virus.'

Sixteen people told us that they had difficulties in accessing general practice appointments. This may be because they could not get through on the phone, *"I tried 27 times to telephone them this morning and never reached a real person"* or because people felt they could not see a GP due to the lockdown *"I was self-diagnosing myself off the internet which caused great amount of stress to me ... still not going to be able to see a doctor anymore because of this Covid."*

They also wanted more access to Covid-19 testing:

I saw a junior Sickle Cell and Thalassaemia doctor (in A&E). She told me that I had Covid-19 but no test was done. I was given antibiotics and went home. More tests need to be done, before telling people that they have Covid-19.'

Good communication

People needed to know how to access services: *"I felt we were not kept informed at all about how to access GP services locally"*, and clear information about digital consultations: *"The video link simply did not work on my phone and the instructions were incomprehensible"*.

They also needed improved communication from health and social care providers about the ongoing treatment of existing conditions.

My heart clinic appointment cancelled and also assessment for orthopaedic problem cancelled. My husband is also waiting for a colonoscopy and cataract surgery. In pain with broken tooth no help as dentist closed. I understand we must wait for things to get normal but information regarding reappointments would be good and helpful.'

My epilepsy medication was supposed to be changed due to continuous seizures. Not able to contact anyone at all in neurology department. Review in four weeks and haven't even started medication.'

Good communication from health and social care providers was also important as lockdown was being lifted. We were contacted by a 70-year-old individual who was shielding and lives alone. He said that he was never contacted by health services and had no idea what will happen after the 12 weeks. Regular updates at least weekly or fortnightly would have been enormously helpful as he felt deserted and neglected.

Hospital discharge during lockdown

Three people contacted us saying that their discharge from hospital had been poor. We were contacted by the daughter of a 76-year-old individual, paralysed from the neck down, who was about to be discharged to a nursing home. She was concerned because the nursing home had some confirmed cases of coronavirus. She said:

The nursing home won't tell me how many cases they have. The complex discharge nurse at the QE didn't give me the full picture, saying the home has only 2 cases, whereas the home has told me it's more than 2, but won't tell me how many.'

She wanted to know if they had the right to be informed of how many current coronavirus cases the home had before her mother was sent back there, and if the number of cases was a factor in whether it was safe for her mother to return.

Emotional support

Approximately a quarter of people said that they needed more emotional support (124/546). They suffered from loneliness, from loss of a sense of identity and some were suffering emotionally. For example:

Solitary confinement is used as a punishment in prisons. Is having a psychological impact, lack of motivation, sleeping more than 12 hours a day, lack of energy ... Loneliness'

Lost job at start of lockdown due to health, so struggling with loss of identity and isolation from friends and wider family.'

A recognition that self-isolation for elderly people who live alone is not easy.'

[Birmingham Mind](#) set up a helpline to support people during lockdown, including key workers. It was very helpful to be able to signpost people who contacted us needing emotional support to that service.



Who did we reach during lockdown?

Our aim during lockdown was to help as many people as possible to have access to the information they needed to increase their wellbeing during that difficult time. Healthwatch Birmingham would normally visit diverse communities across the city to hear their views face-to-face; at community events and through organisations that support vulnerable people. During lockdown the only way we could hear people's views was online which unfortunately, but inevitably, made it more difficult to reach some people. However, overall it was not the case that groups of people who do not regularly use the internet were less likely to complete the questionnaire. Of the people that told us their age, sex etc.:

- 19% (74/379) said they had a disability, indicating that many people with a disability were accessing the questionnaire¹
- 18% (68/379) were 65 years or over (the estimated current population of people 65+ in Birmingham is 13%)^{2 3}
- 68% (255/373) were White British [according to the last census, 53% of Birmingham's population is White British].⁴ White British people are less likely to be internet users than other ethnic groups.⁵ However, we were concerned about this over-representation of White British people and ran a focus group to hear the views of the African-Caribbean community.



Hearing the views of the African-Caribbean community

In addition to inviting people to share their feedback through the questionnaire, we ran an online focus group to hear the experiences of the African-Caribbean community. This was run in partnership with Sandwell and West Birmingham Clinical Commissioning Group (S&WB CCG). We aim to run future focus groups with Birmingham and Solihull CCG.

Twenty-five service users discussed their experiences and concerns during the pandemic and what health and social care providers needed to consider for this community if there is another lockdown. S&WB CCG responded to each of these issues or took the point away for consideration. Issues raised include concern about good access to services for vulnerable and elderly African-Caribbean people, health inequalities and structural racism affecting access to health and social care services and comorbidities during Covid-19 within African-Caribbean communities.

Good access to services for vulnerable and elderly African-Caribbean people

We can't keep having all online systems and saying to our elders, "Sorry, stay back just in case". Well while they're staying back in their homes they're dying, they are actually too scared sometimes, to use the systems that you've got in place.'

S&WB CCG representative Dr. Munir Aslam's response:

Going forward, we've got a responsibility as a CCG to make sure we commission health care services for every person in the population that we take care of. So, the vulnerable people, the people that don't have technologies, we need to think together about a way that we can make this work.'

Health inequalities and structural racism


In terms of learning lessons from Covid-19, what plans do S&WBCCG have in terms of addressing the Impact of Covid-19 of BAME lives and how are they going to start to address the health inequalities that have been identified with BAME Communities?'

I want to know what's being done about the racism in the system. We need to start having a conversation where the approach is different.'


Dr. Munir Aslam's response:

It will have to be part of an ongoing conversation because there are lots of challenges here, they're challenges that we're going to have to meet together. We've been talking, like you said for some time, but we haven't actually managed to change those things. We need to continue having that dialogue and we need to do it quickly and in a way that's meaningful.'

Co-morbidities

 *I have COPD and didn't want to go into hospital because I felt as being in the BAME community the staff put us on wards with Covid-19 patients.'*

Dr. Munir Aslam's response:

 *It's really important that we continue the process of managing chronic diseases through this period. General practice is open, it's available, it will look and feel different to what it was before but, the capacity is there and there are experts available to help. We would not commission anything that would put you at greater risk.'*

Healthwatch Birmingham and Sandwell and West Birmingham Clinical Commissioning Group will conduct follow-up conversations with the attendees, and other African-Caribbean people, to find out more about their concerns and develop plans to address them. Healthwatch Birmingham will communicate the issues raised and responses.


We are also currently conducting a research project with Somali people to hear their views of health and social care services in Birmingham, which we will share with the NHS and Birmingham City Council.

Helping health and social care services recover and restore

As health and social care providers restore their services following lockdown, Healthwatch Birmingham is ensuring those in charge of making changes are considering the views of the public so that services meet their needs.

For example, we are helping the NHS develop telephone and online appointments. The following quotes are taken from a social media survey we ran asking for people's views on remote consultations.

 *Not able to have consultation. The video link simply did not work on my phone and the instructions were incomprehensible.'*

 *Suffering minor problem, called (South Birmingham GP Walk-in Centre) and, after quick chat with call handler, was called back by Dr who arranged video consultation - all in under 15 minutes.'*

We also contributed to a national report to hear the experiences of patients through Healthwatch England, which can be found [here](#). We have shared feedback and the national report with Birmingham and Solihull Clinical Commissioning Group, who are using it to develop how digital appointments are provided in Birmingham.

How we will support citizens, and help improve services, in coming months

Healthwatch Birmingham is here to listen to everyone's experiences of health and social care. Some communities are less likely to share those views, and use our service, than others. We will therefore continue developing new ways of reaching out to these communities. We are also keen to hear from people with 'long Covid-19' and their experiences of NHS services.

We will continue to celebrate the successes that we hear about by sharing positive feedback on social media and invite service providers to respond.

Feedback on services' performances will continue to be shared every three months with NHS and social care commissioners and the Care Quality Commission (who inspect NHS services).

We will also encourage health and social care providers and commissioners to use feedback to identify gaps in support.

New lockdown restrictions have subsequently been imposed in Birmingham and across the country. Our response includes enhancing our Information and Signposting service, and working more closely with other third sector organisations to engage specific groups such as new mothers, refugees and young people with addiction problems.

We would like to hear service user feedback indicating that health and social care commissioners and service providers have:

- reduced gaps in services revealed by the pandemic/lockdown
- communicated improvements in the design and delivery of services
- ensured that service users have heard and understand these changes and the improved support available
- ensured that service users have access to, and are using, health and social care service support and there is no inequality in access between different communities
- developed ways of hearing more feedback from a diverse range of communities across Birmingham.

Finally, in order for Healthwatch Birmingham to know that changes have been made to services based on feedback we receive, we will build our relationships with health and social care services in Birmingham through regular meetings with organisational leaders. We will continue to sit on committees such as the Health and Wellbeing committee where we can encourage patient involvement in the design and development of services, and report back to Birmingham citizens when services have improved based on their feedback.

Thank you

Healthwatch Birmingham would like to thank everyone that completed the survey, used our Information and Signposting service and shared their experiences. We would also like to thank the health and social care services, as well as non-profit organisations, for providing helpful information and signposting over the lockdown period. We look forward to continuing to work with you in the future.

References

¹The proportion of disabled adults in the UK population as a whole in 2016 to 2017 was estimated to be 22%
<https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/articles/exploringtheuksdigitaldivide/2019-03-04>

²https://www.birmingham.gov.uk/download/downloads/id/11387/older_adults_profile_2018_to_2019.pdf

³ The older a person is the less likely they are to regularly use the internet. We did find this in our survey; as age increased over 45 years the number of people who completed the online questionnaire decreased [4 (1%) were 16-18 years; 7 (2%) 18-24 years; 51 (13%) 25-34 years; 65 (17%) 35-44 years; 107 (28%) 45-54 years; 77 (20%) 55-64 years; 68 (18%) 65+ years].

⁴https://www.birmingham.gov.uk/downloads/file/4616/census_2011_population_profile_for_small_areas_in_birminghamxls

⁵<https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/articles/exploringtheuksdigitaldivide/2019-03-04>

About us

Local Healthwatch were established in every local authority area across England following the Health and Social Care Act 2012. Our key role is to ensure those who commission, design and deliver health and social care services hear, and take into account, the public voice. Healthwatch Birmingham listens to and gathers public and patient experiences of using local health and social care services such as general practices, pharmacists, hospitals, dentists, opticians, care homes and community-based care. We hear these experiences via our Information and Signposting Line, our online Feedback Centre, and through our community engagement activity led by staff and volunteers. You can read more about the work of Healthwatch Birmingham here:

<https://healthwatchbirmingham.co.uk/about-us/>

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