

HWMK Coronavirus Survey Results 4 May to 18 May 2020

During this challenging time, it is more important than ever that people are able to share their experiences of health and social care services so that Healthwatch Milton Keynes can help resolve key health and care issues now, and so that we can support our local system to learn lessons for service quality and delivery the future.

To aid the professionals who are working hard to ensure that the people of Milton Keynes receive the support they require, Healthwatch Milton Keynes are collating the results of our ongoing survey so that there is up to date information about what is working well, and where further support or communication is needed.

This first report contains the survey results from 101 Milton Keynes residents who responded between 4 May 2020 and 18 May 2020.

30 respondents identified themselves as Carers. The majority of responses were from people of a White British background, with 18 people telling us they were from various BAME backgrounds.

Age and gender demographics of respondents to date:



Information & Advice



Most respondents reported finding it relatively easy to find and understand the information they needed to keep themselves and others safe.

The survey asked if they, or the person they cared for, had any further communication needs and were told that there was a need for braille, audio or large print, easy read information, and for information to be published in a screen reader-friendly version.

Just over half of those who said they had additional communication needs reported that they had not been able to find it in the format they needed.

We asked if any specific information or sources of information had been especially helpful, and why.

The Healthwatch Milton Keynes weekly e-alert, website and social media posts were reported by respondents to be as especially useful as the Gov.uk website and NHS websites. MK Hospital were also mentioned for their informative updates on visiting/attending the hospital.

Kidney Care UK's information, acting as a coordination point for all major renal organisations, was reported to be helpful also. The BBC, especially the daily briefing, was listed as a very useful source particularly for those who didn't access the internet.

The reasons given as to why the information from these local and national sources was especially helpful were: that information was factual; up to date; concise; and coherent.





How easy have you found it to find the information you need about how to keep yourself and others safe during the Coronavirus



How easy have you found it to understand information you need about how to keep yourself and others safe during the Coronavirus Pandemic?



Information & Advice



What specific topics would people like more information on?

"What support is available should a member of our household get infected?"

"Testing station at MK with availability three mins walk away, why are we being sent to Peterborough for testing?"

"How the virus would affect people with ME, chronic fatigue syndrome, fibromyalgia syndrome, hypermobility syndrome, osteoporosis"

"Grocery shopping. Cannot get delivery slots. Forced to queue with no provision for disabled. Cannot follow arrows on floors"

"Early warning signs and when to access help sooner"

"Having medicines delivered"

"How to access dental services"

"How to stay safe at my Mums funeral"

"How to access care services"

"How to access the health visitor services now we are locked down and how we attend weigh in clinics for new-borns"

"How will I get my child their immunisations?"





Some people chose to tell us more about the changes, good and not so good, they have experienced

"GP surgery did not seem to have a plan for how to perform regular necessary routine tests"

"I said I needed to know before a week on Friday about the medication I am taking, maximum dose and should it be reduced. Receptionist said Dr will call you this afternoon. I kept the phone with me the whole afternoon and evening. Nothing. Now it's bank holiday and so I can't contact anyone until Monday"

"Appointments going to phone consults and it is a lot harder to contact people to ask advice"

"Getting to see a doctor has become harder, having an issue start just before the virus took hold meant that follow-up appointments were hard to get and were handled over the phone, not great when you actually need to be physically seen, in my opinion"

"I have had my vitamin B12 injections stopped. This has led to me having added tiredness, numbness. This has not helped me as I am still working full time."





"I have a health need which can only be fulfilled by an in-person appointment with the GP. This is supposed to be 3 monthly and was due at the end of April. GP has asked that I wait at least another month, preferably longer. There is an infection risk the longer I delay but she gave me no confidence that she would see me in another month. I feel there needs to be a plan and risk assessments put in place for people like me who need face to face appointments because the situation with Covid is unlikely to change in the near future"

"I phoned the number that I had for the yearly urology clinic and was told that the urology people would ring me back. I kept my phone with me all that day and the next day but had no answer to my request for some much needed advice to stop my pain. Two and a half weeks later I still had heard nothing so contacted the surgery to tell them that I was feeling better by then and had solved the problem myself"

"I have been left without support even though I'm under the integrated community support team. My husband has still had to work and I've had to home educate my children. It's been hard."

"Non coronaviral medical help is non-existent"

"I was unwell with a chest infection and my GP refused to see me, sending me instead to A \pm via the 111 telephone service"





"GP surgery has been very good at telephoning me and sorting out what they can although I often use GP telephone services anyway" "GP now making phone consultations which work better for me as I find visiting the surgery stressful"

"The surgery have always responded quickly to my health concerns, and enabled the GP to phone me for advice"

"Doctors have informative voice recording. You are then put through promptly to speak to someone. Telephone consultation same day and pharmacy works very hard to get script ready asap. They have all been brilliant."

"Phone consultation- all ok"

"Very easy to get medical advice without having to wait weeks for an appointment or being spoken to like a child by a receptionist"

"Called to see if my 11yr old could see a doctor due to something serious, but not covid related. Lady on desk said a GP would call me within an hour. That was 4 days ago. Rang again today, still no call. She needs a blood and urine test. Cannot access any healthcare during this time"

Experience of Change in Hospitals



"I have communicated more via telephone and visited the hospital less. I have received appointment dates and times via telephone (sometimes at very short notice) but had to wait for the unit doing bone scans to reopen before I could have my scan. Overall I have been very impressed with the care I have received during this time."

"All hospital services have been suspended and I am not getting the osteoporosis treatment that I need to avoid fractures which is a bit of a worry"

"I was referred to gastroenterology at the start of the lockdown. I received a letter saying to call hospital if I had not received an appointment by 1 April. I have called and been told there are no appointments and to wait. No info on how long the wait will be yet the government are advising not to delay getting referrals. Meanwhile my symptoms get worse and worse and I do not know if my problem is causing more permanent damage or even could prove life threatening."

"I was sent an automated message three days before my eye appointment to check that I would still be attending. I couldn't quite believe that the appointment would go ahead on 1st April so I telephoned the eye clinic and they said they were shocked that the message to confirm the eye clinic appointments were still going out at the very end of March. They had asked them to stop"

Experience of Change in Hospitals



"Appointment changed to Stoke Mandeville and a month later. Almost impossible to get there on public transport. No consultation at all, not offered any alternatives."

"Essential procedures at the hospital meant I had to go to ophthalmology dept. They made me feel safe and things were handled well. The evening I had a debilitating headache and couldn't stop vomiting. 111 told me to go straight to emergency and take an ambulance if no-one was around to take me. Triage made me feel like I was wasting everyone's time and told me I shouldn't have listened to 111 but the Dr I saw was amazing and comforting and told me I did the right thing. It turned out to be my first ever migraine triggered by the procedure.

"Was referred to Urology and Cardiology departments in early December. Urology appointments rescheduled or deferred several times even before the pandemic took hold. Not received a cardiology appointment at all.

It's a year since my pacemaker was fitted privately. Follow-up not covered by insurance and I've been unable to feed back into NHS care to confirm whether or not the PM has improved my heart failure and whether my (pre-PM) meds can be changed."

"I had a telephone call from the hospital cancelling my appointment and have since received numerous letters accusing me of not attending the original appointment"

"X-Ray cancelled. Consultant interview delayed"

Experience of Change in Maternity Services

"I was aware that as a result of GPs restricting access there may be changes to how I access midwife appointments at the GP so I called the community midwife team prior to my appointment to ask. They told me to call the GP who informed me that unless I was told otherwise by the midwife to attend the appointment. I attended the appointment only for the midwife not to show up. She eventually called later that afternoon, made no apology and spoke as if I should be aware of the changes without receiving so much as a text or letter from anyone from the team."

"Cant have the visits from midwives and health visitors you normally get"

"Letter doesn't explain where the immunisations for my baby will take place. We have had the 8 weeks and 12 weeks injections at the Doctor's surgery without problems, so don't see why it has to be done at a separate facility and communications does not explain"

Experience of Change in Dental Services

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"Without information about dental services people become anxious about problems that may arise" "Dentists closing with no reopening date is a major problem. Left in severe pain and don't know why. Can't sleep, eat properly or drink"

"I was due to begin dental treatment in March at my dental clinic. This did not go ahead because a) the dentist was leaving and wouldn't see me through the treatment, and b) the Covid-19 situation meant the surgery was closing anyway. I was anxious about the discomfort I had around the tooth that needed treatment and, since then I have spoken to the receptionist who is taking calls. She has tried to be helpful and referred me to a dentist by phone. He also tried to be helpful by giving me some advice on pain relief. However, it seems the dental clinic cannot open yet because they don't have the advice or PPE they will need. Apparently there is a 'hub' somewhere but basically it's just for emergency extractions. I can't understand why a front-line service like dentistry seems to have such low priority. There must be hundreds of people waiting for fairly urgent treatment"

Experience of Change for Carers and people with disabilities



"I had to find out for myself that respite care would not be happening! I care full time for my husband who is verbally abusive and difficult to deal with due to his dementia. He is also physically disabled and brain damaged due to a stroke so looking after him is very stressful! No one cares about the unpaid carers who do a very demanding job caring for a family member! The impact of not being able to take a break from the stressful daily caring is having an affect on my mental health and the longer this goes on the worse it will get"

"My household worker cannot visit"

"People with disabilities are forgotten. When pushed, the response has been a vague assurance that there will be voluntary, unregulated, untrained help. Otherwise the advice has been to make your own contingency plans with no PPE"

"My carers are isolating and I am doing without many many basic needs"





"Without knowledge as to who to contact about drug collection and delivery I am left risking my health or the health of my wife by having to collect medicines in person from the pharmacy."

"Had to attend my Psychologist appointment by Zoom"

"Chiropodist made special effort contact use and to provide a safe service keeping to guidelines"

"I cannot trust strangers to get my money. I need standing orders paid but can't transfer money"

"Cancellation of some procedures regarded as routine, in particular removal of ear wax. I have a severe hearing loss, compounded at present by wax which needs to be removed and is further dampening my hearing and interfering with my hearing aids. In the best of times communication at a distance of 2 metres is extremely difficult, now it is virtually impossible" "It is very difficult to get my prescriptions, it involves danger for me and I cannot access the advice from pharmacy because I am too afraid to go into the shop/ pharmacy and talk and they have been too busy to answer the 'phone."

"I also had a telephone physio appointment and he emailed me some exercises for my frozen shoulder. None of the exercises seem to be for my shoulder and 3 are impossible to do with my disability so I think I was given someone else's by mistake. I've not been able to get hold of the physio since to discuss it for 3 weeks now, and have looked up exercises on Google"



"Standardise care and communications. i.e. my neighbour is in a shielding group and the doctors advised the local Age UK of this. They do her weekly shopping and she has had two free food parcels delivered. I received a letter to say I was vulnerable and to shield for 3 months. End of. As far as the doctors and government are concerned I could have starved to death by now. No emergency food until arrangements could be made. Fortunately, a colleague from the charity where I volunteer was able to help. At the beginning I was scared"

"Sort testing out. I had tests on 4/5/2020 and still no results. Had to go to Peterborough for the tests. Not acceptable for something so important" "Sort tout dentistry—at least for emergencies"

"Notifications. Please tell me what I should do"

"More access to GPs"

"At end of each interaction say - 'is there anything else I can do that will make life easier for you? And then do it"

"Have access to a local information hub where such information and concerns that I have raised could be found. This matter raised with my local councillors and MP but no positive response"



"Never make any plans or guidance or regulation without including people with disabilities. To have to say that after decades of people fighting for the DDA and EA is a scandal"

"That everyday illnesses and follow up appointments continue to be reviewed as normal, that requests for hospital services are actioned so that normal issues are treated in the normal timeframes"

