

Unpaid Carers Experience of Mental Health during the Pandemic

NHS E&I Commitment to Carers Rapid Learning Pandemic Legacy Project



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Introduction

Healthwatch Swindon and Healthwatch Bath & North East Somerset (BaNES) are independent champions for people who use health and social care services. We're here to make sure that those running services, put people at the heart of care.

Our sole purpose is to:

- Understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf
- Provide information and advice to the public about accessing health and social care services
- Gather feedback from people about their needs for, and experience of, local health and social care services and making those views known to those involved in the commissioning and scrutiny of care services
- Promote and support the involvement of people in the monitoring, commissioning, and provision of local health and social care services
- Ensure the views and experiences of people are known to Healthwatch England to help it carry out its role as national champion
- Write reports and recommendations about how those services could or should be improved
- Make recommendations to Healthwatch England to advise the Care Quality Commission to carry out special reviews or investigations into areas of concern



You can also speak to us to find information about health and social care services available locally.

Healthwatch Swindon and Healthwatch BaNES are working with NHS England and NHS Improvement to support the rapid learning and commitment to carers and unpaid carers, focusing on unpaid carers experiences of mental health during the pandemic.

Amongst many enduring inequalities and hidden needs highlighted by the pandemic, the stress on people taking care of others in an unpaid capacity has come to the forefront. The pandemic saw an increase in carers caring, as 4 in 5 carers provided more care than before the pandemic and over half of the carers said their mental wellbeing had worsened. Adults who are providing unpaid care are on average spending over 25 hours per week looking after loved ones. Over half of unpaid carers believe that they are doing two full-time jobs by looking after someone, many believe they must do so.

Carers UK stated in 2021 that around 6.5 million individuals in the UK were performing unpaid care. They are a growing demographic but remain an invisible workforce which plays a crucial role in sustaining our overstretched health and social care system within the UK. [Carers Trust social care survey findings, 2022](#)

NHS England define a carer as anyone who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction, and cannot cope without their support. The care they give is unpaid.

Unpaid carers have been a vital resource in the health and social care systems in Swindon and BaNES during the Covid 19 pandemic. But still, their role is poorly recognised with little help to support their health and wellbeing. Unpaid Carers need to be recognised for the difficulties they have experienced during the pandemic, respected for all they are doing, provided with information, and given the support, they need to care safely whilst safeguarding their own health and wellbeing.

Our aim

Our research aimed to gather feedback from unpaid carers and to capture their experience of mental health during the Covid 19 pandemic and accessibility to Health and Social Care support networks and providers within both localities.

This required:

- Up to date information about the experiences of unpaid carers in both Swindon and BaNES and the impact of the pandemic on their mental health.
- Unpaid carers experience accessing Health and Social care services and support during the pandemic period in both Swindon and BaNES
- Direct feedback from Carers Centres based in both areas
- Unpaid carers views about what has helped or would help them when it comes to supporting their mental health.

Understanding the impact of the Covid 19 pandemic on unpaid carers is essential to help inform how to best support the health and well-being of those who care for others. The research undertaken by Healthwatch Swindon in collaboration with Healthwatch BaNES provides valuable insights into unpaid carers' experience of mental health over the past year. Our understanding of what we heard was that many of the challenges faced by unpaid carers have been long-standing but further exacerbated by the pandemic.

We want health care decision-makers to understand and properly attend to the existing and future demands of unpaid carers, including a need for greater investment in services locally directed towards unpaid carers, including mental health. This would include core NHS services, local authorities and third sector organisations that work with carers to remove barriers to mental health support and ensure access to services which meet unpaid carers' needs.

The valuable learning gained from this work will also be shared with the Care Quality Commissioners (CQC) to help shape how they monitor and inspect services with Unpaid Carers in mind and hold Health and social care services accountable for adequately providing provisions for care.

What We Did

Between mid-February to April, we reached out to carers and unpaid carers who had experienced poor Mental Health personally or through the person they cared for. We engaged with the Carers Centre in both Swindon and BaNES, health and social care services including the voluntary sector which played a key role in providing care and support during the challenging times of Covid 19 taking the strain of Core NHS services.

How we did it

Between March to April, we ran a Mental Health Survey with carers in mind. The survey was run in both Swindon & BaNES.

Additionally we:

- Held a public engagement event in central Swindon inviting people living with mental ill-health to come and share their experiences of services and support networks.
- Attended focus groups and collected feedback when engaging at planned meetings for community groups and local VCSEs.
- Attended group meetings/sessions with unpaid carers and families/advocates experiencing mental ill-health (conducted either face-to-face or remotely online).
- Analysed information/data supplied from carers centres based in each locality.
- Analysed national statistics taken from Carers UK.
- Incorporated existing sources of feedback/reports so that people don't have to repeat themselves (data collected by Local Healthwatch).
- We ran a Twitter poll.

Reviewed key reports:

KS2 / St Mungo's – 'What's going on?' Event Mental Health Report - focus groups, survey and event (11/8/21 – 5/10/21) ['What's going on' Event Mental Health Report | Healthwatch Bathnes](#)

Healthwatch Swindon, Wiltshire and B carried out a joint project in Oct 2021 looking at what local organisations think of mental health support which had relevant information. [What local organisations think of mental health support | Healthwatch Bathnes](#)

Organisations/Groups we engaged with:	What they do:
<p>Swindon Carers Centre:</p> <p>Swindon Carers mental health support group</p>	<p>Part of the Carers Trust network, they provide help and support to unpaid carers of all ages. Working in partnership with other local organisations and Swindon Borough Council to help improve the wellbeing of carers and ensure the best care solutions are in place.</p>
<p>Swindon SEND Family Voice</p>	<p>Is a charity that listens to parents and carers of children and young people who have any kind of special educational need or disability. They then collaborate with the Local Authority and the Integrated Care Board to improve the services to such families.</p>
<p>Avon Wiltshire Mental Health Partnership (Swindon and BaNES)</p>	<p>Lead provider of healthcare for people with serious mental illness, learning disabilities and autism across BaNES, Swindon and Wiltshire, Bristol, North Somerset and South Gloucestershire.</p>
<p>Live Well & Public Health</p>	<p>The team's main work involves handling referrals and giving people access to opportunities and services which can help improve their health and wellbeing.</p>
<p>Swindon Hub</p> <p>Pop Up Mental Health Café run by Healthwatch Swindon at the Swindon Hub</p>	<p>An accessible, friendly space run by the community, for the community. They have an affordable cafe, a relaxing snug, a selection of books to read or buy and various items for sale from local retailers. They also have upcycled furniture by Renew Men's Shed and surplus stock items for sale - donated from shops - with profits going to Swindon Night Shelter.</p>
<p>New College Swindon (both Queens Drive and North Star campuses)</p>	<p>The current College was created by the merger of New College with Swindon College in 2020.</p> <p>Held New College Swindon Mental Health Event</p> <p>Held an Employability Fair for Health and Social Care students</p>

B&NES Carers Centre	<p>Local charity and part of the Carers Trust network;</p> <p>Providing a range of advice and support to all unpaid young and adults carers in the area.</p> <p>Works in partnership with B&NES Council, the Community Well-being Hub, HCRG (formerly Virgin Care) and the Clinical Commissioning Group.</p>
KS2 Bath	<p>Voluntary peer support and information group for carers of people with mental ill-health (KS2 carers). Hold monthly meetings and more informal meet ups. Promote needs of KS2 carers with AWP and others through collaborative working.</p> <p>Developed training package for KS2 carers</p> <p>Helped develop the Carers Charter for AWP.</p>
Swallow BaNES	<p>A charity providing user-led support for teenagers and adults with learning disabilities. A parent's /carers/ forum is also supported.</p>
Age UK BaNES	<p>Age UK Bath & North East Somerset is a local, independent charity supporting older people in Bath & North East Somerset, including older carers. It also runs a number of Dementia groups</p>
Southside BaNES	<p>Southside supports people to make positive changes in their lives and to help build strong, resilient communities. It works with people and families who are grappling with problems such as domestic abuse, substance abuse, mental health difficulties, problems with finance and debt, housing issues or concerns related to education and employment.</p>
Bath Ethnic Minority Senior Citizens Association	<p>BEMSCA provides a range of activities, support and information for older people from black and minority ethnic groups within the area.</p>

Strengths and Limitations

In terms of strengths, we engaged with a wealth of services in both localities, speaking to individual carers through our public engagement events held in central Swindon and attending the carer's cafés and focus groups in both localities to gather essential feedback for this project.

However, we recognise that the data collected from the survey and engagement represents only a small proportion of carers, not least because many unpaid carers do not recognise themselves as carers when caring for loved ones.

Primary care, acute and community healthcare providers faced barriers in allowing Healthwatch to carry out enter and views to gather feedback directly from their staff and service users. This was due to strict Covid guidelines still in place and the added system pressures they faced on both staffing levels and the high levels of anxiety of the people accessing their services. Both Healthwatch localities respected their decision in this and did not want to add further anxiety to those experiencing mental ill-health



What we found

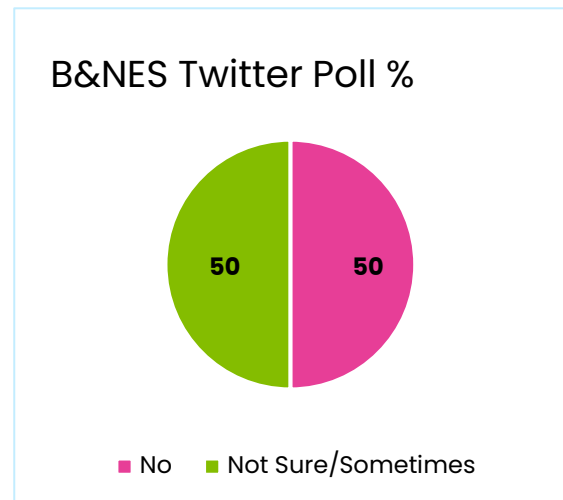
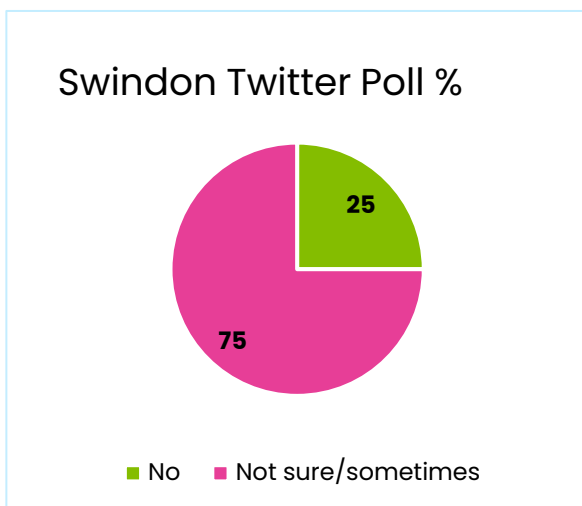
We received 109 responses from our mental health survey in total from both localities along with user stories from the engagement methods already listed.

Responses were received from a range of unpaid carers including those caring for partners, children and parents; those caring for individuals with physical care needs and mental health needs or conditions such as autism and dementia and for those who had been caring for a short period to many years.

Carers in both Swindon and BaNES raised the need for more awareness, especially within communities about support services that are available and how to access them. The majority of unpaid carers we spoke to were not aware of the local offer of support available or if these were accessible to them as unpaid carers.

Twitter Poll Results

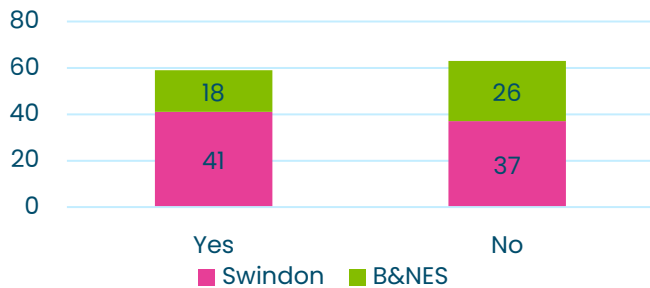
We ran a Twitter poll on both Healthwatch social media platforms asking: 'do you feel recognised as a carer'? The responses received indicated that people were unsure about identifying as a carer, and what this meant, and whether they were recognised as such.



Data from our mental health survey:

Figure 1

Do you consider yourself a Carer?

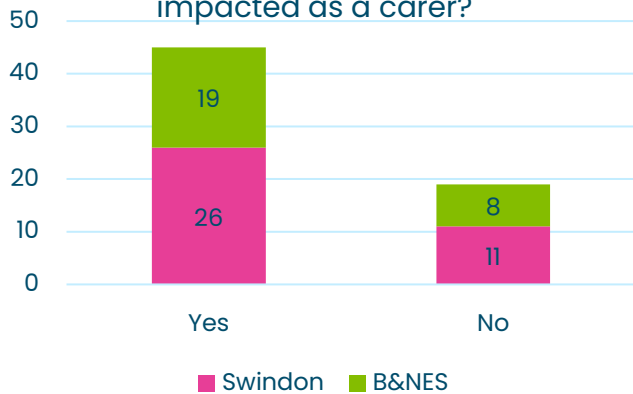


59% of people filling out the survey considered themselves as a carer. (Figure 1)

7% were paid carers, 47 % told us there were unpaid Carers and 46 % of people preferred not to say whether they were paid or unpaid. We asked people if they needed additional support over 2021. (Appendix 2)

Figure 2

Has your mental health been impacted as a carer?



The overwhelming feedback was that the people who replied did, but that many people faced barriers in accessing support.

45% of carers told us that their mental health had been impacted by being a carer during the pandemic (Figure 2).

38% of carers felt that whilst supporting the person they cared for their thoughts and feelings **were** considered by the health and social care providers, whilst 51% **did not** (Figure 3)

59% considered themselves or the person they cared for to have a disability, 32% didn't consider themselves to have a disability and 9% preferred not to say.

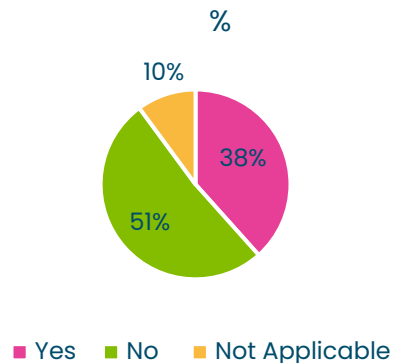
80% of people who responded to our survey were women only 14% were men and 6% were non-binary.

The majority of people answering the survey were aged between 26-64 years of age with a small percentage under the ages of 18 years old.

83% were white British with only a 1-2 % of people filling out the survey were from ethnic minorities. (See Appendix 2)

Figure 3

Were the feelings and thoughts of the person you cared for considered



Key themes

Social Isolation



“Isolation, loneliness” (Unpaid Carer)

“No one seems to care” (unpaid carer)



Many carers reported during one-to-one discussions or group sessions, that they found the second year of Covid more difficult than the first year.

During 2020 there was more of a sense that everyone was having to cope with the restrictions of Covid and behave differently, but as 2021 progressed many non-carers' lives began to get back to 'normal' whereas carers had to continue to isolate themselves due to the vulnerability of the person they cared for.

This was to the extent of 'feeling laughed at' for continuing to wear masks when others had stopped, and in another case, a carer was unable to attend both the funeral of a very close relative and the marriage of another due to continuing medical concerns about the vulnerability of the individuals they cared for.

The biggest impacts of Covid on carers' lives in terms of the number of responses reported were the experience of isolation and loneliness, the stress of caring and feeling in many cases more alone in having to deal with that responsibility.

We heard direct feedback from carers who had supported someone through the crisis but felt that they were not always involved in conversations about the care and follow up or offered any support for their mental health and wellbeing which resulted in a strong feeling of isolation and loneliness.

Stress was experienced mentally, emotionally and physically, including through insomnia, poor nutrition and lack of exercise. One person reported that they had felt suicidal at times due to the stress and difficulty of caring and not being able to access the care and support needed. Another had been traumatized as a result of caring for their child, who self-harmed and needed constant supervision.

Lack of support groups and accessing services



“Battling against the system to get the right support” (unpaid carer)

“Not able to give the support or find the help a mother feels she should give to her child” (Unpaid carer)

“long waiting lists to access mental health support” (Unpaid carer)

“Instant support, not waiting months where things get a lot worse” (Unpaid carer)



There was a mixed response to the question about how supported carers felt during 2021 and the second year of Covid. The online survey focused more on formal health care and the response to the question about whether as carers their ‘thoughts and feelings were considered by health and social care providers’ produced mixed results. Overall, 38% of respondents felt their thoughts and feelings were considered as against 51% who did not, with 10% saying this was ‘not applicable’. (Figure 5)

When broken down between the two areas however, the results for Bath and North East Somerset were more balanced with 50% saying ‘yes’ and 44% ‘no’ compared to Swindon where 29% said ‘yes’ and 57% said ‘no’ with 14% saying ‘not applicable’.

Responses varied from “totally unheard” to “when I shared issues, I was directed to someone who could listen and give advice, I was able to attend safeguarding meeting on line and speak in person to those involved”

During the one to one and group engagement there was a positive focus more generally on the support provided through carers’ groups including the Carers Centre and KS2 especially located in Bath. With services helping to reduce isolation and also providing carers with a voice to express their views and share their experiences (carers cafes, carers voice, KS2 peer group).

There were also some specific comments about the difficulty of getting a carers assessment and also the lack of practical support with tasks such as form filling to claim support or benefits.

In addition, when we spoke to Wiltshire Police and local Community Support Officers, the lack of support and access to services outside of core hours was echoed. With a rise in mental health cases, due to ambulances not being able to get to people during a mental health crisis and members of the public calling the police for support as the ‘crisis’ team was unavailable for over a week.

High thresholds for accessing care

Carers experienced frustration and stress due to the thresholds of care being so high for the person they cared for – in particular around access to care and support for mental ill-health / eating disorders. Feedback received included:

- The person they cared for had to be at the point of being sectioned due to safeguarding concerns
- They had to be at death's door or extremely unwell (including as a result of eating disorders)

As well as impacting on the cared-for person the impact on the carer is very high.

- One person reported feeling grief that the person they knew had become so mentally unwell due to the difficulty in accessing support that they didn't know if the mental health damage was permanent or if they would recover.

Lack of services or insufficient services

As highlighted above, carers' mental health and wellbeing is directly impacted by the care and support received by the person they care for, and the following paragraphs about gaps in services emphasise this connection by flagging the issues raised directly by carers about the issues which impact on their wellbeing.

- Gaps in services of services highlighted by carers included:
- Support for autistic children with mental health difficulties
- Lack of local eating disorder services, including a lack of beds and specialist support (for example, one parent said their child was offered a bed in Rotherham – this would impact very severely on a carer who lived in BaNES)
- Lack of trauma therapy and insufficient time allowed ('6-8 weeks not enough')
- Lack of care coordinators

Rural versus city - for rural areas there is a lack of accessible community-based services compared to Bath, with more limited services being available in Keynsham and the other towns

Many of the respondents highlighted the difficulty in navigating between the health and social care services – this is partly about clear information (see below) but also about free and paid for services. With the additional issue that for carers trying to 'buy in' more social care, the impact of Brexit and Covid has meant that it is very difficult to find paid hourly carers.

Confidentiality and recognition of carers of people with mental ill-health

Carers' needs vary greatly, with those caring for people with mental ill-health facing particular challenges, including for example confidentiality, with a feeling that some service providers and care coordinators do not fully understand confidentiality and that they are wrongly excluded from engagement in discussions around service delivery for the person they care for.

This was also described as an issue of trust that is needed between carers and practitioners, and that protocols are needed to support good relationships.

Many carers had reported, through the 'What's going on?' process led by KS2, feeling excluded from any discussion of the person they cared for when they were 'an expert' in their care.

Feedback was received that the initial assessment question by AWP which asks patients if they have a carer, is too simplistic, with just a 'yes / no' answer without any description of what having a carer might mean in practice. They believed that this resulted in a large number of carers not being recognised and therefore not included in the ongoing care of the patient.

An additional example was around the transition between child and adult services – where a parent would stop being involved once their child reached 18 years without the consent of the 18-year-old adult.

Physical health concerns and decline in mental health



"Very stressful due to looking after 3 children during the pandemic - Mental Health has not been good" (Unpaid carer)

"The pressure of caring whilst suffering from a mental health issue of my own" (Unpaid carer)

"The impact on me as a carer over the last 6 years has not been acknowledged, and my mental health is failing as a result of the ongoing stress from trying to manage my son's illness" (Unpaid Carer)

"Carers are not considered in the slightest" (Unpaid carer)



The majority of all carers reported a significant negative impact on their mental health or well-being during Covid and 2021.

A smaller group of the carers described experiencing anxiety and fear or depression – for themselves but also for the person they cared for. Unpaid carers told us that it was only when they reached breaking point or crisis point that an organisation would step in to help them.

Caregivers also commented about the lack of support, information and follow-up that they had received after a crisis.

In the majority of cases, it was difficult for people to separate the care needs of the person they cared for and their own well-being and needs as carers'.

One carer reported experiencing fear during Covid that the only other person that shared their caring role would become ill or even die as a result of Covid and this would leave them without any support – they, therefore, took immense care to keep safe.

Another related the experience of having to fight to get help and support for the person they cared for and navigate and coordinate a bureaucratic minefield was a major stress factor.

A small number of people reported that they had opted to pay privately (as they were able to afford this) for health services linked to diagnosis or psychiatric support – it is not known if this was an impact of Covid making access to services more difficult, or if this would have been the case without Covid. Certainly, access to services, especially face-to-face appointments was more difficult as a result of Covid.

Fear of Covid and lack of respite



carer)

“Working throughout Covid’ (Paid carer)

“Carer burnout” (Unpaid carer)

“Concern over the person I was caring for who was unable to visit family and friends as normal and the obvious impact on her mental health” (Unpaid



The experience of the small number of paid carers who responded included concerns about being on the frontline during a pandemic and the extra stress and responsibilities of working under these circumstances. Resulting in more carers seeking respite.

A few carers reported that the pandemic and the various restrictions imposed in response, had led them to spend extra enjoyable time with the person they cared for, which became beneficial for their relationships and had reminded them of the importance for instances of shared enjoyment.

How are local organisations helping?

Swindon Carers Centre

Swindon Carers Centre is a charitable organisation, which is part of the Carers Trust Network, established to provide help and support to the 21,000 unpaid carers in Swindon.

Providing a wide range of support and services and work in partnership with other organisations, including local

NHS services, Swindon Borough Council's Adult Social Care and Children's Services and other

local voluntary organisations to identify as many carers as possible and to provide the most relevant support for your caring situation.



As of 1st April 2022, Swindon Carers Centre had 4297 carers registered with them, caring for 4170 dependants. 223 dependants are registered with them as having a Mental Health condition or Covid related illness. 176 (4%) carers are registered with them as having a Mental Health condition or Covid related illness.

Statement from Suzanna Jones CEO – Swindon Carers Centre

Becoming an unpaid carer can happen gradually or it can happen overnight. Any one of us could be a carer (at any age). Every carer's experience is unique. But what we do know is that caring has significant health and wellbeing, financial and practical challenges; and it is not sustainable long term without respite and support – and in the case of employers or schools, flexibility. Our carers, whether new to it or not, cannot just back fill social care or health services. Unpaid carers need to be recognised, valued and supported and we have to acknowledge that their resources, however strong, are not infinite and that they should not be seen as a 'contingency' that will always be available when the system is overloaded. Carers' wellbeing is of paramount importance and this report outlines that very starkly.

There is further work to do to ensure all services for carers are fully inclusive and support is able to be accessed by all who would like it. This is crucial, especially for communities where caring is seen as a traditional family role, but it will take time.

One positive from Covid is increased awareness of the crucial roles unpaid carers play in our streets, villages, towns and cities. Let's seize that momentum and ensure unpaid carers across BSW are given the recognition they deserve and it becomes the norm to "think patient – think carer".

The Carers' Centre, Bath and North East Somerset

They are a local charity and Network Partner of Carers Trust, offering a range of services to help unpaid carers support their health and wellbeing, connect with others and navigate the challenges of caring.

They work closely with local organisations like Bath and North East Somerset Council, HCRG Care Group and NHS to improve the recognition and support for unpaid carers, as well as the local community.

The latest published Annual Report showed that in the year to March 2021 2,788 adult carers were registered with them and 535 young carers (under the age of 18 years old). In the year to March 2022 these figures had increased to 3,952 adult carers and 676 young carers (under the age of 18 years old)

During the pandemic many activities were able to be moved on-line until face-to-face meetings could again be resumed, proactive support calls were made to registered carers and the telephone support line was extended through additional funding to give more time to answer and respond to carers' calls.

In 2021 young carers were asked by the BaNES Carers Centre for their views about the impact of Covid. Feedback included that negative impacts of Covid included decreasing opportunities to get away physically from their caring role due to lockdown (including due to increased anxiety) and increasing their caring role as other services reduced. Trying to manage school work from home whilst caring was also an issue exacerbated by Covid.

B&NES Carers Centre also reported:

- 3,914 carers accessed vital support
- 642 young carers under 18 years old received their support
- £12,713 in financial aid was accessed with their help
- 850 queries were responded to via their online support line
- 1,960 times where their wellbeing activities provided essential respite for carers.



Statement from CEO Jacqui Orchard – The Carers’ Centre, Bath and North East Somerset

The pandemic shed light on the essential role of unpaid carers in society, yet unpaid care is rarely understood by most. Caring can have a significant impact across many areas of a person's life – health, wellbeing, and finances to name a few. Everyone's caring situation is different, and people can take on caring responsibilities at any age. A key barrier to accessing essential support is identification, by professionals and carers themselves. Countless carers are not recognised in healthcare, employment, and education settings for many years before they seek support, often reaching out because they have hit a breaking point. Unpaid carers need to be heard, valued, and supported to live a life alongside their caring role.

It can be difficult to prioritise your own needs when looking after someone, especially with an overstretched health care system. Caring for a loved one is an emotional rollercoaster. It should not be forgotten by healthcare professionals that they have the right to say no to caring. This can be hard for carers to do when they are not part of the conversation.

This report has brought into sharp focus the need for all healthcare settings to 'think patient, think carer'. To ensure that both patient and carer get the right support at the right time.

Swindon SEND Families Voice

Swindon SEND Families Voice are a non-profit making Community Interest Company formed by parent and carers in January 2018. They are a group of parents that have children with additional needs. They are passionate about ensuring the services in the area meet the needs of Swindon's disabled children and their families and that all parents and carers feel supported. Are a recognised forum by the Department for Education and the National Network of Parent Carer Forums (NNPCF).



Swindon SEND Families collected and found 127 mentions of support around mental health from Jan-Dec 2021.

Due to how data is collected they cannot always differentiate between carer/ children and young people (CYP) support in each case, they found that 92 cases mentioned parent support, and the support they were

after was mainly signposting to services that can help them or acting as listening ear.

It was noted that while this data is collected regularly, it is dependent on their reps remembering who they have supported and the subjects too so are likely to be skewed by numbers that have been forgotten.

Additionally, the support given within the social media support group is not accurate data collected as it often appears through conversation on a post that may not have started as a mental health issue. However mental health does seem to be a topic that gets raised by both carers and young people.

Conclusions

Our research shows the effects of the pandemic on carers has been substantial. As a system, we need to continue to recognize and research the impact of the Covid 19 pandemic on the mental health of carers from all communities.

We also need to acknowledge that some of these issues have been amplified by the pandemic not caused by it. Establishing a strong network of support and communication is essential for carers who play a key role in the lives of millions of people in the UK.

The majority of unpaid carers who came forward in Swindon and B&NES were predominantly white British with only a small percentage from ethnic minorities.

The reason for this may be due to pressures within BAME communities to keep caring issues 'in the family' and for BAME carers to be less likely to self-identify. Which can result in many experiencing a high risk of ill health, loss of work, and social exclusion.

We know that there can be additional challenges for carers from some ethnic backgrounds, mainly due to experiencing language barriers and difficulty in accessing culturally suitable services.

Health and social care services need to add an additional description of what carers do; this needs to be included with a question asking patients 'do they have a carer?'. This would be likely to increase the number of carers recognised and start a discussion around them being included in the ongoing care of the patient. To address this from the start and look at what support needs to be put into place to enable them to look after loved ones without having to compromise their own health and wellbeing.

Within BaNES there are issues around accessibility of support services, which impact especially on people living in the rural areas. The Carers Centre, for example, run Carers Cafes in multiple locations but they cannot cover every village.

One positive to have arisen from the pandemic in both localities has therefore been the expansion of virtual 'get togethers'. People with access to a smart phone/laptop may already have used this technology to meet virtually with family members. The pandemic led to organisations such as Carers' Centres to look very quickly at how they could use these technologies to continue to support members when in-person groups suddenly shut down and extend the

offer to those who previously were unable to access service (due to their caring commitments).

One person gave feedback during an engagement event that it was far less stressful and more enjoyable to join a zoom get together with other carers than to come out physically to the Carers café – as they didn't have to worry about leaving the person they cared for.

The Carers Voice meeting attended was 'hybrid' allowing people to choose whether to join remotely or in person. In an area such as BaNES especially it is hoped that virtual or remote options will continue to be offered alongside the resumption of face-to-face gatherings.

This is in itself an issue of course of accessibility as not all carers have access to digital technology to be able to participate in remote meetings. For older carers especially the availability and knowledge of how to use digital technology should not be assumed.

The BaNES Carers Centre set an ambition at the end of 2021 to create 'carer friendly communities' where carers were visible and valued and where informal support systems were strengthened to add to direct services. This could be especially helpful approach for rural parts of the area.

In addition to improved communications, respite care and urgent support services should be improved. By supporting our carers, we can help improve not just the carers wellbeing but the those they look after too. Before situations escalate and require intervention.

Next Steps

Ensuring we continue to work with the groups, individuals and organisations who contributed to our project by sharing their experience with us will be an important next step. This will be achieved by directly responding to individuals who left us their details along with returning to the groups we engaged with making ourselves accountable for how we at Healthwatch support carers.

In addition, the report will be published on our website and key messages shared on our social media channels. We will also share our findings with our commissioners, local Health and Wellbeing Boards, Quality Care Commission, the BaNES, Swindon and Wiltshire Integrated Care System (BSWICS) along with third sector organisations.

Healthwatch Swindon and Healthwatch BaNES will set up a webpage dedicated for Carers, "Keeping Carers connected" with support and advice services including the local offer of support services for unpaid carers.

We observed that some carers found their experience of Mental Health too emotional to share with us via completing our survey. Our hope is to use this dedicated page to allow more carers to not only share their experience but seek support and alternative ways to share their experiences.

Next Steps for Healthwatch Swindon

Swindon is one of the most ethnically diverse towns in South West England. This report has highlighted more outreach work is required to engage with people and unpaid carers from ethnic minorities who don't always come forward. We want to fully understand their experiences of support and accessibility to services and the challenges they face coming from an ethnic background.

Healthwatch Swindon will be putting processes in place to invite individuals from all communities in Swindon to form a diverse focus group. This will enable us to discuss health and social care, needs and experiences in Swindon.

We will gather further insight into what needs to change locally to ensure people have the right support and accessibility to health and social care services when they need them in Swindon.

What we learn and find out will be shared with our commissioners in the local authorities, we will also share key themes with local health services by raising this at the Health and Wellbeing quarterly meetings which are attended by Adult Health and Social Care, Public Health, Housing and local MPs to drive these messages forward.

This project has allowed Healthwatch to gain valuable insight to the needs of Swindon. Our hope is to strengthen the relationships formed through this project and increase our community engagement to further support the people of Swindon. We have already begun to do this, by working with Swindon City of Sanctuary, to gain the trust of refugees who have been granted the right to remain. Liaising with organisations to run a series of engagements over a longer time frame in some of the most deprived areas of Swindon. Along with running

more pop-up events of our own to capture experiences of people who prefer not to complete an online survey.

Next Steps for Healthwatch BaNES

Within Bath and North East Somerset our aim following on from the project is to help extend recognition of carers in two key ways:

- As individual carers needing help and support in carrying out their caring roles.
- As key partners in the 'triangle of care' so that carers' views, feelings and needs are also considered as part of the consideration of the cared for person's needs.

To do this we will build on our engagement with the Carers Centre and organisations such as BEMSCA (Bath Ethnic Minority Senior Citizens Association) and Bath Welcomes Refugees, and other geographically based groups such as WERN (the West of England Rural Network) and local community-based groups to help increase recognition and registration of carers across all communities in B&NES including non-white communities

We hope these will improve our communication with unpaid carers and the effectiveness of our signposting for both practical support with the caring role and for well-being support including promoting their recognition by health and social care agencies.

Acknowledgements

Healthwatch Swindon and Healthwatch BaNES would like to extend our appreciation to all the Carers/Unpaid Carers, families and individuals who took the time to complete the survey and share their experiences of mental health and accessing services during the pandemic.

This report was written by Amritpal Kaur, supported by Sue Poole, Ann-Marie Scott and Josephine Fliski.

We would also like to thank all the Healthwatch Volunteers who helped with this project, and health and social care services and organisations in both Swindon and BaNES who advised and shared key information with us. With particular mention to the Carers Centre which provided essential data and the opportunity to meet with unpaid carers.

References

[What local organisations think of mental health support | Healthwatch Bathnes](#)

['What's going on' Event Mental Health Report | Healthwatch Bathnes](#)

[We're here to make life better for carers - Carers UK](#)

[Home - Swindon Carers - Supporting Carers in Swindon](#)

[The Carers' Centre | Supporting those looking after someone \(banescarerscentre.org.uk\)](#)

[Carers Trust social care survey findings, 2022](#)

Appendix 1 – Mental health survey

Mental Health Survey Questions

1. Do you or someone you care for suffer from mental ill-health

- Yes No

2. Did you or the person you care for need to access/receive additional support during 2021?

- Yes No

3. If you or the person you care for did NOT receive any additional support for their health, can you please explain any reasons or factors that may have prevented you receiving help?

4. If yes, would you consider your experience:

- Positive
 Mixed
 Negative

5. Can you please list the service(s)/organisation(s) you have accessed? for e.g., Old Town Surgery, Swindon

6. If you feel able too, can you please share your experience of this service/services?

7. What about the service(s) could be improved or worked well for you?

8. When did this happen? *(if it is more than one incident please add as many dates as needed)*

9. Do or did you work or volunteer for this service (s)/organisation (s)?

- Yes No

Which service(s)/organisation(s)?

10. Have you shared this with the service(s)/organisation(s)?

- Yes No

If Yes Which service(s) /organisation(s) did you share it with?

11. Have you told the authorities?

This is asked in case what you've told us is about abuse or neglect. When we read your feedback, we'll decide if we think someone is at risk. If we think they/you are at

risk, we'll need to contact the police or council. It helps if we know who you've already told

- The Police
- The Council Safeguarding Team
- Both the police and the council safeguarding team
- Neither of these

12. Did you hear about this survey through a charity?

- Yes
- No

13. If Yes, please name

14. Can we contact you for more information?

Name

Postal Code

Organisation (if applicable)

Email Address

City/Town

Phone Number (optional)

15. Do you consider yourself to be a carer?

- Yes
- No
- Prefer not to say

16. Do you consider yourself or the person you care for to have a disability?

- Yes
- No
- Prefer not to say

17. If you are are carer are you

- Paid
- Unpaid
- Prefer not to say

18. If you are a carer has your mental wellbeing been impacted in the last year?

- Yes
- No

If yes, in what way?

19. While supporting the person you care for were your thoughts and feelings considered by the health & social care service providers?

- Yes Not applicable
- No Any comments

20. Gender: How do you identify

- Man Non-binary
- Women Prefer to self-describe

21. What is your age?

- Under 18 55 to 64
- 18 to 24 65 to 74
- 25 to 34 75 or older
- 35 to 44 Prefer not to say
- 45 to 54

22. What is your Ethnicity?

- Asian/Asian British – Chinese
- Asian/Asian British – Bangladeshi
- Asian/Asian British – Indian
- Asian/Asian British – Pakistani
- Asian/Asian British – Any other Asian background
- Black or Black British – African
- Black or Black British – Caribbean
- Black or Black British – Any other Black Background
- Any other Ethnic Groups – Arabic
- Any other Ethnic Groups – Iranian
- Any other Ethnic Groups – Iraqi
- Any other Ethnic Groups – Kurdish

- Any other Ethnic Groups – Turkish
- Any other Ethnic Groups – Any other Ethnic background
- Mixed/multiple ethnic groups – White and Asian
- Mixed/multiple ethnic groups – White and Black African
- Mixed/multiple ethnic groups – white and Black Caribbean
- Any other mixed/multiple background
- White – British
- White – Eastern European
- White – Gypsy
- White – Irish
- White – Irish or Scottish Traveller
- White – Roma
- Any other white Background
- Prefer not to say

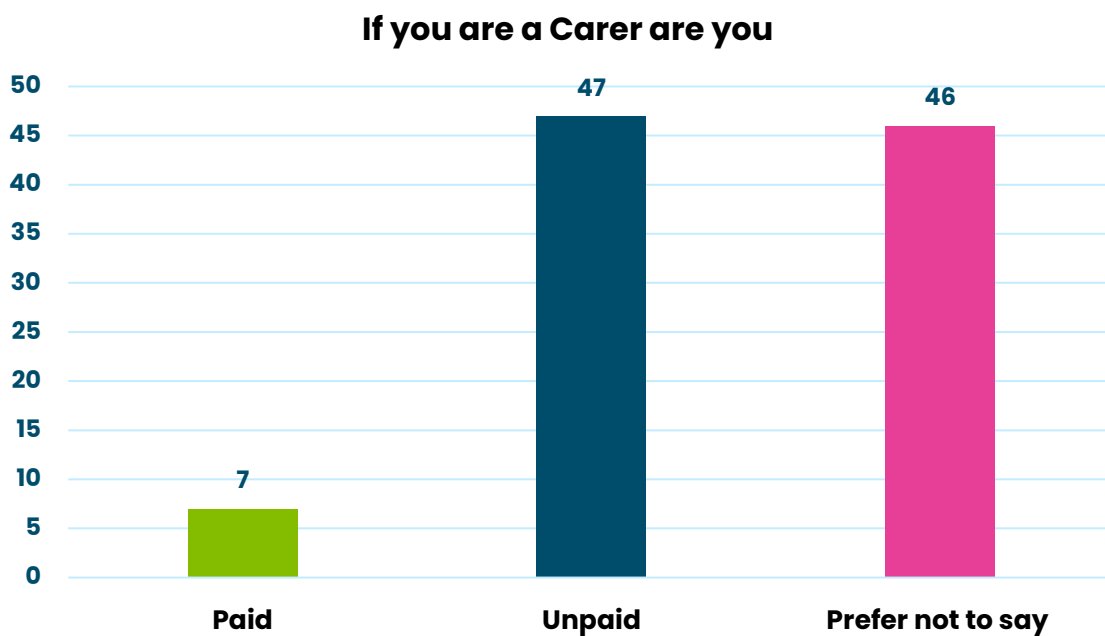
23. What is your religion?

24. We may use your first name and quote your story when publishing our findings. If you would prefer to remain anonymous, please indicate below.

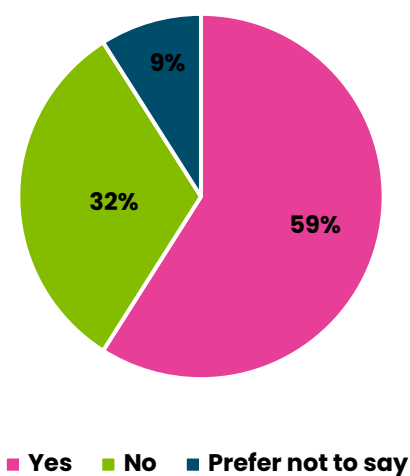
- Don't use my first name

Appendix 2

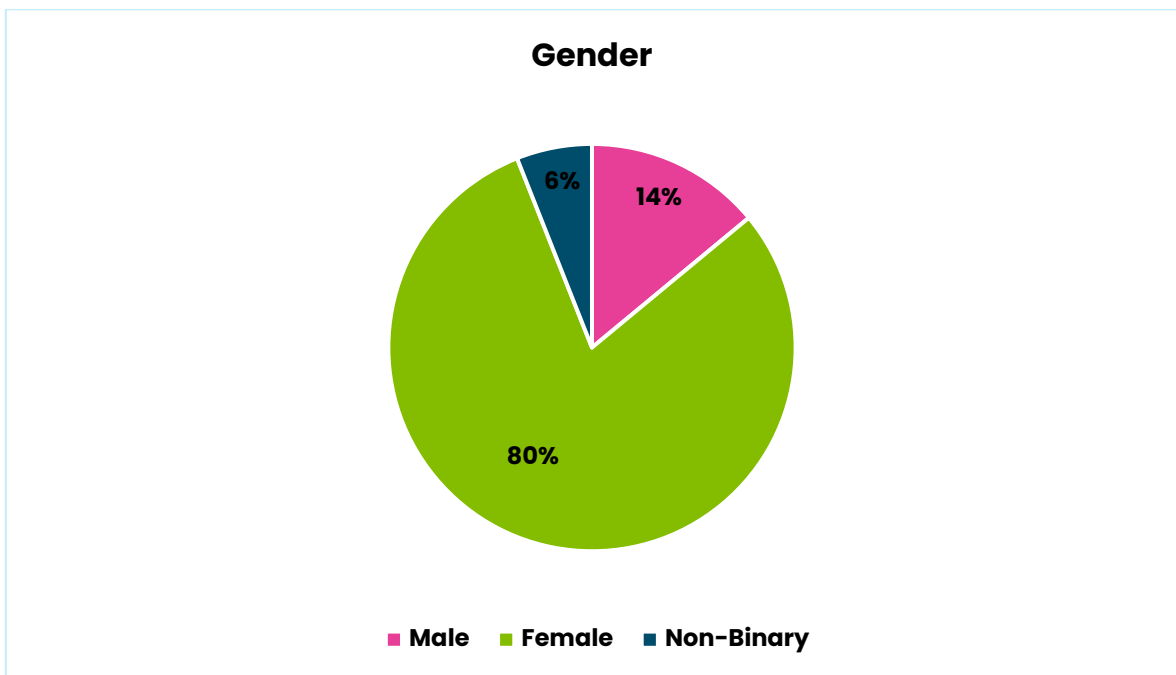
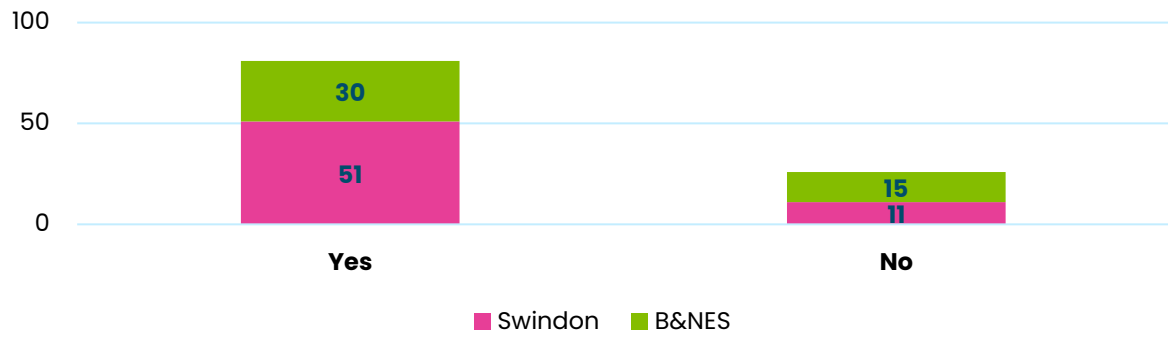
Monitoring Information for Mental Health Survey Respondents



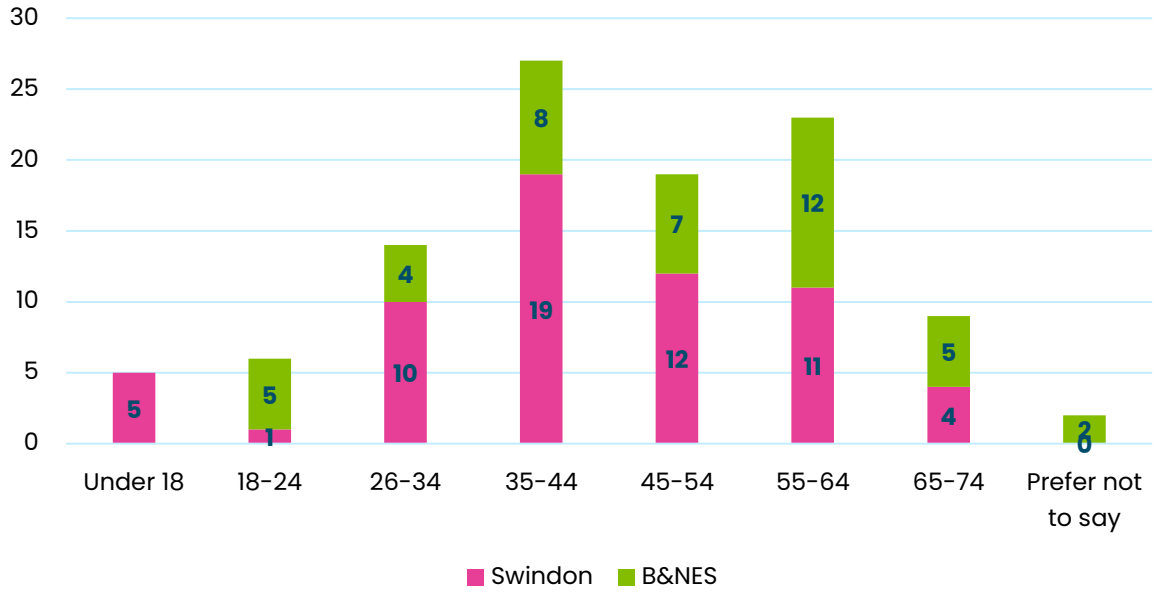
Do you consider yourself or the person you care for to have a disability



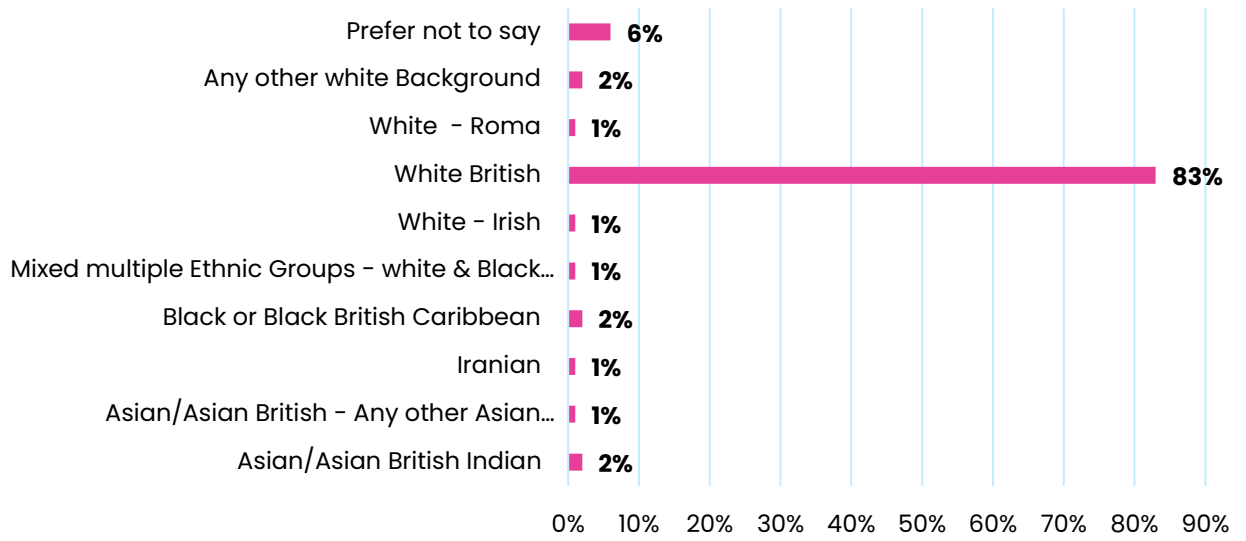
Did you or the person you care for need to access/receive additional support during 2021?



Age



Ethnicity



healthwatch
Swindon

healthwatch
Bath and North East
Somerset

Healthwatch Swindon
Sanford House
Sanford Street
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