



## What's it like for people right now?

## Public Insights from Healthwatch Kent & Kent User Forums

January 1st-14th 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 first two weeks of January, 59 people shared with us their experiences of the Covid 19 pandemic and life under social distancing. We have combined this with anecdotal feedback from 7 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:

- People told us about struggles to get their GP to action agreed treatment plans, to amend medication, or to provide consultants with key blood test results.
- We continue to hear about routine hospital outpatient appointments being cancelled.
- People talked about issues physically getting to vaccine centres and concerns that they didn't understand what the appointment was for.
- We continue to hear from people who are having difficulty getting dental treatment.

#### **COVID VACCINE**

#### **Problems accessing the vaccine**

- Through our social media gathering insights, we heard 3 stories of people who were struggling to access the vaccine. One woman had a call from her surgery to confirm her appointment but she has dementia and could not understand the phone call. She missed her appointment slot and her family is now struggling to get another appointment booked on her behalf.
- "My 83 year old aunt, who lives on her own and has no online access, contacted her doctors to ask about when she may hear about her Covid-19 vaccination. The receptionist reply was " it could be months for you." This has really upset and confused my aunt as at 83 she is in a priority group. My Aunt lives on her own and has been unable to form a social bubble with anyone. She is lonely and isolated. I am unable to form a social bubble with her as I am shielding. Being told this by the surgery receptionist is irresponsible and has caused unnecessary extra worry for my Aunt"
- A community support hub told us that they have had calls from people who are anxious because they haven't heard when they will receive their Covid vaccination.
- The community support hub also told us that they have had volunteers offering to drive people to get their vaccination, who otherwise would have struggled to get to the vaccination centre.
- An organisation supporting carers told us that they are receiving a lot of calls regarding the vaccine, in particular people asking if they can get a vaccine so that they can protect their loved-one, who has already received their dose.
- Our helpline spoke to a Carer in Deal who said that their 86-year old cared-for person needed the vaccine but their GP surgery hadn't opted-in to the vaccine distribution.
- We also spoke to two callers in Sittingbourne who were extremely concerned that their area had no central hub for testing or for vaccination, despite having high numbers of cases.
- Our helpline has also had called from carers asking for help to get them onto a priority list for vaccinations.

### **Receiving the vaccine**

• "I took my mother to XXX in Hythe this morning for her coronavirus vaccination. All organised very well, but particular thanks should go to the many "Covid-19 volunteers" and "Age UK helpers" meeting everyone and showing them to the correct entrance at the rear of the building. After they had their initial jabs, they then escorted everyone individually to the Age UK centre next door to sit down for 15 minutes in the warm to ensure they were ok afterwards. Great job everyone!"

#### **Vaccinators**

We heard four stories from our social media insight from professionals who had tried to
join the vaccinating programme but struggled to get through the mandatory training and
requirements for the role, despite being active healthcare professionals.

#### **TRACK & TRACE**

- On social media we heard of one person who didn't get a notification via the Test & Trace App, despite living with a sibling who tested positive.
- "I requested a home test as I had one day of symptoms. I received it and posted it back the next day using a priority post. I contacted 119 as I hadn't had my results and they were unable to trace my test. I used the priority postage tracker to see that post had not been collected from the priority postbox for some days. I still have had no result and the app is not allowing me to book a new test due to not having a result of the last one yet"

#### **TESTING**

- We heard through social media feedback from someone who used the rapid test centre in Gravesend. They reported that it was well organised but under used.
- "We booked our no symptom COVID test online and went to the testing centre in Ashford at our allotted time. There was a small queue which moved very quickly. The whole experience was well organised and members of the army were running it. Whilst in the queue an army member asked to see our booking codes and then using a QR scanner on your phone, you are directed to a Government website where you fill in a form which asks for your name/DOB/if you've been to work/symptoms. Once that is filled in and you are at the entrance you sanitise, are given instructions and a swab from the man on the door and take a tissue. Once inside you are directed to a numbered booth where another army man instructs you on how to do the COVID test. The whole process was quick and we all received our (negative) COVID test results within an hour. Everyone was wearing a mask and you could maintain social distancing"

#### **CONTRACTING COVID**

• We heard two stories through our social media insights of people who had contracted Covid, one person had a fall and had to go to hospital for the day and then contracted Covid. The other person contracted it from their school-aged children.



#### **HOSPITAL TREATMENT**

• "The cardiology department at XXXXX asked me to attend an appointment about my heart but I was very concerned about Covid19. The nurse spent 6 minutes on the phone to me explaining how everything worked and the precautions taken to over Covid-19. I am now able to go for my appointment without any worry"

#### **Discharge process**

- "My husband was ill before Xmas but it didn't feel like Covid, more like a bad cold or flu and exhaustion. Eventually he took a Covid test and it went missing when he posted it back and when they found it again it had an inconclusive result. On Xmas Eve he got worse and was having severe heart palpitations. We called 999 and the paramedics came at 4am and they said that they were sure it was Covid. They said that if they took him to hospital in the ambulance the hospital were not accepting ambulances to them. They told us to get in the car ourselves and go to A&E. We did this and my husband got admitted and was straight up to a ward. He tested positive for Covid. He was then released the same day but NOT discharged. He was sent home to free up space on the ward but he was still having virtual ward round consultations with doctors for a few days on Zoom. Hospitals are clearly at breaking point"
- A mental health support group talked to us about someone who had a suspected heart attack. They were taken by ambulance to XXXXX hospital. It wasn't a heart attack but they did test positive for Covid, despite having Covid in April. They live in a bedsit and are very worried that their mental health will suffer during self-isolate. The outpatient Covid ward has been ringing them at home every day and they are feeling reassured that they can access the hospital ward if they feel unwell.

### **Inpatient experiences**

Our helpline spoke to someone whose mother had been taken to hospital with a
suspected stroke. Both her and her mother had tested positive for Covid. Her Mum was
placed on a "light Covid ward". As they were both positive, she was allowed to visit her
mother. They visited on Christmas day to find that their mother had removed the drip and
insulin cannula and was bruised. Staff told her that her mother had kept trying to bite
them, and there weren't any Doctors around to sedate her mother. Since then, she's
made good progress with her recovery.

## **Cancelled appointments**

- "We had a telephone appointment with the hospital consultant on 14th January. This was cancelled as the consultant was unavailable, because they were going to work with the staff dealing with Covid"
- "My daughter is 18 and in full time education, she has hearing loss. XXXXX have cancelled another appointment to see her. It's been over a year since she was last seen. She needs to have her annual check and micro-suctioning done"
- An organisation providing advocacy told us about a client who wants to live an
  independent life but has developed cataracts. During lockdown the cataracts
  deteriorated very quickly and they are now virtually blind, which has led them to become
  frustrated and verbally aggressive on occasions. They were due to have the cataracts
  removed this month but it was cancelled due to Covid and has not been rescheduled.

#### **ACCESS TO MEDICATION**

- We heard through social media insights that people are still struggling to access medication that they regularly had, such as vitamin B12 vaccinations. Instead they are being offered a tablet form. We know that it has been agreed with GP practices to temporarily suspend B12 vaccinations unless there is a clinical reason.
- A community support hub who told us that they have seen a rise, since Christmas, in requests from people asking for help to collect prescriptions
- A mental health support group told us that one of their service users was unable to
  receive their medication for over a week because the pharmacy had run out. It could not
  be substituted without a prescription from the doctor. They sent a request, but they didn't
  hear back from the doctor.
- Another support group told us that a client has not had their anti-depressant tablets since
   December 27th despite chasing it up with their doctor at XXXXX surgery.

#### **DENTAL TREATMENT**

• We spoke to eight people in two weeks who were struggling to get access to an NHS dentist. One person told us they had tried 13 dentists but couldn't find anyone taking on NHS patients. Another caller told us that their husband's mental health was suffering because his teeth were giving him so much pain and he was pulling them out himself.

#### **MATERNITY**

• We heard from a lady who told us about her recent antenatal scan. "The scan was straightforward, and I was happy with the sonographer. I really appreciated the monitor on the wall in front of me so I could watch everything. I missed having my husband along with me and was quite nervous, as I would have been alone if any bad news needed to be told. Thankfully, the baby looked great! If this was my first pregnancy, I think I would have been more upset by having to attend alone. I would have also been very disappointed that my husband couldn't experience this special milestone in parenthood"

#### NHS RESILIENCE

Our social media insights revealed the concerns of a family, whose relative worked as a
hospital nurse. They talked about long ambulance waiting times and high numbers of
Covid patients in hospital.



#### MENTAL HEALTH

- One person, through our social media, spoke about trying to convince their parents that they were coping with lockdown, but the reality was that they have been struggling.
- An organisation supporting vulnerable families told us that they are training their volunteers in mental health awareness, to better assist the families that they work with. A lot of the families that have been referred for support have parents struggling with depression and anxiety.
- A mental health support group told us that one of their service users accessed the
   "Release The Pressure" phoneline support because they were particularly lonely and
   isolated between Christmas and New Year. They reported that the phoneline service was
   very helpful and understanding and that they were comforted by the fact that they were
   able to call daily if they need future support.

#### **Community Mental Health Teams**

- A service user told us that throughout the pandemic, XXXXX from the Community Mental Health team has been in regular contact with them, through weekly welfare calls. They told us how helpful this has been, especially as they have been extremely isolated during lockdown.
- A mental health support group told us about someone who has been in regular contact
  with XXXX Community Mental Health Team during a period of suicidal ideation. They said
  that this has been vital for them to keep well.

#### **Crisis Team**

- "I thought I was doing well but I am not the crisis team are aware of it and I have rung them when things are difficult. You can't fault the crisis team as they do everything to help me."
- A mental health support group talked to us about one of their service users who
  attempted suicide over Christmas. After that the Crisis Team became involved and visited
  them every two days. They felt that this was very helpful in keeping them well, particularly
  over the holidays.

#### **Children & Adolescent Mental Health Service**

We heard of stories from parents who were having difficulty accessing CAMHS; one
parent has been waiting for 2 years for an ASD assessment for their daughter and had a
call from someone only to be told they would be waiting for another 2 years. Another
parent needs support from CAMHS as their child has been threatening siblings since
being home-schooled again, she said that CAMHS only sent a reading list of books.

#### **Health Service Responsiveness to Mental Health issues during lockdown**

- A mental health support group told us that one of their service users called 111 because they were at breaking point. The service user said they were turned away because they were already being treated by a Community Mental Health Team.
- A mental health support group told us about a service user, and their advocate, who have been trying to get in touch with the GP surgery regarding ongoing issues. The GP surgery, XXXXX, has not got back to either them or the advocate for several weeks.
- A different mental health support group told us that a service user's consultant has been requesting blood tests from their GP in order to properly facilitate their treatment and ensure that the medication they have prescribed is doing its job and is safe. The consultant has not yet been sent the blood test results by the GP.
- A gentlemen told us that their GP at XXXXX has received several treatment updates from their consultant that have yet to be acted upon. Updates from their September and November appointments have not yet been put into place by their GP despite multiple requests by them and the consultant.

#### **FINANCE**

 We heard a story through social media of a single parent who was self-employed and also clinically vulnerable. They don't qualify for Government help and they have been forced to ask their University-aged child for their student loan in order to manage finances.

#### **CARE HOME**

Our helpline spoke to someone who was concerned about their relative in a care home.
They paid for a care company to sit with them in the care home just to keep her
company, as the care home staff did not have a visible presence. Since lockdown, the
private company have not been able to help. The talked to us about being concerned
that the home wasn't meeting her care needs and they were more anxious now that they
couldn't visit.



#### **ACCESS TO FOOD**

- We heard a story through our social media gathering about an elderly and vulnerable person who was charged £26 by an agency to do some shopping on her behalf on top of the cost of the shopping.
- "During the first lockdown our school didn't give parents the food voucher to spend, they asked us to come to the school to collect a packed lunch every day. In September when school started back, the schools gave us a bag of shopping every 2 weeks, even though kids were back and getting their free school meal. They said that they had a surplus of money. This is continuing now during the third lockdown. I get given a bag of shopping that someone (a teaching assistant?) has done from the supermarket. The value is around the £30, with meat, veg and fruit included. There is always something that isn't necessary though, and I don't know if they do it to put a smile on our faces, but I wish the money was spent elsewhere. There is a bunch of flowers or a box of chocolates included, which I really think is £2-3 that I would rather have spent on a block of cheese or something. Before lockdown the teacher would bring the massive bags of shopping out and give it to parents who qualify when they pick their kids up. It made it obvious in the playground which parents are low-income and shamed quite a few of them in front of others"

#### **SHIELDING**

- An organisation supporting carers told us that they are receiving many calls about shielding again and clients are confused by the government guidelines.
- A mental health support group told us that one of their service users wants to know why
  they are not on the vulnerable list; they have COPD and cannot go out shopping because
  of the risk.

#### **EDUCATION**

We heard from two parents on social media about their struggles; one person is a single
parent and is struggling to keep their family safe whilst their school has a high rate of
Covid. The other has concerns about how much education has been lost in the past year,
particularly for young people with additional learning needs.

#### **COMMUNITY SUPPORT**

- An organisation supporting vulnerable families told us that they have had to stop
  volunteer input on a face-to-face basis. Before Christmas, volunteers were able to leave
  their homes and support families who needed their help. Now in lockdown 3, the
  volunteers are depending on video conferencing platforms to chat to families, which isn't
  ideal as many of the families need a physical contribution. There is also an increase in
  the number of referrals, and it is difficult to introduce a volunteer to a family via video
  calls.
- An organisation who supports independent living told us that they had four people asking for help recently. However they weren't able to because the services they need are unavailable due to the lockdown.

#### **LOCKDOWN 3**

• One person told us, through social media, that this lockdown felt different than previously because more shops were able to open to sell "essential" goods.

#### **IMPACT ON WORKFORCE**

- Through our social media insights, we heard from one person who found out that their colleague had tested positive, whilst doing a job that involves personal care. Not all staff were made aware of the positive result which they felt put other employees at risk.
- We spoke to a community hub who are trying to manage staff illness, at a time when the infection rate is very high. It has meant that staff who are currently furloughed are being brought back on a temporary basis to cover for those who are ill.

#### IMPACT ON YOUNG PEOPLE

- An organisation supporting young people with emotional difficulties told us that the
  planned online activities that they ran over the Christmas holidays were well received
  and appreciated by the families. Now that Lockdown 3 has started, they won't be able to
  see any of the children that need their support. They will plan some online meet ups for
  the next half term, but they told us that children will go a long time without support until
  then.
- An organisation supporting carers told us that they have continued to support many
  young carers. However the third lockdown has put added pressure on young carers and
  they are becoming more in need. They told us that calls with them are lasting a lot longer
  due to the support that they now require.

#### **TECHNOLOGY & EXCLUSION**

- "I filled in all the requested fields on the form to get a home test, near the end of the form it asked for a mobile telephone that a reply could be sent to by test. I do not have a mobile phone that will receive text, therefore I could not complete the form. This excludes me from being able to take a test. This is not an acceptable way to be treating older people"
- A community support hub who told us that more people are calling them to ask for help with remote learning for school children. The hub told us that some people "cannot afford the extra mobile charges that remote learning takes"

#### **DEATH & BEREAVEMENT**

 We heard stories through social media of people suffering the loss of loved ones, made all the more difficult because they were unable to share one last Christmas with them.

# Thank You



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