



What's it like for people right now?

**Public Insights from
Healthwatch Kent & Kent
User Forums**

**January 15th-31st
2021**



Background

Every day both Healthwatch Kent and the Kent User Forums are working together to hear feedback from people about how they are coping right now. In the second two weeks of January, 56 people shared with us their experiences of the Covid 19 pandemic and life under social distancing. We have combined this with anecdotal feedback from 14 organisations who support a wide range of Kent residents including people living with mental health, physical disability, sight loss and impairment, carers and those suffering domestic abuse.

This report details everything we've heard. Its purpose is to enable decision makers and planners to understand how people are coping during the COVID epidemic.

Methodology

We have been gathering feedback through a number of routes:

1. The number of calls to our Helpline has steadily increased since March
2. People also share their experiences with us via our website, email or text
3. We've been running a series of social media campaigns to capture feedback
4. The Kent Forums have been proactively gathering feedback from the communities they represent
5. Regularly talking to community groups and voluntary organisations to understand how their clients and members are coping

Since March, Healthwatch staff and volunteers have been building relationships with voluntary organisations and community groups. This has enabled us to hear from communities who may find it harder to share their feedback such as people living with Dementia.

What do we do with the feedback?

Every month, we bring together all the feedback from the multiple sources into one report. This is then shared with decision makers to provide a timely snapshot of how people are coping.

What are we trying to achieve?

This report aims to summarise and reflect the changing experiences of people living and working in Kent during the Covid 19 pandemic.

Our aim is that the feedback is used to support emergency and recovery planning across the health and social care system in Kent.

Things to remember when reading this report

- The comments in italics are direct quotes from people. They are people's personal views, not the view of Healthwatch Kent or the Forums. Other comments are anecdotal pieces of feedback from organisations.
- This is a snapshot of feedback over a month-it is not intended to replace an organisations own responsibility to gather feedback from the public.
- Wherever possible we are raising issues and sharing feedback directly with relevant organisations.
- You may read some worrying stories. Some of these have come directly from the public and they have given us contact details, we are following up with them and escalating if necessary. However, not everyone will give us contact details. Where organisations have shared concerns with us, they are following their own safeguarding and escalation protocols.
- The previous months reports are available on our website.

Thanks to everyone who contributed!

What are the headlines?

This is a long report with a wealth of information. We would encourage you to take the time to read all of the feedback.

The headlines from this month are:

- **We continue to hear about health care service disruption, with cancellations of outpatient appointments and no news of rescheduled appointments.**
- **We have heard more stories about the struggles that people face when trying to access NHS dental treatment.**
- **The continued lockdown is having a lasting impact on people's mental health and wellbeing.**
- **We have heard multiple stories about people accessing their Covid vaccine, with a mixture of stories about how well run the service was, to the issues around queuing outside in bad weather for it.**
- **So many of you have been in touch to share your experience of being vaccinated, or to ask questions about the vaccine programme. We asked the Head of the Vaccine Programme all your questions, and more. Listen the answers [here](#)**

ACCESS TO VACCINES

SITES/HUBS

- Our social media insights heard of 4 stories of people who visited the vaccine hubs; they were all concerned because they had to stand outside in bad weather and were concerned about other clinically vulnerable people.
- My father (80 years) got his letter today in Dover. He was then given an appointment for 6.15pm this evening at XXXXX but was eventually seen at 7.20pm. There was a hell of a wait because he said he was outside for 45 minutes and the queuing went on once inside the building. People need to be aware that if you can't stand for that long then you should take a fold up chair and extra clothing as it's so cold.
- An organisation working with people who have vision impairments told us that they have received many calls about the vaccination appointments; people have been concerned about travelling to GP hubs or vaccination centers and require transport and assistance, and others are asking if they can request to have the vaccine at home.

RECEIVED IT

- Through our social media insights, we heard of 2 people who had received their vaccine. One person felt that the process was well organised. Both stories told us of the effects that they had after the vaccination (sleepless night, shivers, whole body aches).
- *"My sister works in a school and has had her covid vaccine now because people were not turning up to their vaccination appointments, so it was all going to waste. Luckily the GP hub doing the vaccination contacted the school to get teachers in to stop them going to waste".*
- *"My husband and I were telephoned last week to come in for our Covid vaccinations at our local surgery, XXXXX. Today we duly went to get our vaccinations. We were expecting the huge queues we had seen on TV, as I am unable to stand for long, I was quite apprehensive about the whole procedure. However, on entering the car park, we did not see any queues at all. We went into the surgery at the designated time. We were then seen by a nurse and had our vaccinations. Everything was very well organised and all appropriate measures taken. Within 20 minutes of our arrival, we were on our way home. We were both very impressed with the whole system set up by our practice"*
- *"My elderly neighbour received a call from our local GP, offering her a date and time for her Covid Vaccine. The local GP surgery (XXXXX) were really helpful and explained everything clearly, setting our expectations of travelling to another surgery for the vaccine. On arrival at the other surgery, XXXXX, we were greeted by friendly volunteers who marshalled us through the car park and into a queue to check off our name. We were then ushered onto a pathway, in what was obviously a one way system, and were met at the door by a third friendly face who welcomes us and again checked our name off the list. As soon as we had entered the building we were greeted by a friendly man who introduced himself as a Dr and he asked a few questions before we were again greeted by a friendly face calling us into a side room, where the vaccination was given within a minute. The experience was rounded off by a warm and friendly volunteer in the waiting area, chatting to everyone and working hard to keep all surfaces clean. We were in and out so smoothly. My elderly neighbour felt that she had had a good trip out! Well done NHS, an impressive feat of organisation!"*

NOT HAD IT YET

- *“There is a lot of stress developing in our household at present as people in our vicinity and those we know are reporting having had the Covid vaccination, regardless of age and my wife and I who are both at the top end of 70 and are vulnerable health wise have heard nothing. We have been observing the instructions not to contact our surgery”*
- *“How can I find out if I've been missed for the Covid vaccination as most of my friends of my age and some younger have had theirs? We are all registered at the same surgery. I don't want to bother the busy health centre staff”*
- *“I'm very concerned that we in East Kent do not seem to be getting any vaccine. It has been 3 weeks and nobody I know has had it yet and our clinic does not seem to have any. I am in group 4 of the 1st phase but I don't know any of group 1 in Folkestone who have had it. My dad lives in Maidstone and he had it already”*
- An Age UK in the east of Kent told us that a large percentage of their clients have not heard anything about their covid vaccine, and many of them are feeling vulnerable and confused because of this.
- An organisation supporting people with neurological conditions told us that none of the people living with motor neurone disease that the organisation support on a regular basis, have been contacted by their GP practices yet with regards to having the first vaccine - these people range in age between 35 and 85 and not one of them has been contacted yet.
- An Age UK centre in the east of Kent told us that one client is 95 and received their vaccination. Their spouse, slightly younger, had not been called for their vaccination and they were upset and confused.
- An organisation that run a foodbank told us that not many of their clients will be eligible for the vaccine at this point in the rollout programme, but they are aware that many of their clients are not registered with a GP. This is mainly due to coming straight from domestic rehoming or going into adult social care.
- An organisation supporting older people in the community told us that they are aware of people who are 85 years old and have not had any correspondence from their GP for 2 years; they have yet to hear about their covid vaccine.



DECLINED

- We heard about 2 people who have not yet had their vaccine yet, through our social media insights; we heard that one couple declined the appointment because they couldn't afford the cost of a return taxi and they don't have a phone number to call to make a closer appointment, and another person has no transport to get to a hub and is too afraid to use a taxi or volunteer driver for the 14 mile round trip.

VACCINATE PARTICULAR GROUPS

- Our social media insights told us of 2 stories, where people believe that teaching staff in schools and colleges, especially SEN staff, should get priorities for the vaccine. Another person speaks of the importance of getting unpaid carers vaccinated, the carers that look after a vulnerable person at home.
- *“I have a tetraplegic friend who is paralysed from the neck down. He was told neither he nor his 3 carers are priority for vaccines. He was told by Spinal Injuries Association that he must have the Oxford/AstraZeneca vaccine, and he must tell his GP. He was also told that as he employs his carers he must lobby the government to include them in the priority list. He feels too ill to do this, and his GP is overwhelmed and doesn't have experience in caring for someone so badly injured”*
- Our helpline spoke to a caller who wanted to know how eligibility for the vaccine is determined, as they have 3 members of their family, all with underlying health conditions.
- An organisation supporting people with learning disabilities told us that they are organising the practicalities for the people that they work with, as they prepare to receive the vaccine. In particular, they are thinking about consent and they are looking out for the people who live alone and have no one to guide them. They are aware of the “best interest” policy and will get the process ready in the event that they will need to use it.



TESTING FOR COVID

- *“They (the army) were fantastic. Kind, patient and very reassuring. They ran the place with absolute efficiency but were friendly and nice when giving clear instructions and maintaining the social distancing rules. Well done lad and lasses of our wonderful army at XXXXX”*
- *“I had my asymptomatic test at XXXXX. I went online to book the appointment and there were dozens of available slots. We were able to do the swabs ourselves, I was worried that someone else would do it for us. No one else was in the hall at the time, the army staff said that no one had been for the past half hour, the uptake of asymptomatic tests is really poor in the area. We went straight home and I got my text message within 20 minutes of taking the test to say that I was negative. It's much easier and straightforward than I imagined, but it needs to be advertised locally much more”*
- *“My doctor has asked me to get a covid test; I have COPD. I have tried on line but cannot get a test. I live in Leysdown-on-sea. I am shielding and they are no test sites here. I get bad travel sickness on a bus so I do not travel I do not know what to do”*
- An organisation working with people who have vision impairments told us that they have had many people contact them about the home Covid test kits; they can't get them in large print or braille.

COVID EXPERIENCES

- *“I've had a fairly mild case of covid and I returned to work this week. My oxygen had dropped and my heart rate was very fast, but mostly I just had a bit of a cough, fatigue and my nose was blocked and a fuzzy head. I managed ok at work but I struggled in the last 2 hours and my manager let me leave early. I went home to lay down for a rest, I needed it. Today I feel awful - headache, exhaustion, body aches and nausea, just like I had in the 1st week of infection. I don't think this is a recovery that can be rushed, even for mild cases”*
- A mental health support group told us about a service user that had contracted covid on 2 occasions. It has left them with a long standing cough, which the service user believes draws attention and they feel victimised when they have to use public transport. This has heightened their anxiety.
- Another mental health support group told us that a service user had contracted Covid, and was very impressed with the Covid Virtual Community Team; the team called the service user every day and then every other day when they had improved. They had delivered a pulse oximeter which reassured the service user. They were also encouraged to call into the team if they felt that they were deteriorating. The service user was very thankful for their contact and support.

ACCESS TO PRIMARY CARE

- A volunteer service told us that 8 of their clients had issues getting a much needed face-to-face appointment with their GP in the past few weeks, due to a lack of appointments in their surgery. Another 2 clients had face-to-face appointments, but it wasn't with their own GP.
- An organisation supporting vulnerable families told us that one client was advised to come to their GP surgery for a face-to-face appointment, even though they were told that some of the staff had covid. The client declined the appointment. Another family couldn't get an appointment with their GP due to the lack of availability of the GP.

HOSPITAL TREATMENT

- An organisation supporting people with learning disabilities told us about the struggles that one family faced when they all tested positive for covid; their adult child has autism, and their covid symptoms deteriorated and they were taken to hospital. This caused a lot of anxiety in the family because there was no communication initially, with regards to their child's condition. This was only resolved by one of the parents who made calls to every ward in the hospital to find out where their child was. Communication became easier after that.

DISCHARGE

- An organisation supporting stroke survivors told us about some issues around discharge from hospital; they have heard several stories of early discharge from the hospital due to the need for hospital beds. Other clients have spoken about their concerns about being discharged too early and sent home with inadequate support services in place. There have been stories about patients waiting in the discharge lounge for long periods of time, without any means to contact their family.

NOT GOING TO HOSPITAL

- An organisation supporting stroke survivors told us that they are aware of some people making a conscious decision not to call for an ambulance when they are in medical needs, as they are frightened of going to hospital due to the prevalence of Covid. In some circumstances this has led to death, or smaller strokes happening.



CONTINUITY OF HEALTH & CARE SERVICES

- Through our social media insights, we heard of one family who have still been able to access the HPV vaccines for their children. Another household said that they have not been able to access micro suctioning, as their GP clinic has staff shortages. We also heard that one person has been unable to secure an appointment for their cervical screening, they were told that staff were doing other covid work.
- An organisation supporting vulnerable families told us that a small number of families did not want their child to have their pre-school immunisations because they believed that it would also contain the Covid vaccine. The organisation explained what the preschool immunisations included to the families concerned.
- A young mums group expressed concerns around the relaxation of rules around pills being sent home for ladies to have a termination in their own home, either through their own choice or due to an unwanted pregnancy in an abusive relationship.
- An organisation supporting people with neurological conditions told us that there are ongoing issues during the pandemic, where those who have been diagnosed privately due to a delay in a diagnosis in the NHS, are then being referred back to the NHS for treatment. They are then told that treatment could take up to 90 days, which is not acceptable following a time critical diagnosis.
- An organisation supporting stroke survivors told us that community services for stroke patients at home have been continuing, but a lot of it has been on the telephone rather than face to face, due to a reduction in availability of staff members.
- An organisation supporting people with sight impairments told us that many clients are concerned about the removal of services from GP practices, in order to focus on covid vaccinations. Many GP clinics have removed their chiropody services for this purpose.

MATERNITY

- A young mums group explained that the 3rd lockdown was having an impact on their mental health; they were feeling an increased sense of anxiety. Much of this was related to medical visits and going for scans on their own when they were pregnant, especially when they were given sad news if something was wrong with the baby. They also spoke of giving birth on their own, or having to wait before their partner was allowed into the delivery suite.

HEALTH VISITORS

- An organisation supporting vulnerable families told us that they have had a few of the recent new families express their concern over not having face-to-face visits with health visitors for check-ups on new mums as well as no regular mental health check-ups on vulnerable people. The organisation said that this is especially concerning as many people who have mental health problems struggle to explain their symptoms concisely over the phone. It is also very tricky for people who are in a household with partners who aren't supportive, and can cause rapid and severe decline in mental health that isn't noticed by others or taken seriously because they have to stay at home and don't meet health visitors who could flag up concerns.

ACCESS TO MEDICATION

- *“I've spent 2 days trying to find someone who will give an injection to my partner who has to have a b12 regularly every 3 months. He is overdue yesterday because our GP practice is closed due to covid infection and won't be open for at least 2 weeks. There has to be a back up, when a GP surgery closes like this. We've tried 111 twice who have been very helpful, but they say try the local hospitals - we've tried but they won't do it. I don't know where to go, what to do or who to talk to anymore but he does need this injection”*
- A mental health support group told us about a service user who struggled to get their essential medication when they were unexpectedly told to self-isolate due to exposure. The service user requested that a volunteer collect their prescription, but the pharmacy wouldn't give it to the volunteer as it was a controlled drug. The service user explained the situation to the pharmacy, and they would then allow the volunteer to collect the medication if they had the service user's identification. This meant that the volunteer was going back and forth with ID and various prescriptions.

DENTISTS

- *“I have been trying to access a dentist for some months having moved to from North Essex in June, but no dentist NHS dentist will take me on because of Covid. I was halfway through some dental surgery just before the first lockdown in Essex. This all ceased. I contacted the Dental Hotline to be told no dentist In Kent or Sussex was taking on any new NHS patients and should consider going private. I can not afford to go private. I was laid off from work at the end of the first lockdown and have no income at present”*
- Our helpline staff took 3 calls from members of the public who have been struggling to access an NHS dentist.
- An organisation supporting vulnerable families in West Kent told us that several families that they help are struggling to register with dentists (both NHS and private) at the moment. One family were told that there was no emergency treatment option for their situation, and were issued painkillers.



MENTAL HEALTH

- A service user from a mental health support group is very pleased with the support they have been receiving from the MIMHS service. They have carried on with face-to-face home appointments, and extra appointments have been made to ensure continuity of care. The fact they have continued with meetings during much of the covid period has made a huge difference in reducing the isolation felt by the service user and made it easier to engage with their help.
- An organisation supporting vulnerable families in West Kent told us that their volunteers are now calling clients in the evening, as day times are taken up with managing children and home-schooling. The volunteers are doing their best to support families, who say that there is a wider lack of mental health support.

IMPACT OF LOCKDOWN/ISOLATION

- We heard the story of one person through social media, who has PTSD and has now developed agoraphobia. They are unable to leave the house, even for food shopping
- A service user from a mental health support group said: “I am feeling really down at the moment. I am quite low. I am frustrated by lockdown and fed up to be honest of not being able to see people. I have been staying with my parents, partly to take care of them but also for my own mental health and wellbeing. I have put a lot of thought into it and I’m going to move back to my flat this week. I don’t want to, but I feel this is something I need to do before I become too dependent on my parents and my living situation. I’m fed up with lockdown and with there being no face to face connection. I know I can join virtual groups, but it really isn’t the same. I know I need to engage with something, but depression makes this harder”
- A mental health support group told us about a service user who was supporting their parent; they have been in isolation and has been shielded since March and has now had a breakdown. This resulted in a violent altercation involving their spouse. The parent is now in hospital and their spouse is very worried at home, but needs the respite.
- A service user from a mental health support group spoke about the difficulties they had experienced when the lockdown measures changed over the Christmas period. Their daughter & her family had caught Covid, which caused the service user stress and anxiety. Their other daughter works in a nursing home and the service user was worried about her too. The service user said that they cannot visit either of their daughters due to regulations, and it was extremely stressful, and that they were not feeling good at all.
- An Age UK in the east of Kent told us that one of their volunteers had been shielding, but had decided to return as a driver, because they felt their mental health had declined and they needed to have something to do. The volunteer now feels that they have a purpose in life and is much happier.
- An organisation supporting older people in the community told us that they continue to carry out befriending calls; almost all of the families and carers are said to be struggling with isolation and loneliness due to lockdown.

COMMUNITY MENTAL HEALTH TEAMS

- A mental health support group told us that a service user is happier with the service that they are receiving at the moment; they did not usually attend their reviews because of the number of people in the room who also attend. Due to Covid regulations, it has just been the service user and their care-coordinator in the room, with the consultant on the telephone. The service user said that if the reviews would continue to be held like this, then they would always attend in the future.
- A service user from a mental health support group said that throughout the pandemic their mental health had taken a decline and at times they have not received the support they require. The service user has recently been receiving a weekly phone call from a care co-ordinator at XXXX, who they get on with well and the phone calls are helping, however the service user said that they needed this support right at the beginning.

CHILDREN & ADOLESCENT MENTAL HEALTH SERVICE

- An organisation supporting vulnerable families told us that many of their clients are struggling with appointments and waiting times for assessments; they find that appointments are delayed for the foreseeable future, leaving them unsupported and alone. These appointments are for mental health support for children within CAMHS.

IMPACT ON CARERS

- An organisation supporting carers told us that their clients are increasingly wary of doing any face-to-face meetings.
- *“Some of us have had to become carers quite unexpectedly. My husband was critically ill with covid and was ventilated. Thankfully he was able to be discharged from hospital, but we think he's permanently weakened by it all. The recovery from being on a ventilator will take months we were told. He still isn't well and now I've become his carer. I imagine many more people will be in the same situation as their families are discharged from hospital”*

SHIELDING

- An Age UK in the east of Kent told us that their befriending phonenumber is still picking up a lot of people who are shielding, and even some people who are in their 50s.

ACCESS TO FOOD

- We heard of one person through social media insights, who felt discriminated against when they wore their “Sunflower” lanyard and were asked to stay in the car whilst their partner was allowed in to do the shopping.

EDUCATION

SEN

- Through our social media insights, we heard of one parent who noticed that their child's behaviour was much improved from not going to school. The parent is going to consider permanent home schooling.

OPENING FOR VULNERABLE/KEYWORKER CHILDREN

- Our social media insights told us about a keyworker who has been refused a school place for their children because their partner is working from home.

HOME-SCHOOLING

- We heard of one parent through social media insight gathering, who is working full time from home and home schooling 2 children, with no other help. They feel that the school have not been supportive and the parent has to read the lesson plan the night before to make sure they understand the content.
- *"I recently changed my children's school, during a pandemic, whilst they are closed and it has been the best decision I ever made. When I moved to Kent in August 2019 I didn't have a choice of schools so I enrolled them at the only one that had a space. During the 1st lockdown we didn't have any support, no live lessons, the only work was times tables and reading. I found home-schooling very difficult and completely isolating, and in the end I had to do my own style of teaching. My children joined a new school on Monday, the one we originally wanted for them and it's amazing; live lessons from 9-3.15, work set by the teachers, weekly call with the teacher. I know that being at this new school will help my children to catch up on the lost learning. I feel that the old school made no effort to teach new things, they just done times tables over and over again, so the children have missed out on learning. This new school are building up their confidence and they are progressing now. It's amazing the difference that a new school can make. I tried my best but I'm no teacher and I also have a toddler to deal with as well. I just hope that more schools can improve on the quality of home-schooling for our children, it's only January but I think we can all see that this is going to last quite a few more months"*



FINANCE

- An Age UK in the east of Kent told us that they are still receiving a large number of calls requiring help to fill out forms for the DWP, and to change benefits. Many people find it hard to discuss these matters on the phone and the face-to-face discussions are important.
- An organisation supporting people to live independently told us that their clients have concerns because the DWP are working out with normal hours during the pandemic; their clients feel that they have to be available at evenings and weekends in case they are required to call the DWP office.

TRANSPORT

- An organisation supporting stroke survivors told us that one client was taken home from hospital by patient transport, following discharge 3 weeks early, but the transport team could not accompany them into the house due to Covid regulations. The patient was still struggling to mobilise and care for themselves.

TECHNOLOGY

DIGITAL INCLUSION

- Through our social media insights, we heard of 2 stories where people had issues accessing appointments; one person cannot use their asymptomatic testing site because they don't know how to use the internet to book an appointment, and another person had to borrow a phone to book their vaccine appointment as they didn't have a phone with internet access.
- An organisation supporting people with neurological conditions told us that neurologists and GPs are making telephone calls to speak to those who have been diagnosed. It is recognised that these should be video calls or Face to Face calls in order to aid treatment as the recipients of the call are not able to communicate quickly on occasions and could be misconstrued as being disengaged.

COMMUNICATION METHODS

- An organisation supporting vulnerable families told us that some people reported that they found it difficult to be taken seriously when trying to communicate with a GP. In particular, one person used a text service to request medication with their surgery, and they felt that the whole process seems to dehumanise people, with mistakes being made; the person was prescribed a medication that they are allergic to. The service user felt that things would have been different if they had been able to see the doctor face-to-face or speak to them on the telephone.
- An organisation supporting vulnerable people in the community told us that one client has fallen victim to a number of telephone scams in the past. The organisation helped them to secure a new phone system which blocks scammer calls and unknown phone numbers. Unfortunately, this has meant that the client is unable to be contacted by phone from their surgery when it comes to getting their covid vaccine.

IMPACT ON CULTURAL GROUPS

- An organisation working with minority groups told us that there is an element within ethnic groups that do not want to always access medical services as their culture/tradition dictates that they should keep it to themselves, even more so during the pandemic. There is also a language barrier, where many females do not speak English but their partner does, and issues are not always related to professionals due to the partner keeping within the boundaries of their culture and withholding some information.
- An organisation that run a foodbank told us that they support one family where English isn't their first language; they only communicate with the foodbank, and no other service. No neighbours will communicate with them because of the language barrier, and they feel very isolated and lonely.
- An organisation working with youths from a minority background told us that there has been a notable increase in certain types of music within gang culture; this is now more evident because schools & colleges are closed to the vast majority of learners and educators have not been able to observe and monitor trends in conversation.

IMPACT ON THE WORKFORCE

- A carer told their mental health support group that their workload had increased during this recent lockdown, and much more personal care was required for their clients. There has been an increase in shifts and client's expectations, when the carer is already feeling burnt out from the pressures of the past year. It is made more difficult when other staff are falling ill themselves, or are leaving the profession.

IMPACT ON YOUNG PEOPLE

- We heard through social media, about a parent who has a child that has delayed speech. They are concerned that their child has missed some key development and they will withhold enrolling their child for school this September to allow for an extra year in nursery, which will also help their social skills.

BEREAVEMENT

- An organisation supporting people with neurological conditions told us that they have noticed an increase in those dying from neurological conditions in 2020 during the pandemic and the restriction of services, has led to some families not being able to get correct support services. One person lost their spouse in May 2020 and had asked for face-to-face bereavement services as the telephone was no use to them (they had a hearing impairment) but this was not an offered option. It took until December 2020 for a local hospice to contact the client and offer a face-to-face bereavement service of any kind.

Thank You



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