



# Residents with Learning Disabilities Experiences of Croydon's Care Homes during COVID-19

June 2021

# Executive Summary

As a result of the COVID-19 pandemic, Croydon's Care Homes had to respond quickly to protect their residents and the staff that look after them. To understand more about the challenges, they went through and learn more, we undertook a series of surveys with residents, friends and family and staff between August and October 2020. This was undertaken online and via paper surveys sent to a Freepost address

This report presents the experiences of residents who are learning disabled. We heard from 28 residents in 11 facilities.

We asked the following:

- What has it been like living in the care home?
- Changes in staff during the lockdown?
- Spending time with other people in the care home.
- Access to GP appointments and prescriptions
- Social Distancing within the home
- Contact and engagement with friends or family
- Visits from friends and family
- How could things have been made better? How could the situation be improved?

These are our findings based on the responses from the survey:

- **Less enjoyable experience but staffing was good:** Living in lockdown, learning disabled residents felt that living at the care home was less enjoyable, but staffing was not affected in fact they went beyond what was expected. (See pages 9-12).
- **There is a variance in experience for residents between facilities due to adoption of social distancing rules:** It seemed there was a lack of consistency in the application of rules around social distancing between care homes. Some residents seemed to have more freedom than others. (See pages 13-14 and 17-18).
- **Residents found access to prescriptions to be the same as before lockdown but had to adapt to not seeing a doctor face-to-face:** Having to use virtual appointments a challenging expectation and experience for some residents. (See pages 15-16).
- **All residents were able to gain access to their friends and family outside of the care home via phone or video but only half by actual visits:** However, there was a variance in experience both to accessing calls and meeting family and friends between different settings. (See pages 19-20).
- **Most were happy with the way that care homes had supported them:** Suggested improvements ranged from activity suggestions such as baking, sewing as well as access to services such as the GP and Day Centre. (See pages 21).

These are our recommendations:

- Consistency across care homes around social distancing rules by learning good practice from other facilities.
- See how processes can be adapted to allow those who are isolating to meet with other residents in the care home - even at a distance.
- Manage expectations concerning video and phone access with health professionals and ensure effective support is given so that residents can have a consistently good experience.
- Explore ways to improve information and process to effectively support visits from friends and family.

Please note that we also undertook at this time three other surveys with other care home residents, family and friends, and staff. There is a report for each of these at [www.healthwatchcroydon.co.uk/learn-more/our-reports/](http://www.healthwatchcroydon.co.uk/learn-more/our-reports/) as well as an overall report which draws together the overall themes of the experiences of using, visiting, and working in care homes in Croydon.

# 1. Background

## 1.1 Context

### About Healthwatch Croydon

Healthwatch Croydon works to get the best out of local health and social care services responding to the voice of local people. From improving services today to helping shape better ones for tomorrow, we listen to people's views and experiences and then influence decision-making. We have several legal functions, under the 2012 Health and Social Care Act.

### Context

As a result of the COVID-19 pandemic, care homes had to respond to protect their residents and well as providing information and access for family and friends and supporting their staff. Local authorities as commissioners of care home services were asked to coordinate and support care homes.<sup>1</sup> (Department of Health and Social Care, 2020).

This report looks back at the user experience of 28 learning disabled care home residents in Croydon to assess how well the service was delivered and to support future planning until the COVID-19 restrictions are relaxed.

## 1.2 Rationale and Methodology

We ran a survey from 14<sup>th</sup> August 2020 to 22<sup>nd</sup> November 2020 online where we received 29 responses. This survey was shared by the care homes themselves

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<sup>1</sup> Department of Health and Social Care (2020) Coronavirus (COVID-19): adult social care guidance. <https://www.gov.uk/government/collections/coronavirus-covid-19-social-care-guidance>

either virtually or by paper copies sent to a Freepost address. We also offered a service where residents could call our hub number and provide their answers over a phone conversation, but no respondent took up this route.

### 1.3 Method

Respondents received a letter with a link to a survey on Healthwatch Croydon's online survey platform, SmartSurvey, with the following questions. These questions were specifically written to be easy read and were supported by graphics to support understanding. These are the questions we asked.

- 1) Where do you live?
- 2) What has it been like living in the care home?
- 3) Were there changes in staff during lockdown?
- 4) Were you able to spend time with other people you live with?
- 5) About meeting doctors and getting prescriptions/tablet
- 6) Have you been able to see your doctor during this period
- 7) Have you had access to your prescription/tablets during this period?
- 8) Have you had to keep away from others to stay safe? This might have been keeping two metres apart, or it might have been staying in your room?
- 9) Have you been able to speak to your friends or family, via phone or video call (e.g. Skype, Zoom, FaceTime)?
- 10) Have family and/or friends visited you in the last couple of months?
- 11) During lockdown, how could things have been made better? What would you have changed or done differently?
- 12) What you've told us has been really helpful, and will help us make things better. Would you like to answer questions like this again in the future? If you would like to help us again, please tell us your name, phone number and email address.

## Limits of the research

**Size of sample:** We were able to gain the views of 28 residents who were learning disabled across 10 homes, this only represents 15% of homes as there are 65 care homes supporting those with learning difficulties in the borough. There is an unevenness in the number of responses we received from different homes which is discussed in the analysis - three care homes accounted for 19 of the responses, see page 8.

**Representation:** We relied on care homes to share this with their residents. Those facilities that were open to this will have been supportive, but there are limits in representing those who did not share this with their residents. Even though we designed the survey as easy read, most residents would probably need help from staff to read and respond to the survey, which may have possibly had an impact on their recorded responses.

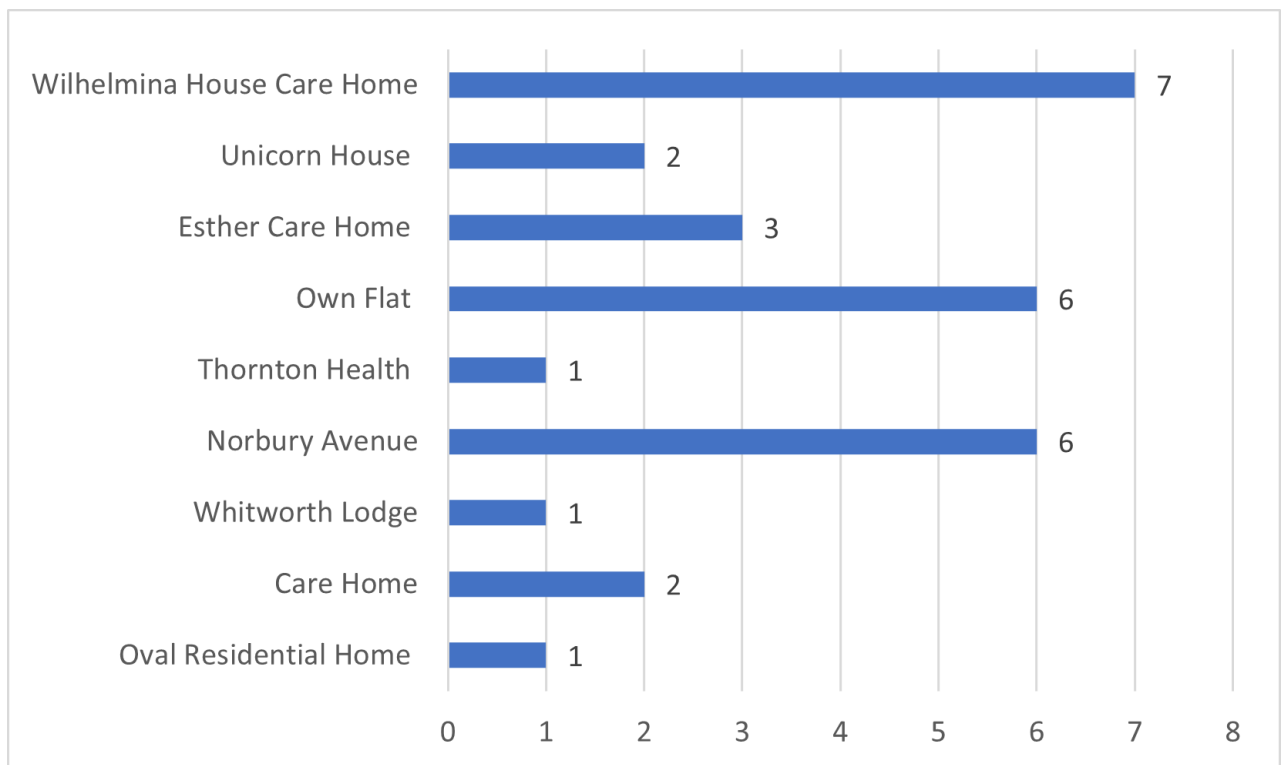
**Context:** Questions were written to gain views on the impact of the first lockdown which ended in July. There may be time lag in responses as some were completed in late October.

## 2. Insight results

These are our findings based on the survey responses we received, here you will be able to see a more in-depth analysis of respondents' answers.

### 2.1 Where do you live?

From the pie chart, you can see that residents with learning disabilities that were spread out across the various care homes that we are able to contact, with a larger proportion coming from Wilhelmina Care Home and Norbury Avenue.








## 2.2 What has it been like living in the care home?

Understandably the rate of satisfaction for the residents for a ‘good’ rating decreased by 20% from 82.8%. This would indicate that several residents were unhappy at the way that COVID-19 procedures were being managed or that they were unhappy with the impact that the pandemic was having on their life at the care home itself.



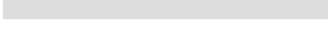
Of the residents citing an ‘OK’ this went up by 24.1%, this could suggest an indifferent opinion on how the pandemic was being handled or an appreciation of efforts the respective care homes were making.

Of the respondents a number have simply detailed that they found that living at the care home was ‘good’ or ‘alright’ or ‘good, I get what I want’. Then there were other respondents to provide more detailed insight with talk of homes now being better and following procedures compared with more relaxed processes prior to lockdown. Another comment which we observed is that residents were feeling more isolated as they were unable to visit day centres or see and visit their friends and family and therefore this took an emotional toll. This links in with one of our core findings that quality of life within the care home was less enjoyable than before the pandemic.

### Before lockdown?

Answer Choices	Responses		
Good		82.14%	23
OK		14.29%	4
Bad		3.57%	1

### Since lockdown?

Answer Choices	Responses		
Good		60.71%	17
OK		39.29%	11
Bad		0.00%	0

Comments:

“I am enjoying staying in the Home. I was taught how to use iPad in painting and colouring, we have dance lesson and exercises. Many activities to do.”

“Better since lock down, they had to follow proper procedures. Before March they were so sloppy-and got away with it.”

“Better since lock down, they had to follow proper procedures. Before March they were so sloppy-and got away with it.”

“Very Good.”

“Good.”

“I have to self isolate with my sister and it was very difficult.”

“It was difficult because I couldn't go out as I use to.”

“It was difficult time for because I couldn't do the things I use to do.”

“It was difficult time for me because I couldn't see my family.”

“Understanding about lockdown, keeping social distancing. Staff to make sure explained to me, updating covid-19 and followed guidelines.”

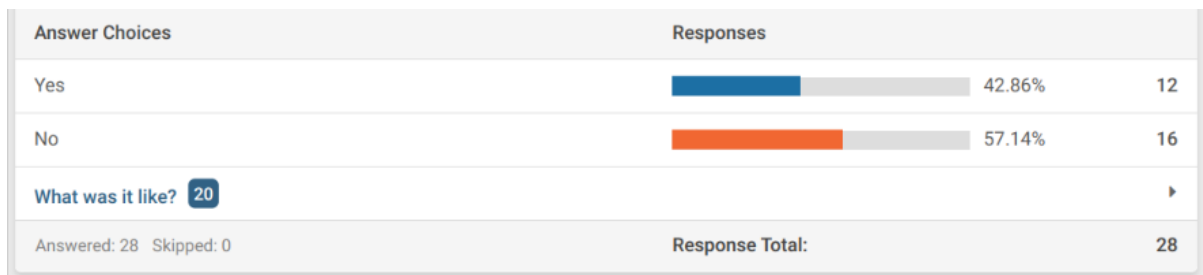
“Before lockdown, we had entertainment and students from the local school coming to visit us, since lockdown things have changed and not so many people are coming to the home, only nurses. We have been doing some activities at a distance, exercise and quizzes.”

“It was a bit strange having to stay in my room. We had to had all our meals in there and saw no other residents only the staff.”

## 2.3 Were there changes in staff during lockdown?

The perception in the change observed in staff by residents was marginal, with 44.8% of residents citing ‘yes’ and 55.1% citing ‘no’.

Across the care home their perception varied, of the 28 respondents that answered this question eight respondents cited that the staff were ‘good’ or ‘okay’. Of the more detailed responses, respondents spoke of it as being like Star Wars in that they were wearing masks. Others saw how hard the staff were working: “We had our usual staff, who worked very hard. I felt sometimes that they were always at the care home and never went home. It was very strange not going downstairs into the lounge or dining room.” and others spoke of staff that worked 24 hours and being supportive. From all the responses, there were zero respondents who made any negative remarks, and again looking at our findings it was observed that went beyond their duties to help residents.



Comments:

“We had out regularly staff and our activities co-ordinator also helped out. They worked as a team together.”

“The staff were the same, just doing more hours than normal and always thinking about keeping us safe.”

“We had our usual staff, they were doing more hours and work then they usually did. They worked very hard.”

“Not Really.”

“More staff in Duty coz they had to do it proper. So much better.”

“They were like "star war" - wearing masks and washing hands often.”

“Not really.”

“Staff were very helpful and supportive.”

“When I return, I meet some new staff.”

“Staff were very supportive.”

“Staff here were very helpful.” “We had out regularly staff and our activities co-ordinator also helped out. They worked as a team together.”

“We had our usual staff, who worked very hard. I felt sometimes that they were always at the care home and never went home. It was very strange not going downstairs into the lounge or dining room.”

“The staff were the same, just doing more hours than normal and always thinking about keeping us safe.”

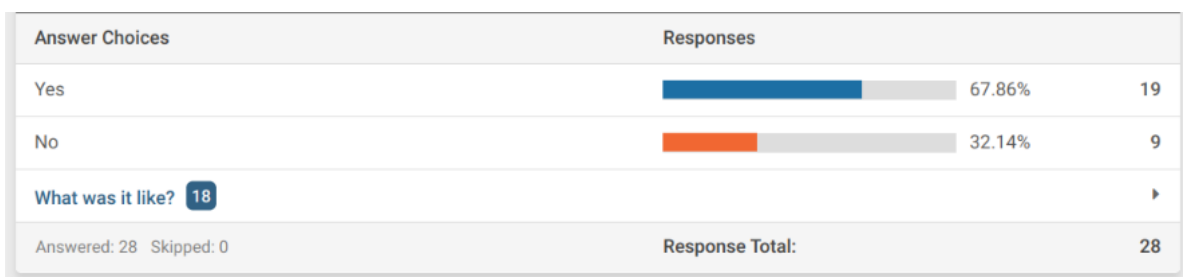
“We had our usual staff, they were doing more hours and work then they usually did. They worked very hard.”

## 2.4 Were you able to spend time with other people you live with?

Residents with learning disabilities were asked whether they were able to spend social time with other residents, with a view to find out if residents were socially distancing within their own homes.

From the respondents, 69% of people said that they were able to spend time with other people that they live with and 31% of residents said that they were not able to spend time with other residents. This suggests that social distancing rules vary from care home to care home, the results might be affected by some homes housing more residents that are required to shield themselves from other residents due to complex health needs.

We further asked residents to explain what the social distancing rules were like for them personally. From the responses, a few residents cited that they were able to mix with other residents and play games such as bingo, cooking and games, whereas there were other responses that detailed that they were shielding or that they were able to mix but only at a 2-metre distance. One of the more challenging comments made a remark about the staff being able to access and provide care throughout a particular home where residents were required to stay within certain allocated quarters. This would be a fair assessment as depending on what infection control measures were implemented, staff could pass the virus within one shielding quarter to the next. However, this may have to have been overlooked due to staffing constraints. In conclusion we observed that social distancing rules varied from care home to care home.



Comments:

“We always enjoy being together we play games, scrabble, bingo and work together in the garden.”

“Very very nice.”

“I was able to see House mates but with 2 metres apart.”

“It was difficult because some of them were shielding.”

“Not really, we had to stay in our rooms. We had all our meals in our room.”

“Yes and no. We were together that’s ok. Could not meet with our next door neighbour wing-in the same care home. Very unfair. Staff just took virus through the whole big building. Shocking.”

“We had out regularly staff and our activities co-ordinator also helped out. They worked as a team together.’

“The staff were the same, just doing more hours than normal and always thinking about keeping us safe.’

“I was able to see House mates but with 2 metres apart.”

“It was a bit strange not seeing the other resident's (sic) like I did every day, and always in your room.”

“I missed seeing the other residents it was like being in prison. Being on your own is no fun.”

“We had to keep our distance and stay in our room.”

“We had all our lunches, dinner and breakfast in our room, seemed very strange.”



“Not really, we had to stay in our rooms. We had all our meals in our room.”

## 2.5 About meeting doctors and getting prescriptions/ tablets


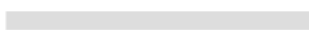
The Covid-19 pandemic has unfortunately reduced access to certain health and social care resources within larger communities and the UK, therefore we wanted to find out whether access to prescriptions and GP appointments had been affected for residents with learning disabilities within these care homes.

We can see that access had been severely affected with 75.5 % of residents not being able to gain access to see the doctor during this period. This may be because their expectation would be to see the doctor face to face and they may not have counted any telephone calls or video calls specifically as a visit, or that they were not able to access telephones or video call services. We are of course aware that many GP services moved online to help the public access their GP, however, this may have proved difficult within the care home setting due to a lack of technology and or mobile phones or poor staffing resources that could not facilitate these phone calls. We also questioned whether residents were about to get hold of their prescriptions as usual and all the residents answered yes.

Have you been able to see your doctor during this period?

Answer Choices	Responses
Yes	 25.00% 7
No	 75.00% 21

Have you had access to your prescription/tablets during this period?

Answer Choices	Responses
Yes	 100.00% 28
No	 0.00% 0

Comments:

“It was difficult to get appointment with doctors during corvid 19 (sic).”

“I couldn't attend any appointments during the lock down.”

“The doctor did not come in, but we had monthly visual contact on the iPad, so I was able to speak to the doctor.”

“We did not see the doctor in person, but did a virtual.”

“I was not able to see doctors and even over the phone it was difficult.”

“All my appointments were cancelled.” “Telephone conversations with the gp.”

“We were able to get our prescription and tablets, we did not see the doctor she was not allowed in our care home.”

“We did not see the doctor in person, but did a virtual meeting every two weeks with the residents.”

“The doctor has not come into the care home, but we have had visual contact with her.

“We did not see a doctor in person, we were still able to get our medication.”



“The doctor was not allowed in, but I was still able to get my tablets.”

“Staff orders our medication to our GP through video.”



## 2.6 Have you had to keep away from others to stay safe? This might have been keeping two metres apart, or it might have been staying in your room?

This question allows for more clarity around whether residents who did mix with other residents were socially distancing in those groups wherever possible. From the data, we can see that 85% of residents had been observing COVID-19 precautions to keep themselves and others safe as well as those that are shielding. We wanted to find out more from this question and so asked residents to detail their experience. From the detailed responses, we found that many were shielding in their rooms and when in the communal area a two-metre distance was observed. This was difficult for many with one respondent stating, “Yes we had to stay in our room for a long time it was hard not seeing anyone only the staff.”

Answer Choices	Responses	
Yes	 85.71%	24
No	 14.29%	4
Tell us more: <span style="border: 1px solid black; border-radius: 50%; padding: 2px;">17</span>		▶
Answered: 28 Skipped: 0	Response Total:	28

Comments:

“We call it E-Ts finger apart, we can feel the tingle without touching.”

“Another home my elders have to stay in each bedroom. Yet share toilets etc, so it’s stupid as loo only gets a clean once a day. Shocking. Elders get bad service. We are youngish and ok 🙄 ”

“It was a difficult time.”

“It was difficult time because some of my friends were shielding.”

“Some of my friends were shielding and I couldn’t spend time with them.”

“I have to separate my self from others to keep my self safe.”




“Yes we had to stay in our room for a long time it was hard not seeing anyone only the staff.”

“I have been staying in my room for the 2 month and then we were allowed in the communal area keeping our two metres distant, having our meals only on a table.”

“We have had to keep the two metres distance from other residents in the home, we sometimes forget.”

## 2.7 Have you been able to speak to your friends or family, via phone or video call (e.g. Skype, Zoom, FaceTime)?

Since the start of the pandemic many people have been able to rely on video calls to keep in touch with other friends and family, often this requires access to relatively newer models of mobile phones and technology. We asked all residents whether they were able to get in touch with friends and family via video calls and 100% of respondents answered yes. This is a very positive outcome as we know that not being in touch with friends and family can negatively affect mental health. Overall residents felt that they were able to gain access to friends and family, but there was a mixed view on how the procedures around this was run.

Answer Choices	Responses	
Yes		100.00% 28
No		0.00% 0
Tell us more: <span>20</span>		
Answered: 28 Skipped: 0	Response Total:	28

### Comments:

“My mum phones me once or twice a month she lives in Ghana. I speak to my sister and brother at times.”

“I have a phone in my room so was able to communicate with my family and friends and also through Zoom on some occasions “

“We have our activities co-ordinator who has arranged Zoom and facetime calls for us which has helped us a lot.”

“I couldn't see my family during the pandemic.”

“I couldn't see my family but was able to speak to them over the phone.”

“I was only able to speak to my sister over the phone.”

## 2.8 Have family and/or friends visited you in the last couple of months?



Within this question we saw a mixed range of responses, with 51.7% of respondents saying yes that they were able to see friends and family and 48.2% answering no. It is important to note that this survey was live throughout the first lockdown, up until the start of the second lockdown and therefore some of the responses consider more lenient COVID-19 precautions just after the initial lockdown. Overall, respondents said that they were able to see friends and family but only outside and at a distance, with a few saying that they were not able to see friends and family, the more detailed responses were predominantly given by those who did see their friends and family with an observation of the COVID-19 precautions.

### Comments:

“They were not feeling comfortable to see me without to hugs, kisses, so they did not come.”

“No, not yet they told me they will see me sometimes but we talk over the phone.”

“Yes my dad came for my birthday.”

“I did not see my family.”

“I saw my family on my birthday in the garden at a distance and yes they did wear a mask it was do lovely to see them.”

“We have been allowed to see them in the garden for an hour.”

## 2.9 During lockdown, how could things have been made better? What would you have changed or done differently?

The last question we asked was on how the situation could be improved if a pandemic was to occur again? Many residents answered, 'nothing' or 'don't know', this would suggest that residents were overall happy with the way the first lockdown was handled, other responses commended the staff on their hard work, whereas there were those who wanted to stop talking about Covid-19 and keep life as normal as possible, indicating the level of frustration experienced from care home residents. Then there were other activity suggestions such as baking, sewing as well as access to services such as the GP and Day Centre.

### Comments:

"I do not know as they made me happy in the Home. All staff are very good to us."

"I think everything was handled well by the home." "To be able to visit my GP."

"Nothing, the staff were all wonderful and all worked very hard."

"To be honest, our care home has done so well, I don't think there is nothing I would change."

"Stop going in about it. Moaning staff. Thus is life now, let's get living it."

"I don't think so something could be done better."

"To be able to go to my day centre." "Cooking, sewing, talking to friends."

"To be able to support people who were really in difficult situation."

"Cooking, baking with other service user, playing archery, writing story (sic)."

# 3. Responses to our research

## Croydon Council/ One Croydon Alliance

Please note that we also undertook at this time three other surveys with other care home residents, family and friends, and staff. There is a report for each of these at [www.healthwatchcroydon.co.uk/learn-more/our-reports/](http://www.healthwatchcroydon.co.uk/learn-more/our-reports/) as well as an overall report which draws together the overall themes of the experiences of using, visiting, and working in care homes in Croydon.

This report will include the overall response from commissioners and stakeholders.

## 4. Quality assurance

Does the research ask questions that:

**Are pertinent?** Yes, they ask learning disabled residents the experience of supporting services users in care homes since COVID-19 lockdown in March.

**Increase knowledge about health and social care service delivery?** This research helps both commissioners and providers of services both in the health and social care sectors about the experience of residents with learning disabilities which will help future planning.

**Is the research design appropriate for the question being asked?**

**a) Proportionate:** Yes, the aim was to gain the views of as many of Croydon's residents with learning disabilities living in care homes as possible.

**b) Appropriate sample size: Has any potential bias been addressed?** We aimed to speak to as many as possible - we spoke to 28 residents with learning disabilities from 11 out of 65 learning disability facilities which was 16% of facilities. There was a bias in responses from some facilities with 19 responses coming from three facilities.

**Have ethical considerations been assessed and addressed appropriately?**

Beyond the usual standards of anonymity, we had to rely on care home facilities themselves in communicating the survey to their staff. The resident's themselves were encouraged to reply with anonymity. The questionnaire was designed under easy-read with careful use of language and relevant graphics to support the questions and help understanding.

**Has risk been assessed where relevant and does it include?**

**a) Risk to well-being:** None.

**b) Reputational risk:** That the data published is incorrect and not of a high-quality standard. We carefully analyse the data that come directed to respondents' answers on the Smart Survey platform.

- c) **Legal risk:** Have appropriate resources been accessed and used to conduct the research? There was no need to refer to legal resources for this research.

**Where relevant have all contractual and funding arrangements been adhered to?** This has come from Healthwatch Croydon's core funding. The local leadership board agreed to taking this project forward in line with our priority matrix and in response the situation because of COVID-19.

### Data Collection and Retention

**Is the collection, analysis and management of data clearly articulated within the research design?** Yes.

**Has good practice guidance been followed?** Yes.

**Has data retention and security been addressed appropriately?** Yes.

**Have the GDPR and FOIA been considered and requirements met?** Yes.

**Have all relevant legal requirements been adhered to ensure that the well-being of participants has been accounted for? ie the Mental Capacity Act.** None required for this research.

**Has appropriate care and consideration been given to the dignity, rights, and safety of participants?** Yes. Anonymity was assured including a Freepost reply option/.

**Were participants clearly informed of how their information would be used and assurances made regarding confidentiality/anonymity?** Introductions and conclusions of the survey explain its use.

### Collaborative Working

**Where work is being undertaken in collaboration with other organisations have protocols and policies been clearly understood and agreed, including the development of a clear contractual agreement prior to commencement?** We worked with Croydon Council's care homes commissioners and the wider Care Homes Strategy Group to gain their views in shaping the project and testing the questions.



Have any potential issues or risks that could arise been mitigated? These are shown below:

Risk factors	Level of risk	Contingency
Cannot get enough responses	Medium	Encourage the care homes to share with their residents
Question set does not work with group	Low	This was tested with Care Home Strategy Group before the launch.
Data is seen as being out of date	Low	Initial top lines to be shared within a month of survey closure. Full report to follow up when effective analysis is complete.

**Has Healthwatch independence been maintained?** Yes, this research is shared with partner organisations before publication for their comment, but only factual inaccuracy would be reviewed. This does not affect the comments of experiences we receive.

### Quality Controls

**Has a quality assurance process been incorporated into the design?** There was a proper process of scoping with Croydon Council and board members

**Has quality assurance occurred prior to publication?** Data collection was checked and re-checked.

**Has peer review been undertaken?** No peer review was undertaken. It was not required for this research project.

### Conflicts of Interest

**Have any conflicts of interest been accounted for?** This project was decided upon by Healthwatch Croydon in discussions with Croydon Council care home commissioners and the Care Home Strategy Group. At all times, board and manager are satisfied that its independence and neutrality has been maintained through this project.

**Does the research consider intellectual property rights, authorship, and acknowledgements as per organisational requirements?** The research is owned by Healthwatch Croydon, who are managed by Help and Care. Other organisations support has been recognised and suitably referenced.

**Is the research accessible to the public?** It appears on our website as of 24 June 2021.

**Are the research findings clearly articulated and accurate?** To the best of our knowledge, we believe they are.

## 5. References

Department of Health and Social Care (2020) *Coronavirus (COVID-19): adult social care guidance*.

<https://www.gov.uk/government/collections/coronavirus-covid-19-social-care-guidance>



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