



## **Carers - Understanding your health and wellbeing needs**

## Carers - Understanding your health and wellbeing needs

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## Introduction

### National Context

The term 'carer' is defined as *"anyone, including children and adults 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** ([NHS England](#))

According to 2011 Census data, there are around 5.4 million people in England who provide unpaid care for a friend or family member. Carers UK estimated that in 2020 there were around 13.6 million people caring for people.

It is understood that increasing hours of care often results in the general health of carers deteriorating. Unpaid carers who provide high levels of care for sick, or disabled relatives and friends, are more than twice as likely to suffer from poor health compared to people without caring responsibilities. ([NHS England - Carers Facts - Why investing in carers matters](#))

### Local Context

The 2011 Census data indicated that around 11% of the population in Warwickshire (59,240) are providing regular unpaid care. However, Warwickshire County Council said in 2013/14 that there were an estimated 108,000 people with caring responsibilities who were registered with Warwickshire GPs.

Healthwatch Warwickshire (HWW) received anecdotal feedback from some service providers that carers were worried about future lockdowns due to COVID19 and how that might impact upon their own mental health and wellbeing as well as the physical and mental health of the people they care for. Most day centres and group activities ceased during previous lockdowns which meant that carers were often left with no respite from their daily care duties.



Healthwatch Warwickshire (HWW) wished to find out more about carers' own situations and how they managed to maintain their own health and wellbeing.

## What the feedback will be used for

The feedback received from local carers will be used to help inform the planning, service delivery and design for the new Warwickshire Carers Strategy 2021. It is a joint strategy between Warwickshire County Council, and Coventry and Warwickshire Clinical Commissioning Group as well as health, voluntary and independent care sectors. They will jointly put mechanisms in place to help to support unpaid carers and to also reduce the impact of illness and disability upon families.

## Carers - Understanding your health and wellbeing needs

Cllr Margaret Bell, Portfolio Holder for Adult Social Care & Health said:



*"Warwickshire County Council is committed to supporting everyone in the county to be as safe, healthy and independent as possible, including those with a caring responsibility. The findings of this survey will help us to design and commission the right services enabling health and care professionals and community partners to continue to support carers through the provision of targeted advice and local services."*

### Aims of the project

1. To understand the **quality** of a carer's life in terms of their health and wellbeing.
2. To understand carers' **experience of accessing support** for themselves to help them maintain their own health and wellbeing and consequently that of the people they care for.
3. To understand the reasons and barriers which prevent carers from **not accessing help** and support for themselves.
4. To identify any **gaps** in existing service provision.
5. **To raise awareness of support services** that are available through Warwickshire County Council to all those with caring responsibilities who may not identify with the term 'carer'.
6. To work with service providers to improve access and provision of support services, to **help carers** maintain their own health and wellbeing and that of the person they care for.

All the data for this report was collected anonymously. We expect that the findings will inform decisions about what services and support are needed for those with caring responsibilities. People who asked to be informed about the outcome of the project will also be kept updated.

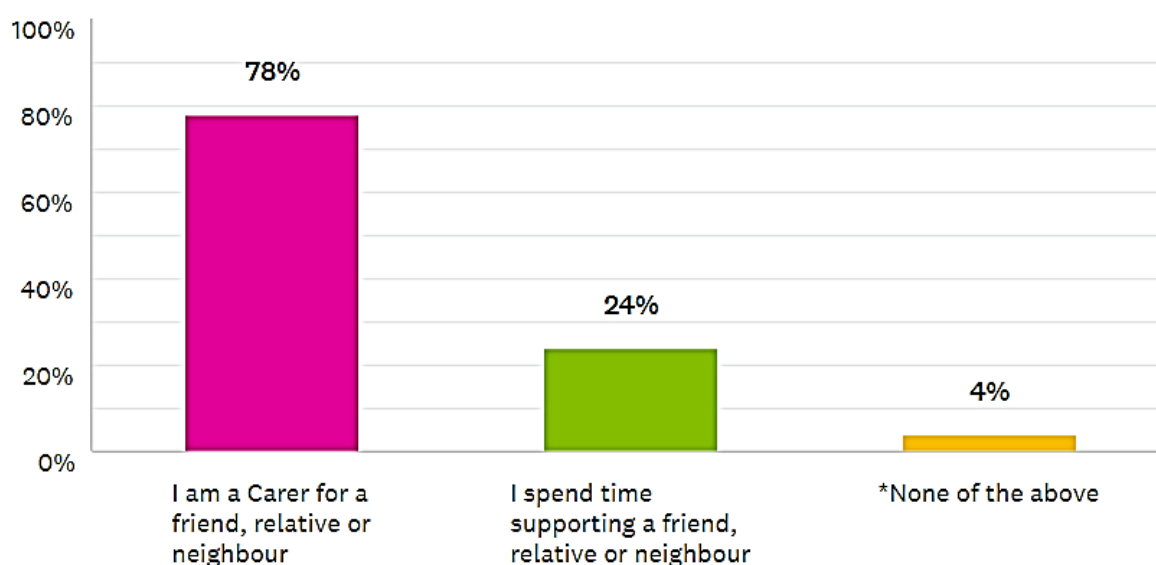
## Carers - Understanding your health and wellbeing needs

### Who responded to the survey?

**239 people responded to the survey**

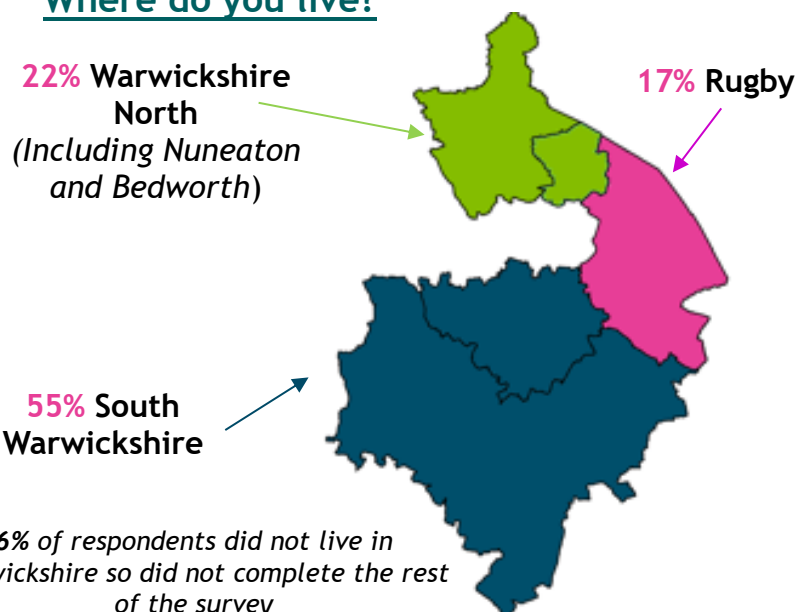
2 of which were paper copies, the remainder was online  
Not everyone answered every question

### Which statement best describes you?



*\*4% did not identify with either statement so did not complete the rest of the survey*

### Where do you live?



### Ethnicity

**89%** described themselves as White/British

### Gender

**83%** of respondents were women

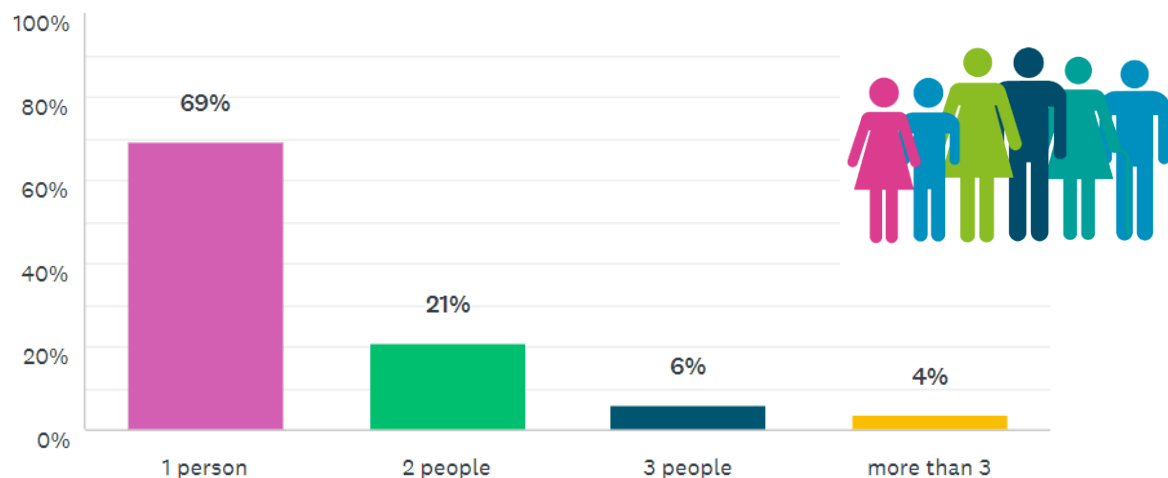
### Age

**84%** were between age 35 and 64

## Carers - Understanding your health and wellbeing needs

### What carers told us

#### How many people do you care for or support?



#### Which of the following Long-Term Conditions do you have?

We wanted to know if the carer or person providing support had any long-term health conditions themselves. The most frequent health conditions people told us they had are:

1. Musculoskeletal (arthritis/back pain)
2. Asthma or long-term chest problem
3. Hypertension
4. Mental health condition

In total, 34 different health conditions were mentioned.

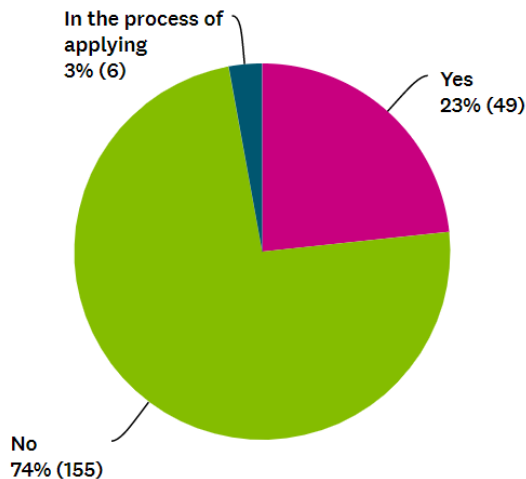
Some people identified as having more than one health condition.

**76%** of Carers who responded to this question told us they had a long-term condition.

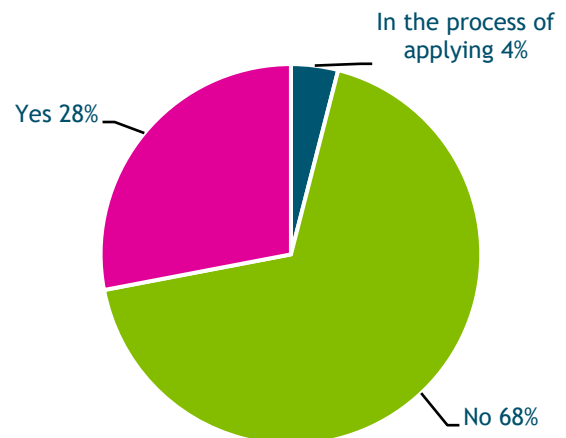


## Carers - Understanding your health and wellbeing needs

### People who told us they receive Carers Allowance\*

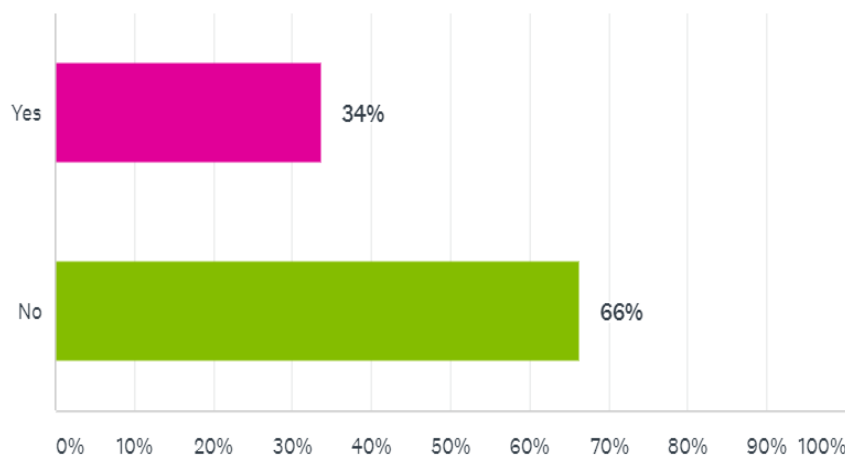


### People who identify as 'Carers' who receive Carers Allowance



*\*Carers Allowance is a benefit for people aged 16 years or over who spend at least 35 hours a week caring for a disabled person*

### Are you aware of the Care Act 2014\*?



*\*This sets out the rights of Carers which include “a focus on promoting wellbeing” and “a right for carers’ eligible needs to be met”*

**66%** of people who responded 'No' to the question were [signposted](#) to find out more information.

Of the **66%** of people who answered 'No' to this question, **28%** identified with the term 'carer' and **18%** identified as someone who 'supports a friend, relative or neighbour'.



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### Who knows they spend time caring\*

We asked carers to tell us who else knows that they spend time caring or supporting someone.

The top 5 responses are listed in order of frequency:

1. Family and/or Friends
2. GP (e.g., receptionist or support staff at your surgery)
3. Diagnosing practitioner (e.g., medical specialist or consultant)
4. Carers Support Service (e.g., Carers Trust, Warwickshire Young Carers, Age UK)
5. Community Health Worker (e.g., District Nurses or Occupational Therapist)



### Experience of telling someone they are a Carer

We wanted to understand what carers' experiences were of telling someone they have caring responsibilities.

**31%** of the comments represented a feeling of either lack of understanding that they are a carer, lack of empathy, or a lack of desire to help them.





## Carers - Understanding your health and wellbeing needs

### What changed as a result of telling someone they were a carer?

We asked people to tell us what changed for them when they told someone they had caring responsibilities.

Multiple choice answers were given. The responses below are listed in the order of most popular response:

1. Nothing
2. It helped that people understood I had caring responsibilities
3. Given an information leaflet
4. It helped me to talk about my experiences
5. Referred to a support service
6. Other\*
7. Given information about mental health support
8. Given information about financial support I can receive

\*In addition to the above choices, a free text box was also provided for people to share their experience. Here are some of the comments received.



*"Only when you are struggling do other organizations intervene"*

*"I had support at work offered, with flexi time given as an option, I also now work part time instead of full time!"*

*"I avoid telling people I have caring responsibilities using 'carer' as they don't get it and is meaningless.*

***It's our lives, not just 'caring'.***

*We need to move beyond 'carer', it becomes an unhelpful simplification*

*"10 years ago, I had a social worker who I could contact when I needed support and help. Gradually any support has dwindled to Carers Trust contact and a carers group meeting once a month"*

*"Health and social care only respond when I approach them, there is no follow up"*

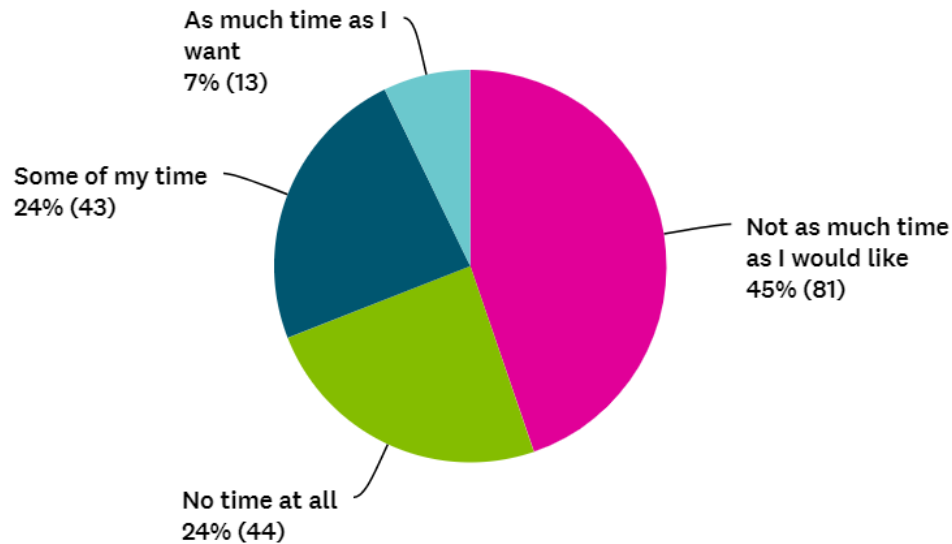


*Anonymous quotes taken from survey feedback*

## Carers - Understanding your health and wellbeing needs

### Carers' health and wellbeing needs

We asked people how much time they spend doing the things they *value and enjoy* (aside from their caring role)



We wanted to know what **impact** caring or supporting someone had on the carers' lives.

#### Respite or breaks from caring

**64%** told us they felt they did not get enough respite or breaks from their caring role

#### Financial impact

**74%** of people told us they were not under any financial strain due to their caring

#### Health and Wellbeing

**82%** of people told us they have not spent as much time focussing on their own health and wellbeing

#### Working and Caring

**52%** of people have had to stop working or reduce their hours because of their caring role

#### Support

**57%** of people told us they have never received any support with their caring role



## Carers - Understanding your health and wellbeing needs

### Where carers would go for support

We wanted to understand where people would go if they felt they needed support with their mental health and physical health

	Mental health	Physical health
1	Family and/or Friends	GP Surgery
2	GP Surgery	I don't know
3	Carers Support Service	Seek respite or a break from caring
4	I don't know	None of these
5	Mental Health service	Carers support

### How they would like to access support

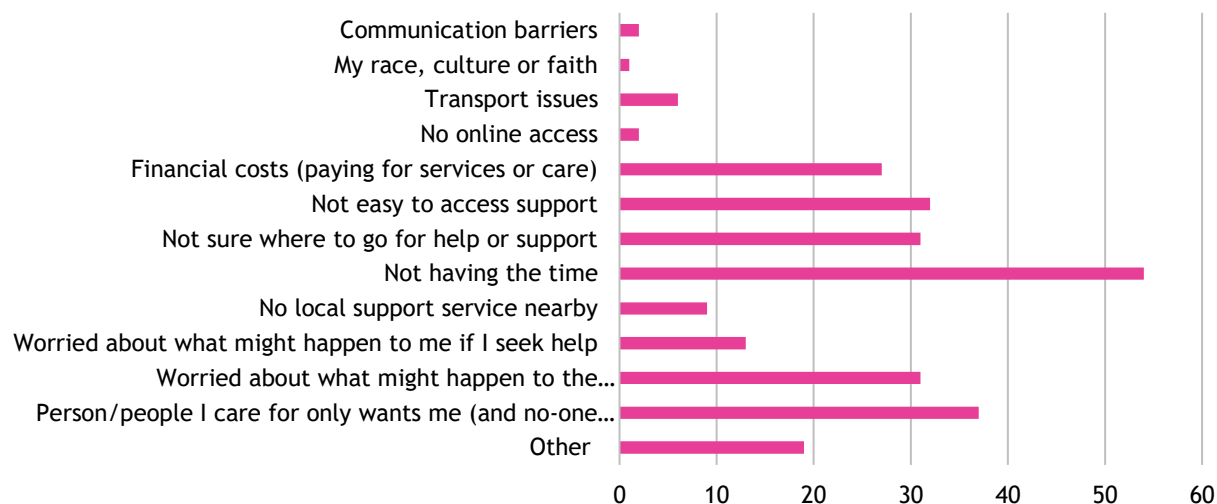
When asked, if they needed support, how they would prefer to access a support service (for both their mental and physical health) most people wanted to use a combination of accessing support over the **telephone**, **online** and **face to face**



### Barriers to accessing support

We asked people if anything had stopped them looking for or trying to access support. **53%** of respondents said 'Yes'. We then asked what the barriers are to looking for or accessing support.

### What has stopped you looking for or accessing support for your own mental or physical health and wellbeing?



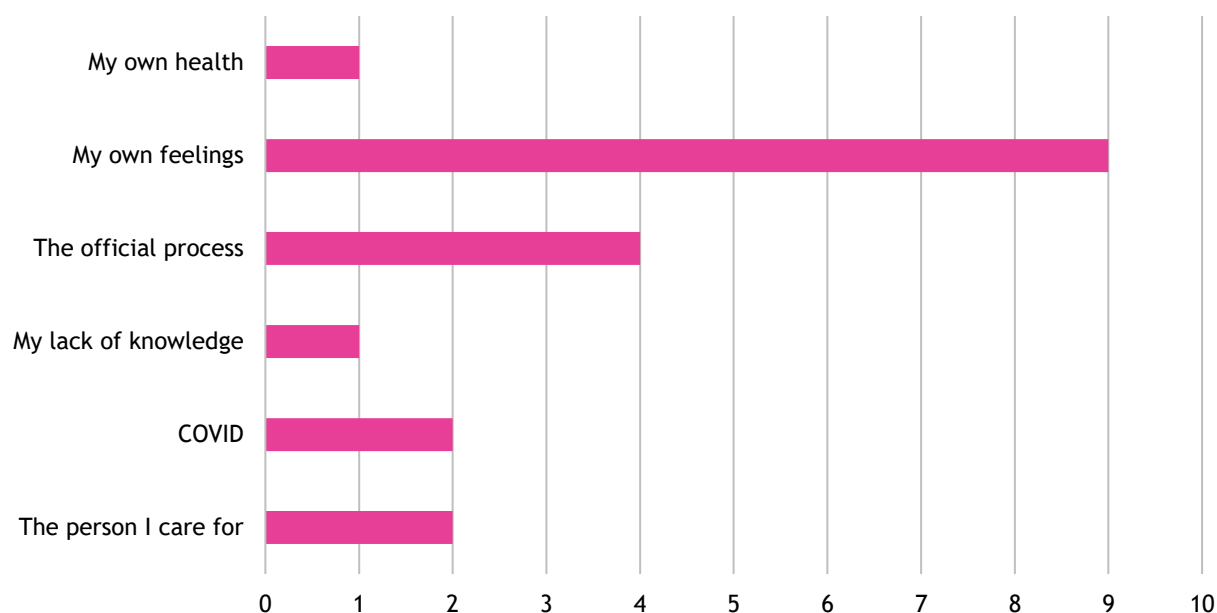
## Carers - Understanding your health and wellbeing needs

The most frequent answers given from the multiple-choice question are as follows:

1. Not having the time
2. Person/people I care for only wants me (and no-one else) to look after them
3. Not easy to access support
4. Worried about what might happen to the person/people I care for if I seek help for myself
5. Not sure where to go for help or support

Other reasons people felt they were unable to look for or access support include:

### Other responses to: 'What has stopped you looking for or trying to access support for your own mental or physical health and wellbeing?'



## Carers - Understanding your health and wellbeing needs

### About the cared for person

#### Age

**49%** of respondents told us the people they care for are 75 or over



#### Long term Conditions

The top 5 Long Term Conditions (LTC) the cared for person has:

1.	Mobility problem
2.	Mental health
3.	Frailty
4.	Dementia
5.	Asthma and Musculoskeletal

**7%** of the cared for people were identified by their Carers as being on the Autism Spectrum

## Carers - Understanding your health and wellbeing needs

### Anecdotal feedback and comments from carers

We asked people if there was anything else they wished to tell us or if they felt there is something we have not covered in the survey. Below is some of the feedback received.



*"Having to access support seems to be left to me alone"*

*"The process of getting respite care is very stressful"*

*"Most carers will not seek help unless things get very difficult"*

**"I feel seen.  
Thank you"**

*"In caring for my son, I have given up a rewarding career and this affects me financially, social and mentally"*

*"There needs to be more emphasis on the role of social care to support families. The worst thing is the battling against the system"*

*"As a 'carer' feel very much left alone to get on with it. Carers Assessment is awful, no help even when you go through it. I'd like to be linked to other 'carers' in Leamington to share insight and knowledge, no platform for that despite asking WCC and CT. repeatedly. I'd like to link to other Advanced MS users for similar insight and foresight"*

*"Mental Health Services have decreased ask any mental health carer - it was broken before Covid and now"*

***"Being a carer is the loneliest, miserable and most heart-breaking experience of my life. I have lost all joy in life; I can't keep friends because I have no time and I'm exhausted. I'm trapped"***





## My caring story – lived experience of a Carer

This is Georgina's story of how she cares for both her elderly parents and what it's like for her to be a carer

*"I have been caring for my elderly parents for 15 years. At first, I was still able to work full time in a job which I loved in a special needs college. It was a very challenging job in itself but I managed to support my parents at the weekend after work and to sort things out over the phone.*

*Then the emergency calls started to come when I was at work, and I would need to leave usually to get one of my parents into hospital because they had not been telling me about a health issue which had become worse. On at least five occasions over the next few years if I had not gone over to sort out a crisis one of my parents would have died. The situation gradually got worse, and I was on the phone to the district nurse at tea break or lunch time and then driving from Leamington Spa to Birmingham after work and then getting home at 10 or 11 at night.*



***"I am lucky if I get two days clear without an emergency of some kind. I don't sleep very well, and I have lost two stone in weight.***

***I love my parents very much and am constantly beating myself up because I can't solve all of their problems, I want everything to be perfect for them, but it can't be. I don't know anyone else in my situation, I have met people who are supporting one parent but never two"***



*We then needed to employ a care agency for my mom to help me out but each agency we tried did not look after my mom well and on one occasion leaving her in a diabetic coma with only my dad in the house who can't dial the telephone due to a stroke, he managed to press the call back button and get me as I was the last person to call the house. I answered to phone for him to tell me he didn't think mom was breathing, the drive over was awful, not knowing what I would walk into at the other end of the journey, luckily this time mom survived. We then needed a new care company, five care companies and five years later we have finally got two carers who really do care about my mom, and I do need to rely on them to help me out.*

*In January mom caught Covid off the carer, she was ok after a few days but by that time Dad had caught it off her and he got it very badly. Two periods in the QE one in Moseley Hall one in Heartlands Hospital and two in an assessment care home, and after three months we got Dad home. We had very little contact with him over that period, I spent hours trying to get through on the phone to try to find out if he was ok, but the system was under terrible pressure, and we were just another family with a loved one in isolation. Dad managed to be home for about six weeks but had one UTI which he recovered from but then another last week which put him in the QE again...*

## Carers - Understanding your health and wellbeing needs

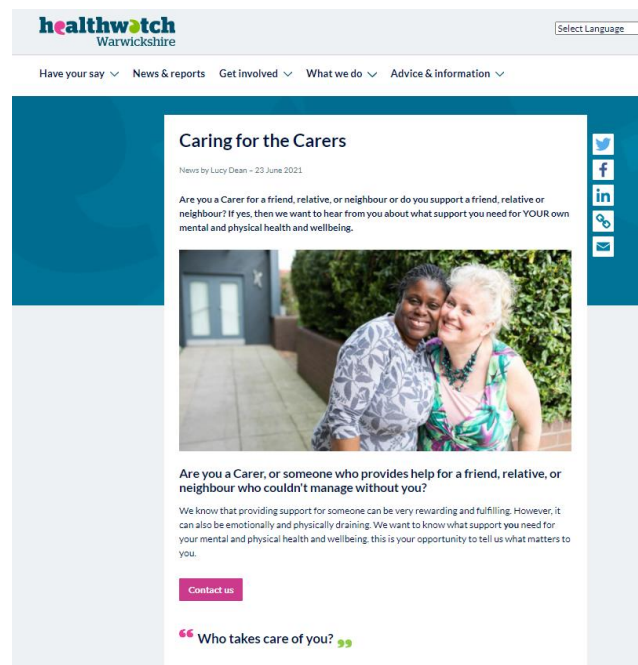
*...I am back on the phone many times a day to try to find out how he is but no luck yet, awaiting a call from the doctor.*

*During the time he was home his urine bag kept leaking all over the bedroom floor, once he tried to hold it over a bowl all night and ended up having a fall. I have needed to get the district nurses out overnight many times. We also have been over at 3.30 in the morning when mom fell because she was exhausted trying to cope with the new situation at home.*

*I am lucky if I get two days clear without an emergency of some kind. I don't sleep very well, and I have lost two stone in weight. I love my parents very much and am constantly beating myself up because I can't solve all of their problems, I want everything to be perfect for them, but it can't be. I don't know anyone else in my situation, I have met people who are supporting one parent but never two.*

*All I can say is that I have learnt so much over the past few years dealing with all the agencies that support older people that I have become an expert."*

## Signposting and information webpage



We were aware that some people completing our survey may find sharing their experiences about their lives emotional.

We provided signposting and advice for people should they need it. 'Caring for the Carers' is a dedicated page on our website which includes a range of support and advice services available.

The webpage also invites people with caring responsibilities to tell us about their experience.

Since 30<sup>th</sup> March to 1<sup>st</sup> June 2021, there have been **658** unique visits to the page.

## Summary of findings

### Key themes from the report for consideration: -

- Our findings suggest that people are more likely to **tell** family and friends and/or their GP about their caring responsibilities
- **82** people told us that '**nothing**' had changed as a result of **telling someone** that they had caring responsibilities and out of those respondents **31%** said that the person they had told had not understood, lacked empathy or had not shown a desire to help or support them
- **82%** of people said that they have not spent as much time on their **own health and wellbeing** as they would like
- When asked about how they could look after their **physical health**, some respondents told us that 'respite or a break from their caring role' would help with their physical health
- **45%** of people told us they do not spend as much time as they would like doing the things they **value and enjoy**, with **24%** of people saying they don't spend any time at all doing things they enjoy.
- The top **barrier for not accessing support** for themselves was "Not having time." Other reasons included "my own feelings."
- If respondents wanted **help with their mental health**, they are more likely to tell friends and family. The least favourable option was seeking help from mental health services.
- **57%** told us they have **never received support** in their caring role.
- **52%** told us they had to stop working or reduce their hours due to their caring role. However only **26%** said they were under financial strain due to caring.
- Respondents told us they would like to **access support** using a mixture of ways, including over the telephone, face to face, and online.

## Carers - Understanding your health and wellbeing needs

### Sentiment of feedback: -

- Throughout the survey there were comments from carers about how there was a lack of support from 'Social Services.' This resulted in carers feeling frustrated.
- There was also general frustration about the process of accessing respite care.
- There were frequent comments about how it was only when the situation reached breaking point or crisis point that an organisation would step in to help.
- There was a strong sense of guilt and loneliness that people felt about being a carer.
- There was considered to be a lack of understanding as to what having caring responsibilities means and the expectation from organisation and friends and family that the person caring will 'cope.'
- Not everyone likes, or identifies with, the term 'carer' as there is often a lack of understanding of what the term means.

## Recommendations

### Access to support: -

- *"Not having enough time"* was one of the top reasons why people have not sought or accessed support. It was felt that the process to get any support would be difficult and time consuming. People told us they would like to access support in a mixture of ways such as online, face to face and over the telephone. **Making services available in a number of ways** would make support more accessible to carers.
- 57% of people had never received support with their caring responsibilities. **Raising awareness of support that is available to the general public** would be helpful especially to those who may not identify themselves as a 'carer'.

### Awareness of caring responsibilities: -

- 83% of respondents were women. **A more targeted approach to encourage men with caring responsibilities** is needed.

## Carers - Understanding your health and wellbeing needs

- Only 1% of respondents were from other ethnic backgrounds. **A more targeted engagement is needed to determine if there are any specific needs from other backgrounds** that need to be addressed.
- People told us their friends and/or family and GP Practice know they have caring responsibilities. Yet when asked what changed as a result of telling someone they are a carer, comments mentioned a 'lack' of understanding, desire to help or empathy. **Wider awareness in the general public as well as with organisations about the support that is available to those with caring responsibilities** would be helpful. Also, **identifying those who may have caring responsibilities and putting them in touch with organisations who can help** could be useful. Healthwatch can promote any campaigns around awareness raising and help with signposting.
- 52% of people told us they had to stop working or reduce their hours because of their caring role. **More awareness raising with employers and flexibility at work** for those with caring responsibilities is required.

## Emotional wellbeing:-

- 45% of people told us they needed help with their mental and emotional health. There is a need to **raise awareness within communities about support services that are available and how to access them**. Healthwatch Warwickshire can work with mental health services and the voluntary sector to help with further engagement with carers.

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There comes a point where  
we need to stop just pulling  
people out of the river. We  
need to go upstream and find  
out why they're falling in.

Desmond Tutu

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## How will we keep people informed about the project?

As well as sharing this report with Warwickshire County Council and key stakeholders, 62 respondents asked to be kept informed about the project. Where people left their details, we will contact them directly to share our findings and keep them updated on what has happened as a result of sharing their experiences with us. In addition to this we will publish this report on our website and share key messages on our social media channels.

## Thank you

We would like to thank everyone who participated in this survey, giving up their precious time to share their experiences. We would also like to give special thanks to groups and individuals who were involved in helping raise awareness of the project:

- Amanda Fawcett, Warwickshire County Council
- Amanda Wilson-Patterson, Warwickshire County Council
- Ben Thompson, member of the public
- Charles Barlow, Warwickshire County Council Community and Partnership Teams
- Warwickshire Carers Support Forum
- Caroline Button, Coventry and Warwickshire Partnership Trust
- Claire Taylor, Warwickshire County Council, Commissioner of Dementia Services
- Fiona Lowe, Local Pharmaceutical Company
- Gillian Grayson Smith, Caring4Carers
- Jackie and Stephen Prestwich, Volunteer
- Jenni Northcote, Chief Strategy and Primary Care Officer, Clinical Commissioning Group
- John Copping, Healthwatch Warwickshire Director
- Louise Richards, Warwickshire County Council
- Melanie Adekale, Warwickshire County Council, Commissioner of All Carers
- Mike Howard, Carers Trust
- Nicola Earles, Health Exchange
- Stephen Merriott, Warwickshire Libraries Services
- Teresa Bird and Anthony Bishop, Warwickshire Young Carers
- Tony Britton - Pam Britton Trust

## Carers - Understanding your health and wellbeing needs

If you would like this report in an alternative format, please contact us directly.

For more information about Healthwatch Warwickshire and what we do, please visit our website. <https://www.healthwatchwarwickshire.co.uk/>

**Please feel free to contact us:**

**Call us:** 01926 422823 (between 9am and 5pm, Monday to Friday)

**Post:** FREEPOST Healthwatch Warwickshire

**Email:** [info@healthwatchwarwickshire.co.uk](mailto:info@healthwatchwarwickshire.co.uk)

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## Carers - Understanding your health and wellbeing needs

### ANNEX

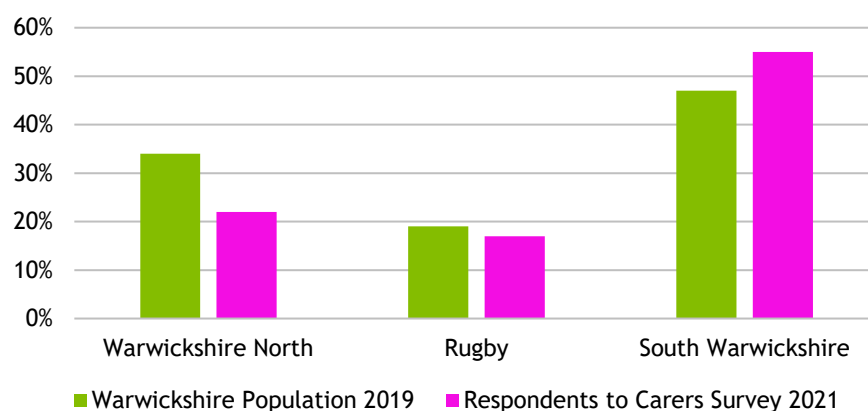
## Prompting survey responses - successes and challenges

### Introduction

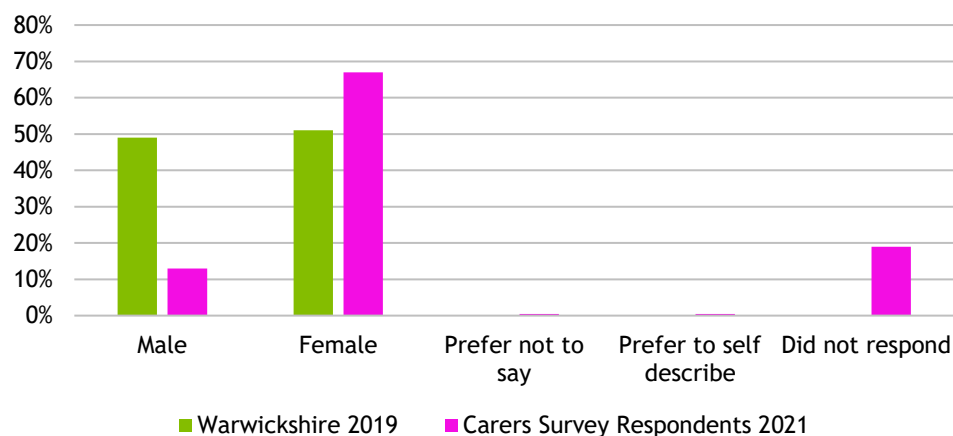
‘Carers - Understanding your health and wellbeing needs’, was a Warwickshire wide project aimed at carers and those with caring responsibilities. Healthwatch Warwickshire wanted to hear from carers as individuals about their health and wellbeing needs.

The purpose of this annex is to assess and analyse the methods used to get feedback from carers and look at areas where we could focus efforts and resources for future projects.

### Population and location of respondents



### Gender in Warwickshire and Carers Survey Respondents

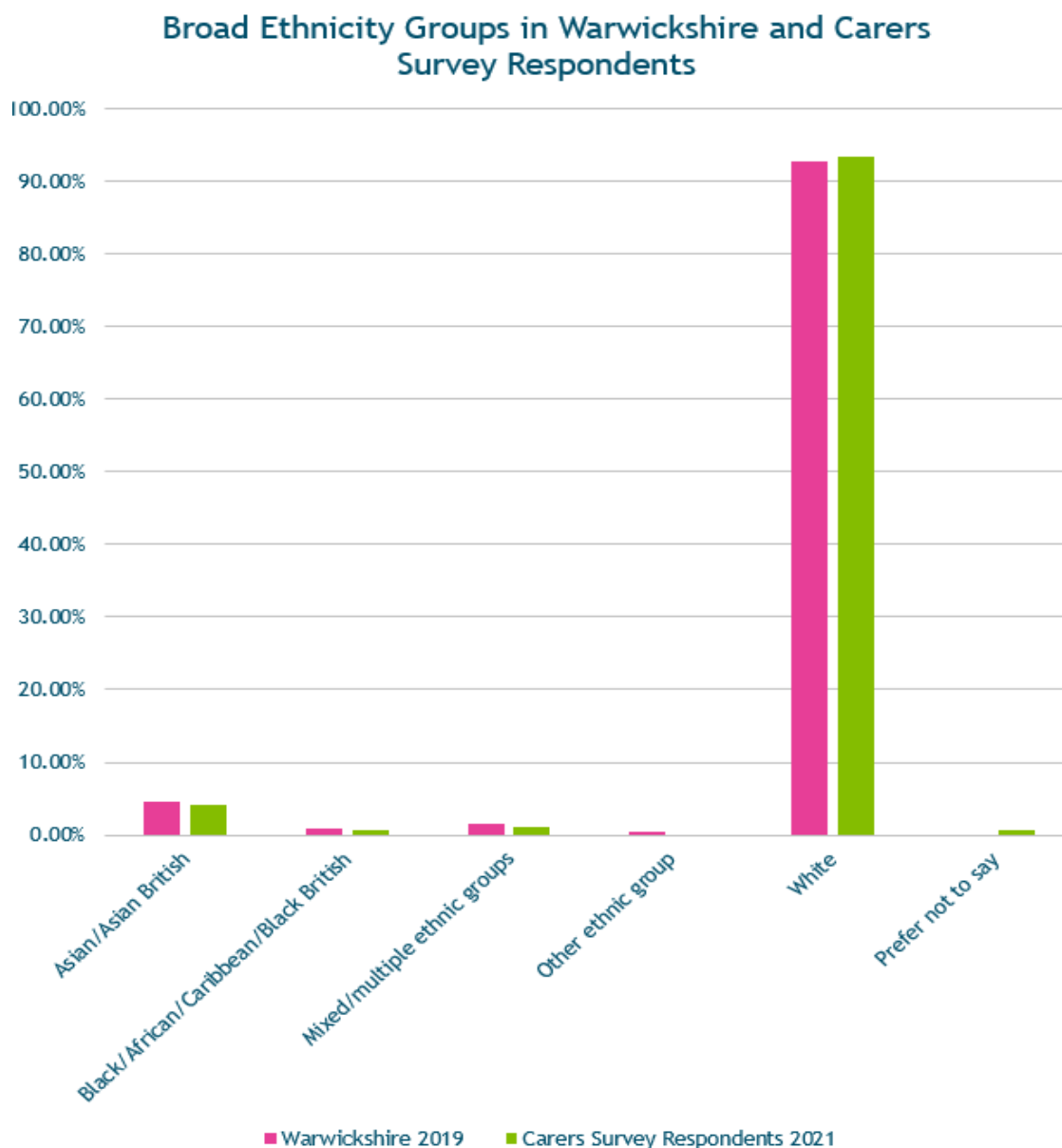


We heard more from women than men. More targeted messaging aimed directly at men may be needed in future projects to encourage a higher response rate.

## Carers - Understanding your health and wellbeing needs

### Ethnicity

89% of respondents described themselves as 'White British'. 93% of Warwickshire's residents describe themselves as being 'White'. To encourage people from different ethnic backgrounds, links with community groups could have been used from the beginning.



## Carers - Understanding your health and wellbeing needs

### Age

The age ranges used in the Carers survey differ from the age ranges used in the Warwickshire Census 2011. Healthwatch Warwickshire are not contracted to work with children (under 12) therefore when we asked for respondents' ages, they started at 12-17. The Warwickshire Census age range starts from 0-9, followed by 10-19. Therefore, it is difficult to compare 'age of respondent' to the latest available Census data.

However, we didn't hear from under 34's as much as we would have liked.

Warwickshire Census		Carers Survey		
0 to 9	11%		1	0.50%
10 to 19	11%	12-17 years	1	0.50%
20 to 29	12%	18-24 years	1	0.50%
30 to 39	12%	25-34 years	7	4%
40 to 49	13%	35-44 years	21	12%
50 to 59	14%	45-54 years	45	26%
60 to 69	11%	55-64 years	54	31%
70 to 79	10%	65-74 years	26	15%
80+	6%	75 years +	19	11%

### Distribution of the survey

Due to the COVID19 pandemic, communication and distribution of the survey was done primarily via:

- Email
- Posters
- Post cards
- Paper copies of the survey

The survey was launched on 30<sup>th</sup> March 2021, during the third national lockdown. The decision was made after the launch of the survey to extend the deadline date to try and encourage more responses from the public through promotion of community groups and public-facing organisations when restrictions eased on 17<sup>th</sup> May. Paper surveys, postcards and posters were made available to all organisations to encourage those who may be digitally excluded to take part in the survey. People

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were also offered access to the survey over the telephone, by calling Healthwatch Warwickshire and staff members completed it for them.

The survey was promoted to over 175 contacts using postcards, newsletters and emails including the following organisations and contacts;

### **Carers and wider public**

- Act on Energy
- Acute Trusts
- BRANCAB
- Carers Support Form - Warwickshire
- Citizens Advice Bureau
- Clinical Commissioning Group
- Coventry & Warwickshire Partnership Trust
- District and Borough Councils
- Hospices
- Other local charities and contacts
- Out of hospital care teams (Home First)
- Northern Warwickshire Toursim
- Parish and Town Councils
- Pharmacies
- Primary Care Networks
- Social Prescribers
- Warwickshire CAVA
- Warwickshire County Council Localities Teams
- Warwickshire County Council, Commissioner for All Carers
- Warawickshire Libraries
- Warwickshire Wildlife Trust
- Pam Britton Trust
- Parenting Project
- Warwick Medical School
- Warwickshire Pension Fund

### **‘Seldom Heard’ groups**

- Benn Partnership (Rugby)
- Black Lives Matter - WCC Staff Network
- Children Safeguarding Support, Warwickshire County Council
- Deaf Club
- Equip
- Faith Forum
- Family Wellbeing Commissioner

## **Carers - Understanding your health and wellbeing needs**

- Food Banks
- Grapevine
- Homeless Groups
- It takes Balls to Talk (mental health charity for men)
- Maternity Voices Partnership
- Men Shed
- MenTALK (Mental health charity for men)
- Nuneaton Asian Ladies Group
- Nuneaton Mosque
- People with Disabilities, Warwickshire County Council
- Poverty Forum
- R.I.S.E (Mental health organisation for under 25's)
- Re-Think
- Sikh Community Centre
- Sikh Temple
- Warwick University
- Warwickshire Fire and Rescue - Equality Diversity and Inclusion Officer
- Warwickshire Pride (LGBTQ)
- Warwickshire Young Carers
- Warwickshire Youth Council
- Warwickshire County Council - Gypsy and Traveller Communities

### **Promotion**

The survey was promoted in various newsletters and websites and reshared on social media. When emailing organisations the request for help was direct, and the links to the survey and social media posts was embedded in the email so people could forward the email onto contacts or copy and paste into an email.

Requests for the survey to be included in newsletters and sent out to any groups were made.

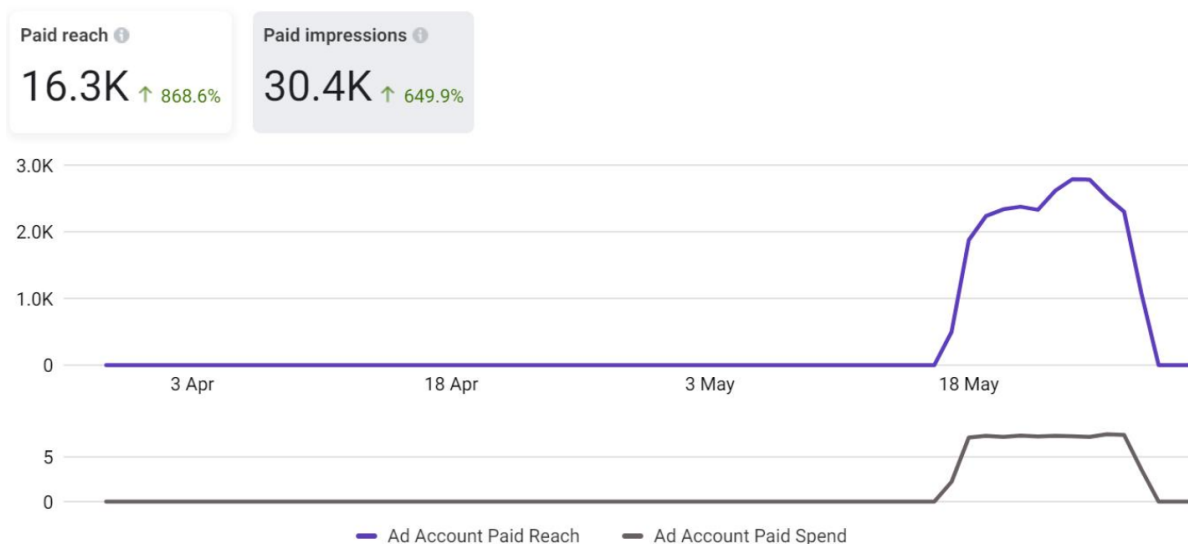
When the deadline date was extended, all contacts were contacted again with a request to promote the survey again.

### **Successes**

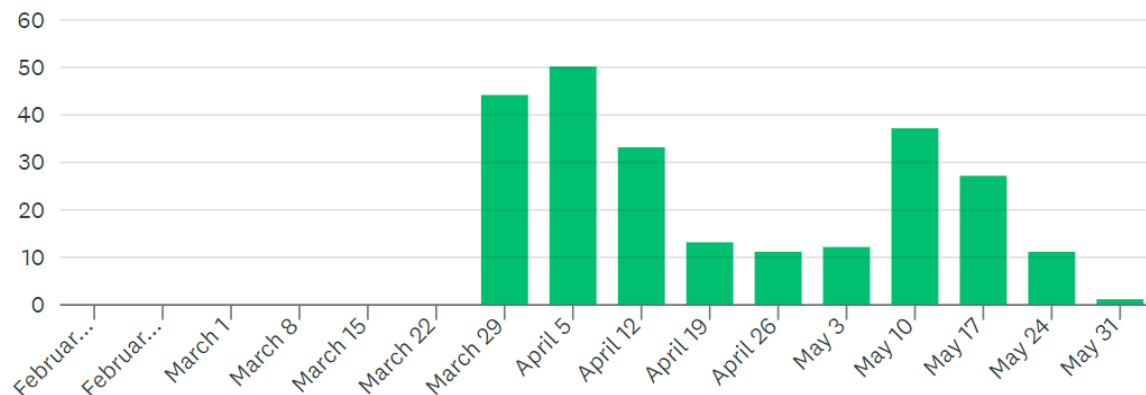
Paid promotion posts were used for Facebook to encourage more men, people under 35, people from Rugby/North Warwickshire, and people from different ethnic backgrounds to complete the survey.

The Facebook boosted posts were launched in May. The below graph shows an increase in the number of people reached.

## Carers - Understanding your health and wellbeing needs



400 postcards were sent out to mobile libraires throughout Warwickshire in addition to the boosted Facebook posts. The increase in number of responses in May can be seen in the graph below.



### Challenges

Not being able to do face to face engagement was a big challenge. We also recognise that most of the people we were asking to complete the survey are under time pressures. We created a separate signposting and information webpage which included information on support and advice services for those with caring responsibilities, which was used to promote the survey.