Carers’ access and attitudes to flu jabs

Analysing the experiences of carers aged 50–64 in England

August 2020

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Supported by an educational grant from Seqirus
I have had one every year. Good to protect myself and others around me. If I am ill and can’t look after my daughter it would cause her a great deal of distress so good to do anything to keep myself healthy. Extra important people have it this year.
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Introduction

The 2011 Census found that there were 5.4 million people across England (6.5 million across the UK) providing unpaid care to a family member or friend who is elderly, disabled or seriously ill. Recent polling estimated that before the COVID-19 outbreak there were up to 7.7 million carers in England. The impact of COVID-19 has caused an unprecedented increase in the number of carers in the UK. An extra 3.8 million people in England have started caring since the start of the pandemic.

Carers are not a static population. Each year millions of people become carers, whilst caring responsibilities come to an end for millions of others as the person they care for recovers, moves into residential care or passes away. The vast majority of care in the UK continues to be provided by unpaid carers. The economic value of this care was previously valued at £132 billion per year (more than the total spending on the NHS in the UK) but given the large increase in the caring population outlined above, this figure is now probably far higher.

We know that while caring can be extremely rewarding, it can also be hugely challenging. Recent research indicates that the coronavirus outbreak has added yet more pressure to the lives of many carers. 70% of carers are providing more care than before the start of the outbreak. Over a third are providing that extra care because of the closure or reduction of local services. These findings are particularly worrying when considered alongside previous research from Carers UK which showed that almost three quarters (72%) of carers had suffered mental ill health such as stress or depression as a result of caring, while well over half (61%) said their physical health had worsened as a result of caring. The GP Patient Survey supports these findings, showing that carers were more likely to report having health problems. It also revealed that carers are more likely to report having a long-term condition, disability or illness – 63% of carers compared to 51% of non-carers. In addition, 63% of carers reported that their condition led to trouble with day-to-day activity compared to 58% of non-carers.

It can take a long time for many carers to recognise themselves as a carer, with the majority of carers taking years. Carers UK research found that over half of carers (54%) took over a year to recognise their caring role, almost one in four carers (24%) took over five years and nearly one in ten (9%) took over 10 years.

It should be noted that carers who respond to Carers UK surveys, including the surveys which informed this research, will have recognised their caring role and therefore be more connected and more likely to be accessing support than the carer population overall. It is likely that the identification rates in the general population are even lower than amongst Carers UK’s networks.

1 Carers Week (2020) Carers Week Research Report: rise in the number of unpaid carers during the coronavirus (COVID-19) outbreak
2 Ibid
3 Buckner L and Yeoandie S, Valuing Carers: calculating the value of carers’ support, University of Leeds and Sheffield, 2015, Carers UK
4 Carers UK (2020) Caring Behind Closed Doors: Forgotten Families in the Coronavirus Outbreak
5 Carers UK (2018) State of Caring 2018
7 Ibid
NHS England guidance states that free flu jabs should be available for people who receive Carer’s Allowance, or who are the main carer for an elderly or disabled person whose welfare may be at risk if they fall ill. This places them in a similar category to key workers, ie health care workers and care workers who are also eligible for the flu jab.9

However, as the research shows, not all carers are receiving their flu jab and carers views towards the flu jab and their experience of it can vary significantly.10

Past research has shown that a significant proportion of carers providing substantial care do not get a flu jab.11 When the 2015 State of Caring survey asked carers if they had received their annual flu jab that year, 55% of carers said yes and 45% said no. Older carers were significantly more likely to have had a flu jab, with 80% saying they received a flu jab that year, whereas carers under the age of 65 were in line with the average with 55% having had a flu vaccine.12 This lower take-up rate is especially concerning given that this group of carers were largely providing substantial care and the impact of getting the flu and not being able to care would be significant.

A contributing factor to carers not receiving the flu jab was their GP not identifying them as a carer, and as a result not having a consistent or accessible pathway to having the flu jab.13

Data from 2018 found that 73% of carers had been identified by their GP as a carer. Certain groups of carers were less likely to be identified, with working carers (carers who are juggling a paid job with their unpaid caring) and those who had recently started caring less likely to be identified than other groups of carers. These same two groups of carers were also less likely to have been directed towards having the flu vaccine.14

The data on which this report is based is largely drawn from the State of Caring Survey 2020. Overall, this survey found that 71% of carers had been identified by their GP as a carer. 55% of these identified carers were then directed towards having a flu jab by their GP. This compares to just 11% of carers who had not been identified by their GP but reported they had been directed to have a flu jab by their GP.15

Black, Asian and Minority Ethnic (BAME) carers had similar rates of being identified by their GP in 2020 with 72% reporting that their GP knew they were a carer. Once identified by their GP, 59% of BAME carers were directed towards having a flu jab, which is slightly higher than the average for carers in the 2020 data. It is worth pointing out that these figures come from a relatively small sample size of less than 200 BAME carers. More research needs to be done on this area given that the GP Patient Survey in 2019 showed that BAME carers found it harder to access services than white carers.16

Older carers were more likely to be identified by their GP, with 82% of carers over the age of 65 reporting that their GP knew they were a carer. Carers aged 50–64 were comparatively less likely to be identified by their GP with 71% saying their GP was aware they are a carer.17

This report focuses on carers aged 50–64. This is an age group with lower rates of take-up of the flu vaccine and lower rates of identification by their GP (compared to older carers). The connection between being identified by a GP as a carer and being directed towards having a flu jab is explored, as are variations and breakdowns within the 50–64 age bracket. Throughout, the report is supplemented by carers’ experiences which they have shared with Carers UK through our information gathering platforms.

It is hoped that this report will also offer insight into where messages might be targeted to ensure greater take-up of the flu vaccination by carers in the 50–64 age group – a new extended group announced by the Department of Health and Social Care for the 2020/21 flu season.18

9 www.nhs.uk/conditions/vaccinations/who-should-have-flu-vaccine
10 State of Caring Survey 2015
11 Ibid
12 Ibid
13 Carers UK (2018) State of Caring 2018
14 Ibid
15 State of Caring Survey 2020
17 Ibid
Impact of COVID-19

Crucial to the context of this report and the recommendations within it is the outbreak of COVID-19.

COVID-19 has been a significant worry for carers who not only have to think about their health, but the health of the person they are caring for. This has led to many making difficult choices about the care and support they and the person they care for receive. 22% of carers reported that they had cancelled services (including ongoing healthcare services) because of concerns about passing on COVID-19 to the person they care for.19

It is likely that concerns about keeping themselves and the person they care for safe will impact on carers’ decisions to have a flu vaccine in 2020. A fear of accessing health services among carers should be a consideration for any organisation trying to increase the uptake of the flu jab.

Traditional public health services such as screening and flu jobs have always been more of a challenge for carers to access because they are either unable to put alternative care provision in place while they are at the appointment, or simply cannot get an appointment.20

It is essential that there is flexibility in these services and that carers are encouraged and supported to access the flu jab.

Carers must also be included on the priority list for the COVID-19 vaccine. The current guidance from the Joint Committee on Vaccination and Immunisation (JCVI) does not include carers as a priority group for any COVID-19 vaccination. If carers have an equivalent ‘key worker’ status for flu vaccination, they should have a similar status for the COVID-19 vaccine. It would not only recognise carers, but make the streamlining of messages much easier.

This report’s findings and recommendations are given a greater urgency by the fact that the Government, and many health professionals, are concerned that the winter pressures on the NHS could be exacerbated by seasonal flu combining with a winter surge of COVID-19 infections.

Knowledge of carers within local GP practices, alongside consistent and robust identification of carers seems to be closely linked to the likelihood of carers being encouraged by GP practices to have a flu jab. These elements are important to effectively managing winter pressures for the NHS, as well as protecting the health of carers and the people they care for.

The Government’s concern over winter pressures has led it to recently announce that the flu vaccine will now be available to all people aged 50–64 later this year,21 adding to the groups who are already entitled, including those aged 65 or over and those with pre-existing conditions and people who are the main carer. Carers UK has welcomed this new extension of the criteria.

To ensure that carers receive the flu vaccine, it is vital that there are targeted communications encouraging them to get it. Again, strong levels of identification of carers within the NHS and good GP awareness of carers will be crucial in ensuring high levels of take-up.

19 Carers UK (2020) Caring Behind Closed Doors
20 See Carers UK research on carers’ inability to attend appointments due to lack of breaks – Carers UK (2019) Carers at Breaking Point
In our State of Caring 2020 survey, carers aged 50–65 were asked if their GP knew they were a carer. 71% of carers reported that the GP had identified them as a carer.\textsuperscript{22}

There is a difference, however, between carers saying their GP knows that they are a carer and having their patient record or other internal systems correctly flag that they are a carer. This is an important difference since the latter is used as the basis of communications with patients calling them in for flu jabs.

**Does your GP know you are a carer?**

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<tr>
<td>Yes</td>
<td>71%</td>
</tr>
<tr>
<td>No</td>
<td>11%</td>
</tr>
<tr>
<td>Don’t know</td>
<td>9%</td>
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This is similar to the numbers of carers that said they had been identified by their GP in 2018. When asked in the State of Caring survey 2018, 73% of carers reported their GP knew they were a carer.\textsuperscript{23}

There was variation between the percentage of male and female carers being identified by their GP. 75% of male carers in the cohort reported that their GP had identified them as a carer compared to 70% of female carers, suggesting that there is a gender imbalance that needs to be addressed.

The results indicate that there is variation in identification across different groups of carers. The tables below show the carers most likely to be identified by their GP and those least likely to be identified by their GP respectively.

**Carers aged 50–64 most likely to be identified by their GP**

<table>
<thead>
<tr>
<th>Description</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Carers caring for 70–89 hours per week</td>
<td>88%</td>
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<tr>
<td>Carers caring for 90 hours per week</td>
<td>81%</td>
</tr>
<tr>
<td>Carers who are looking after family/dependants full time/not in paid employment</td>
<td>78%</td>
</tr>
<tr>
<td>Carers caring for 15 years plus</td>
<td>77%</td>
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<tr>
<td>Carers who describe their health as bad</td>
<td>77%</td>
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**Carers aged 50–64 least likely to be identified by their GP**

<table>
<thead>
<tr>
<th>Description</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Carers caring for up to 9 hours per week</td>
<td>50%</td>
</tr>
<tr>
<td>Carers who are juggling paid work and care</td>
<td>62%</td>
</tr>
<tr>
<td>Distance carers (does not live with the person needing care)</td>
<td>62%</td>
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<tr>
<td>Carers caring for 1–4 years</td>
<td>64%</td>
</tr>
</tbody>
</table>

**Hours of care provided**

Carers who are caring for more hours a week are more likely to be identified by their GP than those caring for fewer hours. Among carers who are caring for 70–89 hours per week, 88% had been identified by their GP. For carers who are providing up to nine hours of care a week, the percentage reporting that they have been identified by their GP drops significantly to 50%.

\textsuperscript{22} State of Caring 2020 Survey
\textsuperscript{23} Carers UK (2018) State of Caring 2018
Length of time caring

The research shows that the length of time a carer has been caring correlates with the likelihood of them being identified by their GP. Carers who have been caring for 1–4 years are significantly less likely to have been identified by their GP than carers who have been caring for over 15 years.

Distance carers

Carers caring for someone that lives in a different home to them, or ‘distance carers’, are one of the least likely groups of carers to be identified by their GP. Only 62% of distance carers reported that their GP knew they were a carer. This compares with 76% of carers who care for someone they live with.

Working carers

Carers who describe their employment situation as looking after the family/home/dependants full time, are significantly more likely to be identified by their GP (78%) compared to carers who are juggling paid work and care (62%).

<table>
<thead>
<tr>
<th>Length of time caring</th>
<th>The percentage reporting that they had been identified by their GP</th>
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<tbody>
<tr>
<td>1–4 years</td>
<td>64%</td>
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<tr>
<td>5–9 years</td>
<td>71%</td>
</tr>
<tr>
<td>10–14 years</td>
<td>73%</td>
</tr>
<tr>
<td>15 years or more</td>
<td>77%</td>
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</table>
Services and support from GPs

Carers whose GP knows they are a carer were asked if their GP had arranged, suggested where they could go for, or spoken to them about, a variety of services and support for them as a carer. Within this list of topics was flu jabs.

For every type of carer, a flu jab was the most likely service or support their GP had offered with 56% reporting that their GP had directed them towards having their flu jab. This is an increase of 5% since 2018. Carers highlighted the importance of GPs arranging a flu jab.

I’ve been getting an annual flu vaccination for about five years. I used to get it free at work but this year was prompted by GP for myself and my son”

Absolutely no problem getting flu jab from GP as soon as I said I was a carer”

Only 11% of carers whose GP was not aware they were a carer had been directed towards getting a flu vaccine. This strongly demonstrates the importance of GP identification.

There was some variation however between certain groups of identified carers when it came to being directed towards having their flu jab.

The groups of identified carers most likely to be directed towards having a flu jab by their GP were:

- Carers looking after the family/home/dependants full time (64%)
- Carers who have been caring for 15 plus years (62%)
- Male carers (62%)
- Carers caring for their spouse (60%).

The groups of carers in this 50–64 age group least likely to be directed towards having a flu jab by their GP were:

- Carers caring for up to 19 hours per week (39%)
- Carers who have been caring for 1–4 years, ie newer to caring (47%)
- Carers juggling paid work and care (48%)
- Carers caring for a parent (51%).

These variations are explored in more detail below.

Amount of hours of care provided

Carers who were identified by their GP and caring for 90 plus hours a week were more likely to have been directed towards getting a flu vaccine than carers caring for up to 19 hours per week. 59% of the former group reported that their GP talked to them about getting a flu jab compared with 39% in the latter group – making this group the least likely of all carer groups to be directed towards the flu jab.

Length of time caring

Carers who have been caring between 1–4 years were significantly less likely to be directed towards getting the flu jab (47%) than those who had been caring for 15 years or more (62%). This repeats the pattern we saw with identification of carers where the longer someone had been caring, the more likely there was to be a positive outcome regarding the flu jab. This means that those newer to caring are not being identified quickly and signposted towards getting the flu jab and other support.

Employment status

64% of identified carers looking after the home/family/dependants full time reported being directed towards having a flu jab, making them the most likely of all groups to be signposted towards the service. This is a significantly higher percentage than carers who are juggling paid work and care, of which only 48% reported being directed towards getting the flu jab. This makes working carers amongst the least likely to be directed towards getting the flu jab by their GP.

Distance carers

There was some variation between identified distance carers (caring for someone living outside of their own home) and identified carers living with the person they care for when it came to being directed towards having the flu vaccine. 51% of carers in the former group reported that they were directed towards getting a flu jab compared with 59% in the latter group.
Who carers are caring for

Carers caring for their spouse or partner were more likely to report being directed towards getting a flu jab (60%) than carers caring for their parents (51%) with the former being one of the most likely groups to have been signposted towards the service.

Other routes for flu jabs

We recognise that our research focusses on GPs and that they are not the only route for having flu jabs. Carers may have flu jabs through pharmacies or through their workplace in some instances. Pharmacies are often seen as a very accessible route for a flu jab as they are local, easily accessible and a carer does not necessarily need an appointment. Because carers are time poor, Carers UK recommends that GPs and local communities work collaboratively and creatively to encourage greater uptake of the flu jab this season.
Carers’ attitudes towards the flu jab

Why carers have a flu jab

Analysis of Carers UK’s communication platforms shows that one of the most common reasons for carers to have flu jabs is to protect the person they care for. Carers feel that by having the flu jab, they significantly lower their risk of catching the flu and passing it on to the person they care for.

Carers often highlight that they care for someone who would be extremely vulnerable to the effects of flu if they contracted it.

I think if as a carer to a person whose life would be at risk if they caught flu, getting a jab is the responsible thing to do. It depends on individual circumstances such as whether there is someone else to take over if the carer catches flu. I have jabs with no side effects besides a sore arm for 3-4 days”

I have had one every year. Good to protect myself and others around me. If I am ill and can’t look after my daughter it would cause her a great deal of distress so good to do anything to keep myself healthy. Extra important people have it this year”

I always get one as have no back up if I come down with flu, so I protect myself in order to protect the people I care for”

Some carers cite past experience of the flu as their reason for getting the flu jab. Fear of this happening again and fear of what would happen to the person they care for were they to be incapacitated is a big motivator to get the vaccine.

In previous years I’ve had flu and still had to care for my son which is awful when you’re very unwell, there is no such thing as rest and recuperation for yourself when you’re caring for a family member”

Being directed towards having the flu vaccine by their GP is another common reason for carers having the flu jab.

My GP practice know I am an unpaid carer for my Mother-in-law so have offered me the jab. I have been caring for her for 15 years and have had it for at least nine. It protects both of us and I am very glad to have it”

Some carers said that the outbreak of COVID-19 has made them want to get the flu jab this year.

I was offered a pneumonia jab during the COVID-19 outbreak and for obvious reasons, I accepted it and was fine, so I will accept the flu jab next time round as well”

It’s especially important that we get the flu jab this year”

I had COVID-19 for about six weeks and I am still recovering from that so I don’t want flu as well. I will be getting the jab”

I had one every year. Good to protect myself and others around me. If I am ill and can’t look after my daughter it would cause her a great deal of distress so good to do anything to keep myself healthy. Extra important people have it this year”

I always get one as have no back up if I come down with flu, so I protect myself in order to protect the people I care for”
Why carers do not get the flu jab

One of the most common reasons for carers not getting the flu jab was because they reported that they had not been offered one by their GP.

- I care for my wife and whilst she has one annually I have never had one and never been offered one
- I have been offered (and accepted) the last four years but wasn’t offered one winter 2019. No idea why as nothing has changed
- I’ve never been offered one as a carer from my GP, only at the pharmacy where I pick up his medication

Carers also reported poor experiences at some GP surgeries as a reason for not getting the vaccine. Carers highlight having experienced staff at surgeries who do not know that carers are eligible for flu jabs and, in some cases, refused to carry out the flu jab because of this.

- I had it two years ago with no issues, however last year I asked for it, got into an argument with the receptionist who was adamant I wasn’t entitled, provided proof of being a registered carer (again) and got told someone would call me. No one ever did
- Last year filled in form at doctors stating that I was a carer for my parents. I was declined

Carers reported that their caring responsibilities meant they did not have time to go for a flu jab, others reported that they could not find an appointment to fit around their caring schedule.

- I don’t have time to see GP
- When would I get time to see a GP?
- I can’t easily get an appointment
- I cannot get appointments, have to do online consulting

Some carers who have not had the flu vaccine expressed doubts over its effectiveness.

- For me, I think that because there are so many different strains of flu which are different every year, the jab does not eliminate the risk. I might be wrong, but I feel better without it

Some carers also expressed concerns over perceived potential side effects of the flu jab which they worried would leave them unable to care.

- I haven’t had a flu jab as I’m worried about any side effects. There is nobody else to care for him if I’m unwell
The impact of COVID-19 and the opportunity of improving outcomes

Carers UK’s research for Carers Week 2020 highlighted the fact that awareness of caring is higher than it ever has been.24 A staggering 3.8 million people in England have taken on new caring responsibilities since COVID-19 began.25 This is both an opportunity and an imperative to ensure that these new carers are clearly identified and registered by GPs, and that they are offered a flu jab. With heightened awareness of unpaid caring, we should see better recognition and take-up.

However, the challenges faced by carers during COVID-19 also place new barriers as previously highlighted – the lack of alternative care, the concerns over infection risk (particularly for the groups shielding) and social distancing measures which are not accessible for certain groups eg people with dementia, a learning disability or autism, mean that additional thought needs to be given to how these groups and carers will get flu jabs.

Carers are often time-poor, tired and stretched to the limit. Creative solutions using community venues, workplaces and collaborative working between GPs and others could increase the take-up of the flu jab, reduce the risk of flu, reduce the NHS winter pressures and make carers’ lives easier.

Flu jabs recognise and value carers’ role

Ensuring that carers are on the priority list and offered a flu jab is a positive way of recognising the role and value of caring, with a useful outcome for them and the person they care for protecting their health and wellbeing. They are effectively listed as being equivalent to frontline health and care workers ie key workers’ need for flu jabs. This is a good investment in support and recognition of carers which can be built on in other areas.

GPs identification of carers – background and opportunities

There have been a series of initiatives over the years to try to encourage GP’s to identify carers, with relevant read codes within GP systems. NHS England has developed a series of good practice quality markers which includes flu jabs.26 These quality markers also contribute positively to the Care Quality Commission’s inspections.

During COVID-19, there has never been a more important time to identify carers, and this shows the value of routine and systematic identification. Not only does this help to promote public health, such as the take-up of vaccination, it will also be a positive element in helping to manage COVID-19 and any further waves.

The GP Patient Survey also provides useful evidence on which carers might face greater barriers in getting a flu jab at a GP practice. The survey found that BAME carers were less likely to be able to get an appointment compared with white carers.27 Although our survey shows some positive results for BAME carers, the body of literature and survey evidence suggests that BAME carers are less likely to identify as carers. Carers UK therefore recommends targeted messages at BAME carers in particular to improve take-up of the flu jab.

Recovery plan for carers

The COVID-19 pandemic has placed greater pressure on carers, and many will have their health and wellbeing affected. Carers UK is calling for a Recovery Plan for Unpaid Carers.28 This needs action from Government, health services, local government, employers, business, supermarkets and local shops, local communities and the general public.

Our Recovery Plan for Carers includes a key recommendation to increase carers’ take-up of the flu jab and ensure that marketing messages are appropriate and correctly targeted.

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25 Ibid
Recommendations

The results of this research indicate that there are a number of steps that could be taken to ensure that more carers aged 50–64 are able to access flu jabs in the future and increase the take-up of flu jabs overall.

**Easy to understand and targeted messaging aimed at carers**

- Awareness around flu jabs should be increased for all carers with a focus on easy to understand resources that outline the benefits of having a flu jab. This should include targeted messaging about the importance of carers themselves receiving the flu jab. It should also draw on the marketing knowledge of Carers UK and others in targeting the correct messages for carers.
- Special focus should be placed on targeting carers who are both less likely to be identified by their GP and less likely to be directed towards having a flu jab including:
  - Working carers
  - Carers not caring around the clock, but providing fewer hours of care
  - Those people caring at a distance
  - People newer to caring – ie very recently to 4 years
  - Flu jab messaging also needs to be specifically targeted at BAME carers.

**A social care system that supports carers to look after their own health**

- Carers should have social care support, if they need it, to ensure they can attend health appointments, including receiving a flu jab.

**Make carers a priority**

- Carers must be included in any COVID-19 vaccine priority list. If carers have an equivalent ‘key worker’ status for flu jabs vaccination, they should have a similar status for the COVID-19 vaccination.

**Identify carers quickly and make services as accessible as possible**

- GP practices need to accelerate their identification of carers, particularly those new to caring.
- Government should look actively at measures to increase the speed and rate of carer identification by GP practices. This would also be important for any COVID-19 response.
- GP practices should be supported to identify carers earlier in their caring journey and to have conversations with them about the support available to help them look after their own health and wellbeing.
- GP practices should be encouraged to integrate flu jabs into other healthcare provision eg they should be carried out during other appointments to reduce the inconvenience to carers.

**Training for GP staff and pharmacies**

- Clinical Commissioning Groups (CCGs) should be encouraged to ensure that adequate training and information is available in their area so that GP and pharmacy staff are aware of the importance of flu jabs to carers and that carers are entitled to have one. This training should also cover the specific challenges faced by certain groups of carers less likely to be directed towards the jab such as carers who are juggling work and care. Carer awareness training should be widely adopted for all frontline workers.

**Supporting uptake during COVID-19**

- Creative solutions using community venues and workplaces as well as collaborative working between GPs and others could increase the take-up of the flu jab, effectively reducing the risk of flu.
Compared to the carer population as a whole, respondents to the survey on which this research is based were more likely to be female and caring for a high number of hours every week. As not all respondents completed every question in the survey, a number of the figures given in this report, including those presented in this section, are based upon responses from fewer than the total number of respondents.

State of Caring 2020
A total of 1,461 carers aged 50–64 living in England responded to this survey between February and May 2020:

- 83% identified as female and 16% identified as male
- 3% identified as lesbian, gay or bisexual
- 11% also have childcare responsibilities for a non-disabled child under 18
- 23% consider themselves to have a disability
- 43% are in paid work. 21% full time and 22% part time
- 26% had been caring for 1–4 years, 24% for 5–9 years, 13% for 10–14 years and 33% for 15 years plus
- 16% care 0–19 hours per week and 43% care for 90 hours or more per week
- 4% have been identified as BAME carers.
Carers’ access and attitudes to flu jabs

Analysing the experiences of carers aged 50–64 in England

Supported by an educational grant from Seqirus