

**Cornwall Coronavirus Survey Report** 

### What Cornwall and the Isles of Scilly say about health and social care during the Covid-19 pandemic



## Contents

Introduction	3
Respondent Demographics	5
Mental Health & Wellbeing	7
Carers	13
Communications	17
Other Issues & next steps	22
Acknowledgements	23

## Introduction

#### Introduction

Healthwatch Cornwall is an independent, publicly-funded organisation. We have statutory duties and a remit to ensure health and social care services in Cornwall are the best they can be for people, now and in the future.

In response to the coronavirus pandemic, health and social care services have had to drastically change the way they provide care. Healthwatch Cornwall has been asking the people of Cornwall and the Isles of Scilly how these changes have been working for them and about the impact of the pandemic on people's mental health and wellbeing.

Listening to people's experiences during the pandemic, we will learn lessons for the future, inform local health and social care provision and provide feedback to Healthwatch England to inform national policy.

This report draws out some key results from a survey run by Healthwatch Cornwall, in collaboration with Public Health Cornwall and NHS Kernow. The survey ran for six weeks in June and July 2020 and asked residents of Cornwall about their experiences during the pandemic, including:

- Views on the quality and accessibility of information and advice
- · Experiences of changes to health and social care services
- · Impact of the pandemic on people's mental health and wellbeing and sources of support
- Changes to employment and uptake of volunteering

The results highlight a range of issues and recommendations for the attention of health and social care providers in Cornwall, summarised within the key themes of Mental Health and Wellbeing, Carers and Communications. Detailed results and survey questions are available on Healthwatch Cornwall's website.

#### Who we worked with to set up the survey

As well as Healthwatch Isles of Scilly promoting the survey to residents on the islands, we also worked with Healthwatch England, Public Health Cornwall, NHS Kernow and Healthwatch Cornwall's volunteers to develop the content of the survey and to share it amongst our networks.

## Introduction

#### Where we advertised

The survey was hosted on SurveyMonkey and advertised on social media networks such as Facebook, Twitter and Instagram. It was also promoted through email newsletters, advertising in the West Briton newspaper and on posters in local community venues. BBC Radio Cornwall also supported with PR via a phone in discussion.

People were given the opportunity to complete the survey over the phone, and a shorter easy read version of the survey was also developed to widen participation. Feedback on Learning Disability services was received from a group of carers in August 2020 and is included in this report.

#### Who took part

1,731 people from all over Cornwall completed the survey. Respondents were predominantly female, between the ages of 35 and 75 and White ethnicity.

When compared to Cornwall's population as a whole <sup>[2]</sup>, there is low representation from males, younger adults under 35 years and older adults over 75. A full breakdown of respondents' demographic and equalities characteristics is available in the Full Report <sup>[1]</sup>.



#### Respondent demographics



#### **Respondent demographics**



Changes to employment since lockdown, 1,247 respondents.

The impact of the pandemic, lockdown and isolation on mental health and wellbeing



#### What we did

We asked people about the impact of the pandemic on their mental health and wellbeing, how they were currently feeling using the Short Warwick-Edinburgh Mental Well-being Scale (SWEMWBS)<sup>[3]</sup> and about the support they have accessed. We analysed over 1000 free text responses thematically and carried out statistical analysis on the SWEMWBS responses.

#### What we learned

People's experiences of the pandemic were wide ranging depending on their situations, with some common themes, such as people experiencing frustrations and anxiety during lockdown. For some, such as those who have lost access to routine care or healthcare, the pandemic has caused practical challenges and isolation which have significantly impacted mental health and wellbeing.

#### Impact of isolation

Isolation and separation from family and friends were two themes that came up very often in relation to people's mental health and wellbeing.

- For some isolation has led to loneliness, loss of motivation or exacerbation of existing mental health conditions.
- For others, home schooling and working from home has been very stressful and it has been difficult to juggle work and family pressures.
- There have been positive impacts too; 27% of respondents described positive impacts, mainly in relation to homeworking, such as spending more time with family, less travel time, saving money and having a break from usual pressures.

"Isolation is the worst as a shielding household and the lack of understanding from other people has been very difficult. My own mental health has been poor with episodes of depression and almost constant anxiety. Stress has an adverse effect on my physical health too. We have also had worries about practical things like food deliveries, and often run out of essentials."

"Working from home while also supporting children with home learning has been really stressful, while panicking about the actual virus at the same time."

"Very good. It's wonderful not having to do things face to face anymore; not having to commute for hours per day; not having to spend hundreds of pounds on petrol every month. I hope working from home becomes permanent."

**Negative impacts** 





Over 1,000 respondents told us about the impact of the pandemic on their mental health and wellbeing. Responses were themed and all themes are displayed with font size providing an indicator of the frequency of the theme

#### Increase in worries and anxiety

Anxiety was frequently described in response to the pandemic, particularly early on in lockdown. People also talked about their worries about finances, family members' health, catching coronavirus and uncertainty about the future, among other worries.

Analysis of the mental wellbeing scale <sup>[4]</sup> shows some evidence of an increase in the number of people with symptoms of anxiety or depression. The Cornwall Residents' Survey in 2017 <sup>[5]</sup> identified 5% with 'probable' depression/anxiety and 22% with 'possible' depression/anxiety, this has increased to 13% and 44% respectively within the current survey sample.

The current sample is smaller and less representative than the Residents' Survey in 2017 and so it is difficult to make direct comparisons, but it does suggest increased levels of anxiety and depression in Cornwall's population and echoes other reports for the UK as a whole <sup>[6,7]</sup>.

Statistical analysis of the mental wellbeing scale also revealed several groups at higher risk of anxiety and/or depression, including:

- People who have a disability or long term condition
- People who have lost employment, either through the furlough scheme, redundancy or temporary or permanent closure of business
- People who consider themselves at higher risk of coronavirus
- Carers

People who have a disability have a higher risk of anxiety and/or depression compared to other groups.

The statistical analysis mirrors thematic analysis of respondents' experiences: anxiety, depression and loneliness were common themes amongst respondents who have a disability; and financial worries and anxiety were common themes amongst those who had been furloughed or lost employment.

"Worried about the future and how different life will be. Wondering when/if things will get back to normal. Worried about my child's education, although they are being set work, the level of teaching is no way near what it usually is. Worried about my job, although I am working from home and am busy, I work in higher education, so the future is uncertain. Worried about a health issue that I don't feel I can get on top of now."

#### Mental health SWEMWBS chart



This chart shows the average score for each item in SWEMWBS. It highlights some of the different impacts the pandemic is having on different groups of people, and the significantly lower scores of those who are permanently sick or disabled or recovering from long term illness.

"Isolation, lack of motivation, anxiety, access to shopping, low mood, not being able to complete tasks, disability limitations, and unable to get trades to do jobs for me."

"Worried about lack of financial support for my household as we are not eligible for anything and currently have no work, and unlikely to for the foreseeable future."

#### Access to mental health services

12% of respondents accessed support for their mental health and wellbeing during the pandemic, from over 50 different organisations. Family, friends and neighbours were the most commonly used source of support, followed by Outlook South West, the Community Mental Health Teams and GPs.

- Of those identified with 'probable' depression or anxiety, only 23% have accessed support for their mental health and wellbeing.
- When asked about additional support that respondents would like, common suggestions were about making it easier to access mental health services, including easier access to counselling, the mental health team, crisis support and a 24 hour helpline, and having access to specialised services, such as autism aware therapy, family life coaching, grief counselling and support for carers, among others.

"The existing mental health services in Cornwall are inaccessible to a large number of people who don't meet the criteria for emergency help. We are pretty much left to fend for ourselves or offered weak, ineffective services."

#### **Conclusion statement**

The results highlight the many practical and social implications of restrictions imposed in response to the pandemic, and the toll isolation and separation from family and friends has taken on people's mental health and wellbeing.

The spirit of being 'in it together' has not been a reality for many, with some individuals and families experiencing significantly more challenges than others, particularly those who have a disability or long term condition, carers and those who have lost employment.

#### Recommendations

- 1. Preventative strategies should be developed to address isolation in the event of a local or national lockdown. This may involve neighbourhood level buddy support systems and telephone and online peer support.
- 2. The Mental Health Commissioner should consider commissioning support tailored to meet the needs of specific groups, such as those with a disability who have lost support, and for those who have lost employment through temporary or permanent business closure or who have been made redundant or furloughed. Solution focused research can be used to better understand the needs of different groups and develop strategies for support.
- 3. Attention must be paid to addressing the issues of access to mental health services. People are confused not knowing what is available or how to access it. The single point of access for mental health services will help with this however effective communication of that service and ongoing evaluation of its roll out will be key.

## Carers

Experiences of those in a caring role or accessing care during the pandemic





#### What we did

We asked about experiences of social care during the pandemic and about carers' experiences of the pandemic in relation to their mental health and wellbeing, as well as their suggestions for support.

82 respondents provided details about their experiences of changes to social care and 246 carers provided details about the impact of the pandemic on their mental health and wellbeing. A group of carers have also provided feedback about Learning Disability Services in parallel to the survey.

#### What we learned

Carers have faced significant challenges during the pandemic, due to formal and informal care and support that was in place for the person they care for either stopping altogether, or being reduced. These changes have left some carers feeling isolated and overwhelmed.

#### **Reduced Support**

- Day services and respite care have closed, increasing the time carers spend in their caring role.
- Paid carers and Personal Assistants have reduced their hours or changed their roles, leading to unmet care needs. People have also lost practical support such as their cleaners.
- Healthcare support for both carers and those they care for has changed and has been more challenging to access. Allied professionals, including physiotherapists, have not been able to visit.
- Some carers described how relatives and friends have stepped in to provide additional support; others are relying on private carers.
- Carers have reported a lack of advice around direct payments, budgets and contractual obligations. For example, Day Services and Taxis have still been charging during lockdown despite services being closed and when transport was not needed; carers managing personal budgets were not given information about alternative ways to pay for a Personal Assistant (PA).
- Although many carers have experienced less or no support during the pandemic, some have felt well supported by care agencies and local volunteers.

"Day care stopped but we are still being invoiced for the same hours. Nobody explained why. Nobody has rung to let us know what their intentions are."

"Cutting back domiciliary carers, and also doing without housework help, has left me with a lot of extra work. My day seems to be one long care session."

## Carers

"Carer visits to one relative have been suspended whilst a family member had selflessly moved in to self isolate with them. But as we were concerned the carer visit slots would be lost, we are still paying monthly for a service. Our choice but it shows how fearful we are of losing access to care once the relative goes home. The other dependant person lost their cleaner and as they are unable to manage their house, another relative had stepped in on top of managing their own home and work."

> "Having volunteers at the local shop dropping medications to my door was extremely helpful."

#### Additional challenges as a carer

- Isolation, which has been a common experience amongst all respondents, has been particularly challenging for carers who usually rely on family and friends for practical, social and emotional support.
- Lack of respite care, along with responsibilities of working and home schooling has put some carers under enormous pressure and has been overwhelming and exhausting.
- Carers' worries about shielding themselves and the person they care for from coronavirus have also brought additional practical challenges and sacrifices.

"Trying to work, care at home for adult child with learning disabilities and care for two elderly people. I also have arthritis. Isolated, I don't have anyone to discuss anxiety and tiredness with."

"Relative having Alzheimer's has been a huge struggle to be with 24/7. I couldn't get out for any break on my own. I don't know how I coped."

"Being overwhelmed - having to work from home as well as having to deal with caring responsibilities - expectations of other professions to be able to do this - little practical or emotional support."

> "Having to care for spouse and shielding means I can't see ever being able to look after my grandchildren again."

### Carers

#### Support for carers

When carers were asked what additional support they would like for their mental health and wellbeing, 106 responded with a wide range of suggestions including:

- Practical support with caring
- Access to good mental health services
- Signposting to available support
- More time to self
- Returning to normal routines and activities
- Financial support
- Meeting with friends and family
- Regular telephone calls to check in

#### **Conclusion statement**

There have been significant challenges to the provision of social care in the context of the pandemic in terms of risks of transmission and staffing, which led to withdrawal of care and support from social care services, care agencies and cleaners, among other services. It has also been more difficult for friends and family to provide practical and emotional support due to social distancing restrictions.

This has left many carers without the support and advice they need. With little information about when social care services will resume, and further local lockdowns possible in the coming months, improving support, respite and information for carers is essential.

#### Recommendations

- 1. Further qualitative research is needed into the local needs of carers. Supporting carers to continue their caring role whilst maintaining their own wellbeing has been a continual theme made more difficult during the restrictions and service changes of the pandemic. Creative solutions enabling carers to have regular, formal and informal respite together with practical and emotional support are needed.
- 2. More accessible and effective communication with carers is required to ensure they are made aware of statutory and non-statutory services available in the community and peer support networks.
- 3. Improve signposting and advice on contractual rights in relation to direct payments and personal budgets. Increased flexibility with use of direct payments, especially in relation to Personal Assistants, will allow a timely response to paid carer absences and changes in service provision.
- 4. Incorporate themes raised by carers into the development of the new Carers Service and through the ongoing implementation of the Carers Strategy (2020-2029). The role of carers on the Carers Partnership Board is important in monitoring this.

Perception of sources and providers of information and communication during the pandemic



#### What we did

We asked people about their experiences of finding, understanding, acting on and keeping up to date with information, about local sources which have been helpful and about topics where it has been difficult to find information. We also asked people about their experiences of changes to healthcare services and communication around this.

#### What we learned

Respondents have found it easy to find information and advice from national government and Cornwall Council websites, daily briefings and updates via their employers, but it has been harder for people to act on information and keep up to date with changes in restrictions. There are some topics, such as shielding and the availability and safety of healthcare services, where people have struggled to find good information and advice.

#### Local sources of information and advice are trusted

- Local advice and guidance is trusted more than national advice. National advice was often described as confusing and contradictory and was questioned in terms of rationality and scientific basis.
- Cornwall Council's coronavirus guidance was the most frequently used local source, found helpful by nearly half of respondents. Other commonly used local sources include GPs, Cornwall Partnership Foundation NHS Trust and Volunteer Cornwall, among others.
- There are some topics where people have found it difficult to get advice:
  - Shielding, in terms of what the rules are, how to keep safe and what support is available for those who are shielding.
  - Availability and safety of healthcare services
  - The use of facemasks and their benefits
  - Local coronavirus statistics, such as the number of cases in the local area and the R rate
  - Access to testing for coronavirus

"In all honesty the only confusion in terms of messaging comes from central not local government. I think Cornwall Council have done well to interpret information to make it easily understood and accessible to residents. Whilst also providing some level of reassurance."

"I've struggled with the government's lack of clarity - making recommendations then changing their minds, making recommendations that disagree with clear scientific principles."

"How to take care of myself as a shielding person, how much risk there is from deliveries, people accidentally getting near you etc. Risk basically!"

Uncertainty about health services - access and safety

- Communication about changes to healthcare services has been mixed. Some people have
  received good communication and support over the telephone in the absence of face to face
  care, whereas others have had very little or no communication about when they will be able
  to access healthcare and what they can do to manage their health condition in the
  meantime.
- Delayed and cancelled appointments and closure of some healthcare services have been accepted by many as 'understandable' consequences of the pandemic, and yet have also caused concern and ongoing pain and poor health to some people.
- 42% of respondents are delaying seeking healthcare due to the pandemic. When asked why, the most frequent reason was feeling a burden to the NHS given by 54% of those delaying, followed by worry about catching the virus and not knowing what services are available.
- Experiences of accessing GPs was mixed, with some people finding it easy to access their GP and others describing difficulties getting an appointment or speaking to a doctor. Common themes amongst those who described problems accessing their GP included unfriendly and difficult to follow answerphone instructions, obstructive receptionists and waiting for call backs.

"Received a letter to say that my appointments were cancelled. Which is understandable. But nothing since. Will my appointment be rebooked or do I need to get reordered by my GP?"

"Can't access a GP at all. Can't discuss issues with anyone qualified. Can't get past receptionists to access any treatment"



216 (14%) of respondents described having either delayed or cancelled appointments and/or no access to health services. Responses were categorised by service and are displayed with font size providing an indicator of the frequency different services were mentioned.

#### Telephone and video consultations

Telephone and video consultations are working well for many people, saving time and money not having to travel to appointments, but some have experienced difficulties, either due to the nature of their medical concern, or because of difficulties communicating over the telephone or being in an inappropriate location when receiving the call.

"My friend asked me to be there when they had their phone consultation with the doctor. I believe they found the whole thing quite hard for a variety of reasons. For one thing they started getting paranoid the doctor had forgotten about them as the call came through about an hour after their appointment time. Also, they are hard of hearing so often misheard what the doctor was asking them. They couldn't show the doctor anything and found it very hard to describe things appropriately."

#### **Conclusion statement**

Local advice and guidance about coronavirus has been well used and valued, and in the absence of face to face healthcare, telephone and video calls have worked well where they have been available, but there are some areas where communications could be improved.

Alongside safety concerns, public messaging to 'protect the NHS' may have contributed to people not wishing to burden the NHS and delaying seeking healthcare they need.

Communication strategies are needed to clarify which health and social care services are open, to address issues of risk and safety and to encourage attendance where appropriate, both for individuals who are waiting for their healthcare, and for the public.

#### **Recommendations**

- 1. Develop a strategy to support and advise those who choose to shield that includes advice about keeping safe, as well as practical support and promotion of health and wellbeing while isolating. Improve signposting to Cornwall Council's existing shielding guidance.
- 2. Build on public preference for and trust in local information, enhancing communication strategies to consistently:
  - address people's safety concerns and reluctance to seek healthcare.
  - advise those who are shielding including advice about keeping safe.
  - clarify which NHS services are open and how to access them.
- 3. Providers should manage people's expectations informing them about when they are likely to receive their delayed or cancelled appointments, advising and supporting people to manage their own conditions in the interim.
- 4. Providers should offer people choice between face to face consultations and telephone or video which may be inappropriate for some.
- 5. Where providers are using telephone or video appointments these should be scheduled enabling people to prepare for the call and organise support.

## End note

#### Other issues arising

Dental services were the most common type of service that respondents have been unable to access, with dental treatments cancelled or delayed and no access to routine dental care. Some also described delays and difficulties accessing emergency dentists.

Healthwatch Cornwall continues to receive complaints about lack of NHS dental services and in recent months has seen an increase in poor dental health consequences arising from lack of treatment.

Some people described difficulties obtaining medication. NHS Kernow are carrying out a survey of people's experiences of GPs and pharmacies, so we will monitor to see if similar issues are raised in their survey.

20% of respondents have taken up the call for volunteers with 12% of respondents indicating that they had received voluntary support. As well as larger organisations such as Volunteer Cornwall, local community groups have played a key role in supporting shielding households during the pandemic, for example providing vital assistance with food and medication delivery, and making scrubs and masks. This will likely play an important role in the context of any second lockdown, but also enhance the support network that people have in their communities.

#### Our next steps

We will share this report with the local integrated care system, commissioners and providers requesting a response to our recommendations.

To assist the design of solutions and inform implementation of the new Carers Strategy in 2021 we will

- Build qualitative research into carers needs into our 2021 workplan
- Work with the Learning Disabilities, Autism and Carers' Partnership Boards

We will work with the Adult Mental Health Strategy Board to co-produce services to meet needs identified in this report.

In line with our current strategy we will also seek to increase our engagement with men, children and young people, young adults and vulnerable groups to reflect their views more thoroughly in future work.

#### Contributors

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#### Share your views and feedback with us

If you have experienced a change to your health and social care services during the pandemic or anything mentioned in this report, please get in touch with us.

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