healthwatch Cheshire West

healthwatch Cheshire East

Experiences of Unpaid Carers Registering with GP Practices in Cheshire

October 2019

Contents

Introduction 3
Summary of Findings 5
What we did 6
Survey Results - Cheshire East 8
Survey Results - Cheshire West and Chester 14
Conclusion 21
Response from Carers' Groups 23
Appendix - Survey Questions 26

Introduction

During Healthwatch Cheshire East and Healthwatch Cheshire West's general engagement activity, anecdotal reports were received of some unpaid carers not receiving or being aware of the benefits they are entitled to when registering as a carer with their GP Practice. Healthwatch Cheshire East and Healthwatch Cheshire West further explored this issue with focused activity to determine the experiences and awareness of unpaid carers around registering with their GP Practice as a carer and the benefits of registering for services to which they are entitled.

We developed a survey to assess the experiences of people registering as a carer with their GP Practice in Cheshire East and Cheshire West and Chester. This activity took place over winter 2018 and 2019, which allowed us to target specific events and promotions to obtain the experiences of as many carers as possible. In total 193 people responded to the survey.

What is Healthwatch?

Healthwatch Cheshire, consisting of Healthwatch Cheshire East and Healthwatch Cheshire West, is an independent consumer champion for health and care across Cheshire East and Cheshire West and Chester, forming part of the national network of local Healthwatch across England. Our role is to make sure that those who run health and care services understand and act on what really matters to local people.

Healthwatch Cheshire East and Healthwatch Cheshire West undertake continuous engagement activities with the public to hear about concerns and compliments regarding health and care services. The information we gather is then analysed so that we can identify and act upon trends and common themes by presenting our findings to decision makers in order to improve the services people use.

Registering as an Unpaid Carer with GP Practices

Across the UK, around 7 million people care for a family member or friend. That's 1 in 10 individuals who care for someone, unpaid.[1] The Carers Trust defines a carer as: "anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support."[2] People are living longer with illness or disability, and more and more people are looking after them. Whether round-the-clock or for a few hours a week, in their own home or for someone who lives further afield – caring can have a huge effect on them, their lives and their plans.

Caring is an important part of life and in many cases, it enables people to get the most out of life. The Office for National Statistics acknowledges that unpaid carers save the UK economy £56.9bn per year.[3] Yet many carers face issues such as juggling care with work and family life, or even struggling with poor health themselves. They often experience financial difficulties if they are unable to work or have reduced their working hours to care for people.

In recognition of this, the Care Act 2014 included strengthening the rights and recognition of carers in the social care system, including, for the first-time, giving carers a clear right to receive services.

[1] Carers Trust (https://carers.org/key-facts-about-carers-and-people-they-care) <last accessed 01/04/2019>
[2] Carers Trust (https://carers.org/what-carer) <last accessed 29/03/2019>
[3] BBC News (https://www.bbc.co.uk/news/uk-40560827) <last accessed 01/04/2019>

The Care Act 2014 included:

- A focus on promoting wellbeing.
- A duty on local councils to prevent, reduce and delay need for support, including the needs of carers.
- A right to a carer's assessment based on the appearance of need and a right for carers' eligible needs to be met.
- A duty on local councils to provide information and advice to carers in relation to their caring role and their own needs.
- A duty on NHS bodies (NHS England, clinical commissioning groups, NHS trusts and NHS foundation trusts) to co-operate with local authorities in delivering the Care Act functions.[4]

More specifically, the Care Act 2014 set out an expectation that people who registered with their GP Practice as a carer could expect to receive certain benefits, including:

- Providing appointments at convenient times to fit in with their caring role.
- A designated 'Carers Champion' at a GP Practice which carers can access.
- Practice staff will be understanding of the impact on them and the person they care for if they are ill.
- Signposting to useful information and support.
- Providing free annual health checks and flu vaccinations for unpaid carers.
- Asking the person being looked after permission to share appropriate information with their carer.
- Involving the carer in the care planning of this person.
- Invitation to join the practice patient participation group (PPG).
- Being kept up to date about relevant events via SMS messaging.[5]

[4] Care Act 2014 (https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets) <last accessed 29/03/2019>

[5] Carers Federation (https://www.carersfederation.co.uk/register-as-a-carer-with-your-gp) <last accessed 29/03/2019>

Summary of Findings

The main findings from this survey into unpaid carers' experiences of registering as a carer with GP Practices are:

- In both Cheshire East and Cheshire West and Chester, around two out of every three people we spoke to had registered with their GP Practice as a carer. This appears to be positively influenced by the work of Cheshire and Warrington Carers Trust, and more recently the Cheshire East Carers Hub, who are commissioned to deliver carers services and projects across both Cheshire West and Chester and Cheshire East.

- A sizeable number of people were not aware they could register as a carer with their GP Practice - 22% of respondents in Cheshire East and 29% in Cheshire West and Chester.

- Of those who were aware they could register as a carer, but had not, our findings suggest that they are not aware of the benefits on offer to them by registering.

- Of those registered as a carer with their GP, a minority felt they had benefited and received a good service. Most people did not appear to receive the full range of possible expected benefits highlighted by the Care Act 2014 and Carers Federation as good practice.

- The majority of respondents did not feel they had benefited a great deal from registering with their GP Practice as a carer. Although there appeared to be some benefits that more people felt they recognised, for examples receiving flu jabs, but that was qualified by an uncertainty it was connected to being a carer or possibly the easiest of the benefits to fulfil.

- Many carers believed that there was a lack of awareness and understanding of carers' rights and the challenges of their role from staff at GP Practices. This could also sometimes be noticed in a lack of support when booking an appointment and a lack of knowledge about signposting to carer support services by GP Practice staff.

- There were particular benefits that some respondents felt more passionate about and would like to see some change regarding. For example, GP Practice staff having more awareness of the role of a carer, more conveniently timed appointments, and being involved in the care planning of the person for whom they were caring.

What we did

Why did we do this project?

During some targeted Healthwatch engagement activity with people attending carers groups it became apparent, both from carer support organisations and people themselves, that there appeared to be an issue with carers registering with their GP Practice as a carer.

Both Cheshire and Warrington Carers Trust and Cheshire East Carers Hub, as two key carer support organisations across both Cheshire West and Chester and Cheshire East, have historically been commissioned to raise awareness of the Care Act, carers' issues and also support unpaid carers with information, advice and guidance.

These organisations have more specifically worked with both carers and health services to progress the registering of carers with their GP and therefore delivering the expected support and benefits.

Following an initial drive and success with raising awareness with carers and initiating action with GP Practices, it would appear that both organisations and carers feel that expectations are not being met.

Our key reasons for completing this research were:

- To collect data and views of unpaid carers in relation to the benefits in registering with their GP Practice as a carer.
- To raise awareness of these issues with the local authorities, CCGs and Carers support organisations.
- For stakeholders to use the report and findings as a basis for further discussion and progress as to how to address the issues raised.

What did we want to learn?

The aims of Healthwatch Cheshire East and Healthwatch Cheshire West's project on unpaid carers' experiences of registering as a carer with their GP Practice were to establish:

- If the people we spoke to were aware they could register as a carer with their GP.
- Whether people have experienced the benefits available to them by registering as a carer with their GP.
- Whether people were aware that there were benefits available to them by registering as a carer with their GP.
- What people's experiences are in relation to their treatment as an unpaid carer with their GP Practice.

What did we do?

- Initial discussions at groups hosted by Cheshire East Carers Hub and Cheshire and Warrington Carers Trust.
- Survey designed in-house, developed and circulated via partners, internet and social media
- Specific engagement activity at carers groups and events.

Healthwatch staff took the opportunity, when attending three carer support groups, to ask for feedback specifically on the benefits of registering as a carer with GP Practices and found a majority of people expressing concern around the topic. This provided rationale for further investigation of people's experiences, and therefore it was agreed to extend the research and organise a survey.

A survey was designed by our team of Community Engagement and Project Officers and Communications and Research Officer using the benefits described above by the Carers Federation of registering as a carer with GP Practices as a basis to understand whether people had experienced these benefits or were even aware of them. The survey was live during winter 2018 and 2019. This enabled us to use the publicity and promotion around Carers' Rights Day in November to encourage unpaid carers to complete our survey. In order to make the survey as accessible to as many people as possible, it was decided to circulate via:

- Paper copies to appropriate carer groups and events, including three major events on Carer Rights Day 2018.
- Electronic copies circulated direct to individuals, via third party organisations or signposted to Healthwatch Cheshire East and Healthwatch Cheshire West websites.
- Through social media activity directly by Healthwatch or shared via third parties such as partner organisations and carers groups.

Healthwatch Cheshire East and Healthwatch Cheshire West also attended engagement events in order to take the survey to the public. This was targeted towards particular carers groups where we could reach unpaid carers, such as parent carers and young carer groups in Crewe and Macclesfield, and a carers luncheon club in Chester. On Carers Rights Day, our Community Engagement and Project Officers held stands at three events in order to promote the survey to people; one organised by Cheshire East Carers Hub in Macclesfield, and two more organised by Cheshire and Warrington Carers Trust in Macclesfield and Northwich.

Who will this report be shared with?

This report will be published on the Healthwatch Cheshire East and Healthwatch Cheshire West websites for the public to view. It will also be shared with key partners in delivering the project who we are thankful to for helping us to promote the survey to unpaid carers. These include Cheshire East Carers Hub, Cheshire and Warrington Carers Trust, Cheshire East Parent Carer Forum, Cheshire West and Chester Parent Carer Forum, and Space4Autism. Furthermore, copies will be sent directly to service providers and commissioners, notably:

- Cheshire East Council Adult Social Care Services
- Cheshire West and Chester Council Adult Social Care Services
- Eastern Cheshire Clinical Commissioning Group
- South Cheshire Clinical Commissioning Group
- Vale Royal Clinical Commissioning Group
- West Cheshire Clinical Commissioning Group.

Survey Results

The survey detailed above received 195 responses from unpaid carers. These were split between:

- Cheshire East – 121 responses
- Cheshire West and Chester – 72 responses
- Other – 2 responses (both from Warrington).

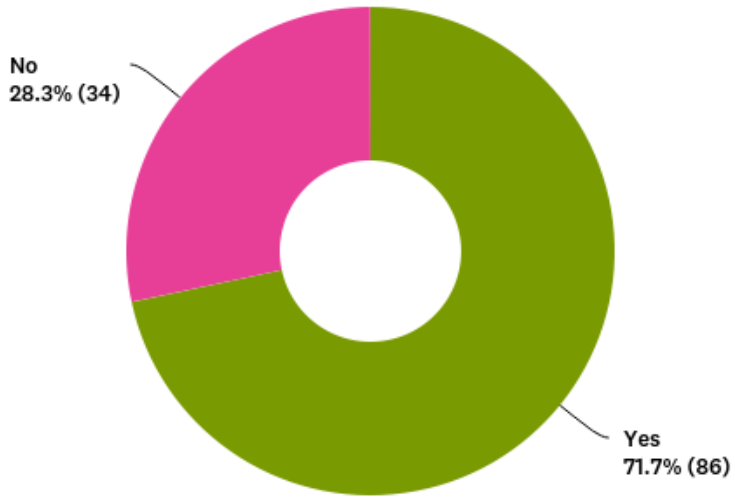
The results from our survey are detailed below, split between Cheshire East and Cheshire West and Chester.

Survey Results - Cheshire East

There were 121 responses to our survey in Cheshire East. The findings are detailed below.

Are you registered as an unpaid carer with your GP Practice?

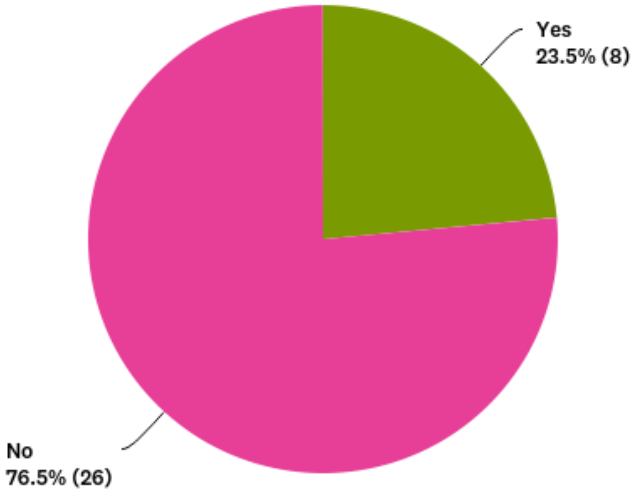
This question was used to determine how many people of those we spoke to had actually registered as a carer with their GP Practice. 120 people provided a response to this question in Cheshire East.



- The majority of people we spoke to in Cheshire East were registered as an unpaid carer with their GP Practice.
- However, a sizeable number, nearly one in every three, were not.

If not, were you aware that you could register as an unpaid carer with your GP Practice?

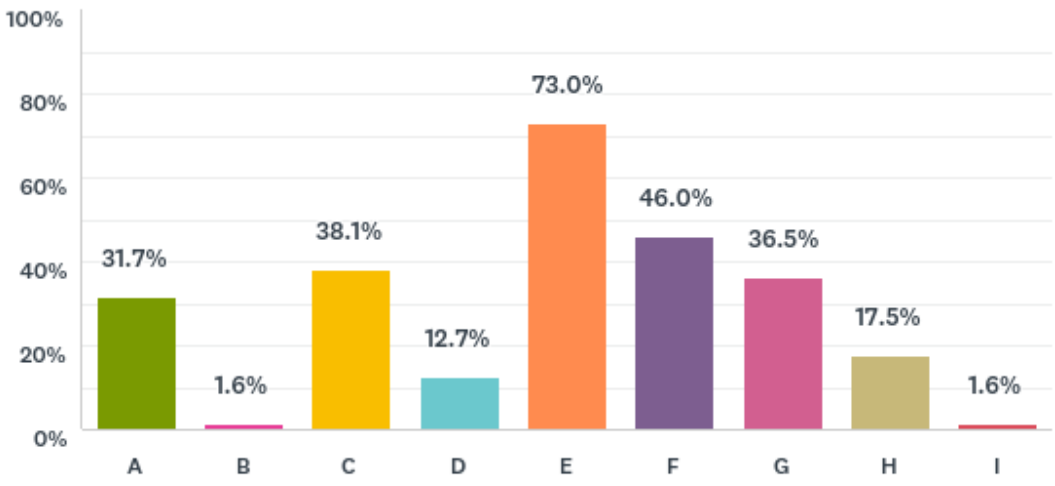
If respondents answered no to the above question, they were then asked whether they were aware that they could. 34 people responded to this question.



- This suggests that the predominant reason that people were not registered as a carer with their GP was that they were not aware they could do so.
- 21.7% of all respondents in Cheshire East were unaware that they could register as a carer.
- Of the people who were aware but have not registered, a common view that people told us was that they did not feel it was worth registering.

If you are registered as a carer with your GP Practice, have you experienced any of these benefits?

This question uses the benefits to registering as a carer with GP Practices listed by the Carers Federation in the introduction to the report, asking people to select which benefits they believe they have experienced. This question was answered by 63 people.



Graph key	Benefit	Number of respondents	Percentage of respondents
A	Providing appointments at convenient times	20	31.7%
B	Many GP practices now have a designated 'Carers Champion' which you can access	1	1.6%
C	Practice staff will be aware of your caring role	24	38.1%
D	Signposting to useful information and support	8	12.7%
E	Providing free annual health checks and flu vaccinations for you	46	73.0%
F	Asking the person you look after permission to share appropriate information with you	29	46.0%
G	Involving you in the care planning of this person	23	36.5%
H	You may be invited to join the practice patient participation group (PPG) so you can have your say about services	11	17.5%
I	Being kept up to date about relevant events via SMS messaging	1	1.6%

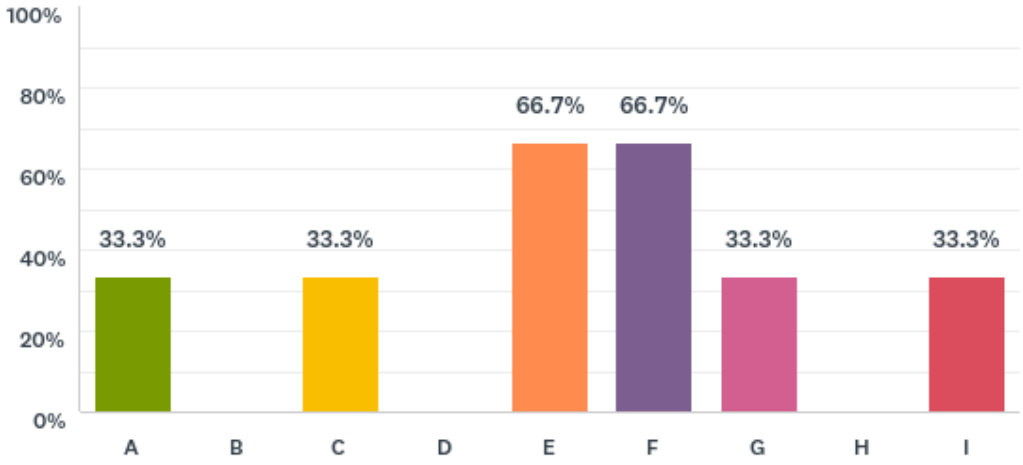
- Providing free annual health checks and flu vaccinations was the only benefit that more than half of unpaid carers registered with their GP as a carer had experienced. From comments it appears that a flu vaccination is commonly given but the annual health check is rarely offered.

- The next highest were asking the person being cared for whether appropriate information can be shared with the carer, and staff being aware of the person's role as a carer. However, only just over one in three people said that they had experienced practice staff being aware of the person's role in being a carer.

- Benefits such as the existence of 'Carers Champions', signposting to relevant support, and being kept up to date by SMS scored very low on our survey.

If you are not registered as a carer with your GP Practice but were aware that you could, did you know that you could gain any of these benefits by registering?

This question was aimed at people who were aware that they could register as a carer with their GP Practice but had not done so. It seeks to establish whether these unpaid carers knew what the benefits are of registering. 3 people answered this question.



Graph key	Benefit	Number of respondents	Percentage of respondents
A	Providing appointments at convenient times	1	33.3%
B	Many GP practices now have a designated 'Carers Champion' which you can access	0	0.0%
C	Practice staff will be aware of your caring role	1	33.3%
D	Signposting to useful information and support	0	0.0%
E	Providing free annual health checks and flu vaccinations for you	2	66.6%
F	Asking the person you look after permission to share appropriate information with you	2	66.6%
G	Involving you in the care planning of this person	1	33.3%
H	You may be invited to join the practice patient participation group (PPG) so you can have your say about services	0	0.0%
I	Being kept up to date about relevant events via SMS messaging	1	33.3%

- 3 people answered this question, suggesting that the other 5 people who were not registered with their GP Practice as a carer but were aware they could, did not know about any of the benefits.

- More people tended to be aware that they could receive free annual health checks and flu vaccinations, as well as the person being cared for being asked whether appropriate information could be shared with the carer.

- None of the respondents to this question were aware that they could be invited to join the PPG, could receive signposting to advice and support, or that 'Carers Champions' existed.

What people told us – Cheshire East

At the end of the survey, we gave unpaid carers the opportunity to tell us more about their experiences of registering as a carer with their GP Practice. Below is what unpaid carers in Cheshire East told us, categorised into themes:

General comments

- *"I have a very good doctor who I can contact at any time."*
- *"I am delighted with care I receive and the helpful approach to my needs."*
- *"I did register but doesn't seem to make any difference - nobody has mentioned it or offered anything."*
- *"Found absolutely no difference registering with GP."*
- *"A really good practice and they have been great with my husband, but don't feel like they understand me being a carer and offer me anything specific."*
- *"Don't think I get any of the benefits you say I might get. If they are available, I have not been told."*
- *"Friend told me it's not worth registering."*

Support with appointments

- *"I get great service from my GP Practice. Double appointments when needed. [Person cared for] always gets to see a doctor on the day I request. No complaints."*
- *"My daughter's GP is very caring and understanding - offers telephone consultations because he knows it is stressful for her to attend practice. Reception staff are also approachable and helpful and go out of their way to help."*
- *"I have email contact with my GP so it means that I can consult this way - saving an appointment."*
- *"I have struggled to get convenient appointments on many occasions."*
- *"I have registered as a carer and it hasn't made any difference, I still have to ask for flu jabs and explain about a carer, I work part time and still cannot get convenient appointments between work and caring. So not a good experience for me."*
- *"Main GP is aware of my caring role but trying to book appointments or access information is impossible from reception team. They do not seem willing to help even though I am registered as carer and getting appointments is still difficult."*

Staff awareness of carers' roles and issues

- *"Practice staff only aware of my caring role when I tell them each time I ring! Surgery is extremely busy - think GPs always try their best - BUT one gets through to receptionists first!"*

Involving carer in care planning

- *"I did register but it hasn't made any difference. See a different GP every time and they seem to know/understand I am a carer but I still have to push for them to allow me to join my husband (dementia) during appointment."*
- *"Although I have registered, I do not find any significant benefit. There are fewer options for access to GPs in the last few years so you appear to be treated just as any other patient. I also have to argue my case when trying to represent my wife who has cognitive issues. It would be easier if it was 'flagged up' - after all our GP knows of our situation."*

Providing signposting information for support and advice

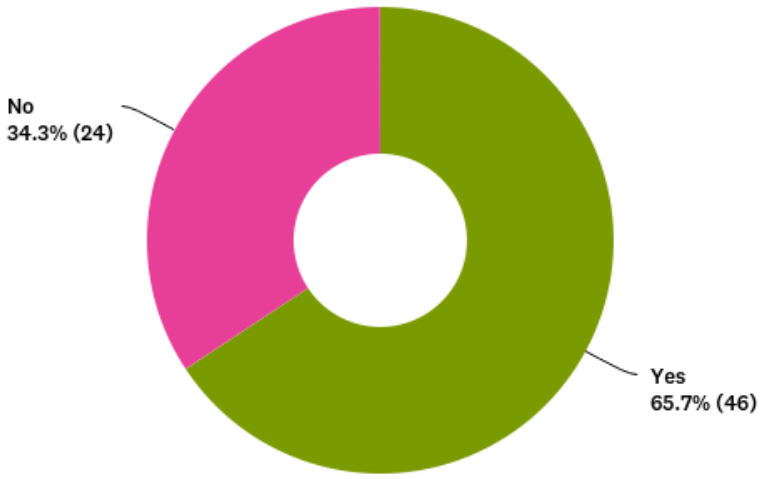
- *"My GP has been the greatest support with regards to [person cared for's] welfare, medical, and even school. He's been there listening at every brick wall I've ever encountered ... I've been very lucky."*
- *"Every time I phone the Practice, I need to remind them that I am a carer. They have never offered me support or information about being a carer. It makes no difference to the service I receive."*
- *"Never offered any advice information etc. from GP about being a carer."*
- *"There is a noticeboard for carers but its way out of date. Name of Carers Champion would be useful. Info could be on screen and kept up to date."*
- *"I have been registered as a carer for several years and apart from being offered a flu jab (no annual health check though) I have experienced zero difference in it being registered in my notes (I actually am now registered as carer for my two autistic sons and very ill bipolar mother). There is a notice board with some information but nothing has ever been said to me one-to-one."*

Survey Results - Cheshire West and Chester

There were 72 responses to our survey in Cheshire West and Chester. The findings from it are detailed below.

Are you registered as an unpaid carer with your GP Practice?

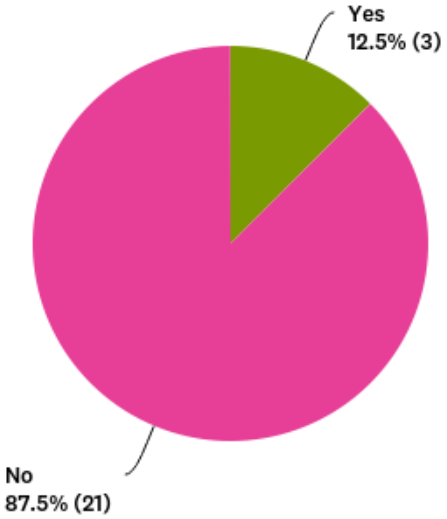
This question was used to determine how many people out of those we spoke to had actually registered as a carer with their GP Practice. 70 people provided a response to this question in Cheshire West and Chester.



- This demonstrates that the majority of people we spoke to in Cheshire West and Chester were registered as an unpaid carer with their GP Practice.
- However, a sizeable number, just over one in every three, were not.

If not, were you aware that you could register as an unpaid carer with your GP Practice?

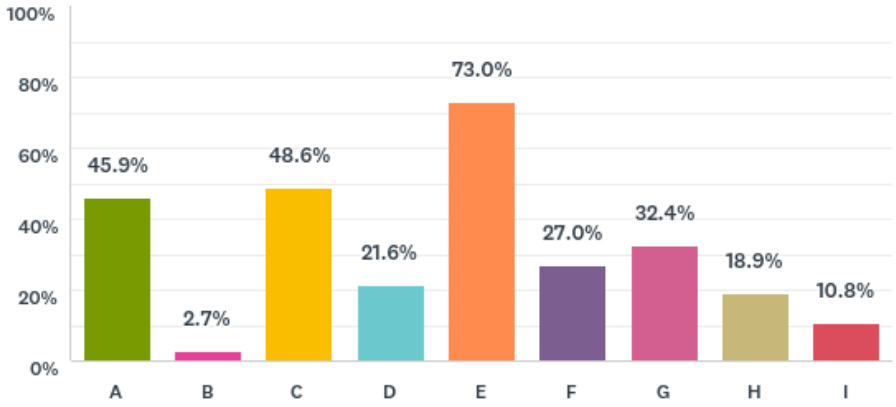
If respondents answered no to the above question, they were then asked whether they were aware that they could. 24 people responded to this question.



- This suggests that the predominant reason that people were not registered as a carer with their GP was that they were not aware they could do so.
- This means that 29.1% of all respondents in Cheshire West and Chester were unaware that they could register as a carer.
- Of the people who were aware but have not registered, a common view that people told us was that they did not feel it was worth registering.

If you are registered as a carer with your GP Practice, have you experienced any of these benefits?

This question uses the benefits to registering as a carer with GP Practices listed by the Carers Federation in the introduction to the report, asking people to select which benefits they believe they have experienced. This question was answered by 37 people.



Graph key	Benefit	Number of respondents	Percentage of respondents
A	Providing appointments at convenient times	17	45.9%
B	Many GP practices now have a designated 'Carers Champion' which you can access	1	2.7%
C	Practice staff will be aware of your caring role	18	48.6%
D	Signposting to useful information and support	8	21.6%
E	Providing free annual health checks and flu vaccinations for you	27	73.0%
F	Asking the person you look after permission to share appropriate information with you	10	27.0%
G	Involving you in the care planning of this person	12	32.4%
H	You may be invited to join the practice patient participation group (PPG) so you can have your say about services	7	18.9%
I	Being kept up to date about relevant events via SMS messaging	4	10.8%

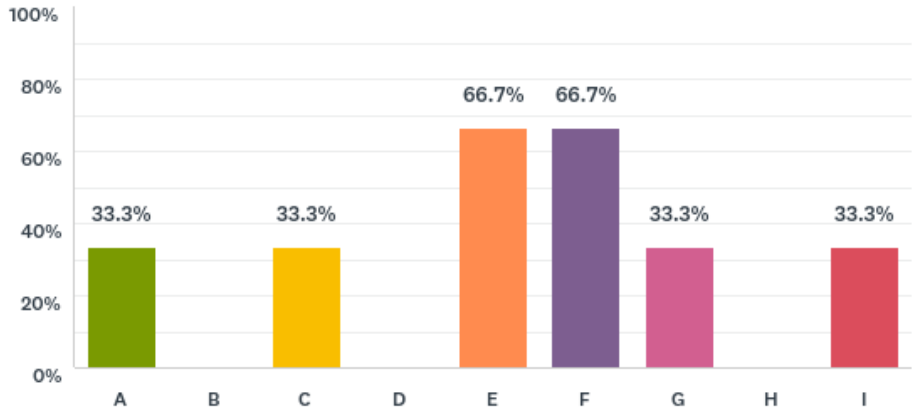
- Providing free annual health checks and flu vaccinations was the only benefit that more than half of unpaid carers registered with their GP as a carer had experienced. From comments it appears that a flu vaccination is commonly given but the annual health check is rarely offered.

- The next highest were asking the person being cared for whether appropriate information can be shared with the carer, and providing appointments at convenient times.

- Benefits such as the existence of 'Carers Champions', signposting to relevant support, being invited to join the PPG, and being kept up to date by SMS scored very low on our survey.

If you are not registered as a carer with your GP Practice but were aware that you could, did you know that you could gain any of these benefits by registering?

This question was aimed at people who were aware that they could register as a carer with their GP Practice but had not done so. It seeks to establish whether these unpaid carers knew what the benefits are of registering. 2 people answered this question.



Graph key	Benefit	Number of respondents	Percentage of respondents
A	Providing appointments at convenient times	0	0.0%
B	Many GP practices now have a designated 'Carers Champion' which you can access	1	0.0%
C	Practice staff will be aware of your caring role	0	0.0%
D	Signposting to useful information and support	0	0.0%
E	Providing free annual health checks and flu vaccinations for you	2	100.0%
F	Asking the person you look after permission to share appropriate information with you	0	0.0%
G	Involving you in the care planning of this person	0	0.0%
H	You may be invited to join the practice patient participation group (PPG) so you can have your say about services	0	0.0%
I	Being kept up to date about relevant events via SMS messaging	0	0.0%

- Two people answered this question, suggesting that the other person who were not registered with their GP Practice as a carer but were aware they could, did not know about any of the benefits.

- The two people were both aware that they could receive free annual health checks and flu vaccinations, whilst one knew about 'Carers Champions'.

- The two respondents were not aware of any of the other benefits on offer.

What people told us – Cheshire West and Chester

At the end of the survey, we gave unpaid carers the opportunity to tell us more about their experiences of registering as a carer with their GP Practice. Below is what unpaid carers in Cheshire West and Chester told us, categorised into themes:

General comments

- *"GP is extremely kind, caring and has great empathy with our son."*
- *"GP and staff are very good."*
- *"It does help when my doctor has child with the same disability."*
- *"The doctor we see is brilliant, but the reception staff are a nightmare."*
- *"Don't think it [registering] is worth it."*
- *"I am registered, but don't receive any of the mentioned benefits from my GP Surgery. Lucky to be able to get an appointment at all."*
- *"I know what the theory is, but in practice it's just not happening. I get a free flu jab because I ask for it. That is the only benefit. And I rate my surgery very highly."*
- *"GP must realise but don't register me. I have only been offered a flu jab once when I took my daughter for hers. Been a carer for 9 years."*
- *"My GP Practice doesn't actively advertise support for carers. I learned about today's event when waiting at another Practice with my mother. The day [Carers Rights Day event] was very helpful and everyone was friendly and welcoming."*

Support with appointments

- *"Staff are very helpful with appointments and doctors are very understanding."*
- *"We have never been offered any carer benefits and even when we asked to have a more convenient appointment due to being carers we were told that this was not possible."*
- *"Practice staff not interested when trying to book an appointment on the day."*
- *"I think that it would also be beneficial if other children in the family could have something on their records to make getting appointments easier as I would be taking them."*

Staff awareness of carers' roles and issues

- *"Whist I have a very good GP service; the Practice does not seem to have a full awareness of the needs of carers. This also applies to other services offered within the community - i.e. mental health services."*
- *"Practice has no understanding of how hard it is to be carer for four people. Don't seem to understand my family's health needs. Impossible to book an appointment at suitable time - particularly at short notice."*
- *"I feel that a more pro-active approach needs to be taken towards carers - carers should be included in any consultations with their loved ones, being asked if they have any health and wellbeing issues relating to their caring role in order to offer preventative support. A carer should automatically be offered an annual MOT for both mental and physical health. Carers are all too often overlooked and when accessing mental health services are not fully understood and in the worst case recently, I felt my needs were dismissed as being of minor importance and I met with a patronising attitude."*

Involving carer in care planning

- *"I registered with my GP as my mum's unpaid carer when I fully became her carer back in 2014. Since then I have had nothing but problems with my GP Surgery as to making*

appointments at times to suit me and accessing mums' notes. Even though I am in contact with the Surgery on a regular basis and my mum's GP knows that I am her full-time carer and that it is on both our notes, they still will not let me query anything as to my mum and my mum has given them permission countless times and yet it has been problem after problem."

Providing signposting information for support and advice

- *"Excellent GP who referred me to carers centre who sent a pack of info, but I was so overwhelmed with caring I never had time to fill in the forms and certainly no time to attend events. Have had flu jab but no offer of health check for me, only the adult with LD I care for."*
- *"Not offered annual health checks, just flu vaccination."*
- *"Carers Links do not support."*
- *"I had no idea that my surgery has carers' link person. I think each surgery should have a picture or information on the carers board in the waiting room saying who link is and what support they can offer."*
- *"Applied to join PPG 3 years ago - couldn't attend on the day and have never been invited again."*

Conclusion

The Care Act 2014 included raising awareness of rights of unpaid carers and challenged health and social services to improve services and support to this group. Healthwatch received some feedback from the Carers Trust nationally that after an initial positive response and the setting up of more robust systems and processes, the feeling is impetus has been lost and there has been a slowing of progress.

In Cheshire, an initial focus on the issues carers face led to both Cheshire East and Cheshire West and Chester local authorities commissioning and funding projects aimed at both raising awareness of carers issues and providing support services. Both local authorities supported pieces of work around carers registering with their GP and raising awareness within health services of carers' rights and issues.

In both Cheshire East and Cheshire West and Chester, around two out of every three people we spoke to had registered with their GP Practice as a carer. This appears to be influenced by the work of Cheshire and Warrington Carers Trust, and more recently the Cheshire East Carers Hub, who are commissioned to deliver carers services and projects across both Cheshire East and Cheshire West and Chester. Both organisations raise awareness with carers regarding registering with their GP Practices and also raise awareness of carers' services with GP Practices.

There was though a sizeable number of people who were not aware they could register as a carer with their GP Practice - 22% of respondents in Cheshire East and 29% in Cheshire West and Chester. Of those who were aware they could but had not registered, our findings suggest that they are not aware of the benefits on offer to them by registering.

Of those registered as a carer with their GP, a minority felt they had benefited and received a good service. The majority of respondents did not feel they had benefited a great deal from registering with their GP Practice as a carer. However, even amongst those that did feel they had benefited, most people did not appear to receive the full range of possible expected benefits highlighted as good practice. There appeared to be some benefits that more people felt they recognised, for examples receiving flu vaccinations, but that was qualified by an uncertainty it was connected to being a carer or possibly the easiest of the benefits to fulfil.

Of the list of benefits we used for the survey, taken from the Carers Federation, there were some that respondents felt more passionate about and would like to see developed upon, most notably:

- Practice staff being more aware and understanding of the role of a carer.
- Providing appointments at a convenient time.
- Providing annual health checks (and less importantly flu vaccinations).
- Asking the person being looked after permission to share appropriate information.
- Involvement in the care planning of this person.
- Signposting to useful information and support.

Qualitative feedback from respondents appear to highlight some common issues and concerns. Many carers believed that there was a lack of awareness and understanding of carers' rights and the challenges of their role from staff at GP Practices. This could also sometimes be noticed in a lack of understanding and support when booking an appointment and a lack of knowledge about signposting to carer support services by GP Practice staff. Some also felt that carers are not offered enough involvement in the planning and management of the health issues of those being cared for.

Many respondents recognised the challenges faced by GP Practices and were quite realistic in their expectations. However, they felt that by simply showing more empathy and understanding towards

what it is like to be an unpaid carer for somebody, along with introducing some focused changes, the experiences for carers would improve significantly.

Recommendations

- Primary Care commissioners and Clinical Commissioning Groups to review outcomes from survey and share with appropriate partners, services and carers.
- Carry out review of Care Act expectations around carers' rights, and organise appropriate awareness raising for health services.
- Primary Care commissioners and Clinical Commissioning Groups to work with carers support organisations to develop a collaborative approach to prioritise benefits and develop an agreed and appropriate improvement strategy.
- Primary Care commissioners and Clinical Commissioning Groups to organise a broader dialogue between GP Practices and carers support organisations to overcome inconsistent approaches from different GP Practices.
- GP Practices to share examples of good practice to support strategy and overcome inconsistencies.
- Clinical Commissioning Groups to engage with carers as a specific group across broader range of health topics, e.g. longer-term conditions – autism, mental health, dementia, etc.

Response from Carers' Groups

After completion of the report, carers' groups who were engaged with during the original research were asked to respond to our findings. Below are the responses received:

Cheshire and Warrington Carers Trust

"Thanks for the really interesting report. Mostly carers tell me that they would like to be able to access flexible and double appointments, those caring for people with autism stress they struggle with waiting times and busy waiting areas, carers wish to be invited for flu jabs.

Our previous project in Cheshire East enabled our staff member to regularly update 'Carers' boards in GP Practices with posters and I do notice these are not always up to date.

We wanted to add some context to the report from our perspective as the commissioned service in Cheshire West and Chester. The service has been in place for over 10 years. It was funded in its current guise in 2012 and was then added into the Carers integrated Support Service in late 2017

The service is well established, we've been working with Practices for over five years to support them to identify and offer support to unpaid carers. Every Practice across the area has a dedicated 'Carer Link' worker who combines supporting and identifying carers with the role within the Practice. The link worker in each surgery is invited to regular 'Carer Link' workers meetings across the borough where they can access up-to-date information about carers' issues and discuss best Practice for carers with their peers. Specialist workers from Cheshire and Warrington Carers Trust visit GP Practices on a regular basis to raise awareness of the issues that carers face. We also provide targeted training for Primary Care staff, in 2018 we delivered 31 sessions to over 280 staff including GPs, nurses, medicines managers, pharmacists and reception staff.

Up to March 2019 there were over 8000 people registered as carers with the 42 GP Practices across Cheshire West and Chester. In 2018, working closely with the links we have developed in each surgery across the local authority footprint we identified over 1000 new carers (adult carers over 18) and 52 new young carers (carers who were under 18). Of the 1017 new carers who registered with their surgery over 517 were referred to the Cheshire West Carer Support Service for information, advice and support. In 2018 we surveyed the carers who had registered with their GP and had consented to a referral to our organisation for additional support, of the 74 respondents 53 were happy with the Carer Support received from their GP Practice.

In 2018 we reviewed our marketing materials that are used in GP Practices to try and identify those carers who do not readily identify with the term 'carer'. All Practices have a carers' board in the main waiting area which highlights our key message "Are you looking after someone who couldn't manage without your help? Register for more support". Most Practices have these messages on their websites and displayed on the envisage screens in their waiting rooms.

The comments from carers in the report reflect our experiences when discussing Primary Care with carers, some carers have had very positive experiences with the Practices whilst others feel that they need additional help and support. We are continuing to work closely with Primary Care providers across the local authority area and have committed to the following actions (in addition to our current work) in response to the report:

1. Carers stated that they didn't know that they could register as a carer with their GP - We will work to develop new ways to highlight this to carers. For example one Practice has sent a text message to all patients to inform them about registering, another is using the automatic check in screen to ask the key question and encourage registration.

2. Carers stated that they didn't know who the carer link worker was - We will audit the current Carer Boards to ensure that the link name is prominently displayed and consult carer link workers about ways to raise their profile in the Practice.

3. Carers don't know about the benefits of registering as a carer - We will work with each surgery to identify the additional support that they can offer to carers and to communicate this to their patients. It should be noted that whilst all surgeries, as a minimum, can provide a direct referral to the specialist service, the additional benefits offered to carers can vary from Practice to Practice.

Cheshire East Carers' Hub

"Thanks for this report, it's very useful and definitely in line, in the main, with expectations. There are a few things I'd like to highlight that may be if use to you.

We have supported 2400 Adult Carers in Cheshire East since the service began in April 2018. Each Carer we have supported has received an assessment from a Carers Support Worker unless they wished to register for information only, which equates to very few.

Our assessment is in depth and takes around an hour and a half to complete on a 1:1 basis. The assessment is very much a two way process and we look at how the caring role impacts, health, ability to take a break, social interaction, relationships with family and friends, safety, finances etc. The Carer and Support Worker then devise a support plan between them based on the assessment.

One of the early questions is around GP registration. Our Support Worker explains why it is important to register as a Carer with the GP. If the Carer hasn't done this, with their consent, we write to the GP on their behalf to do so. This is offered to every Carer in Cheshire East. I do find it surprising that there are Carers who attend our coffee and chats who feel that they weren't made aware of it and possible benefits. All Carers who go to groups have received assessments. In response we will ensure that we revisit registering as a Carer with your GP with our groups.

We are aware from working, where possible, with the 40 GP Practices in our footprint that 'benefits' do vary greatly from practice to practice. Only the offer of a flu jab seems to be common amongst all locations. Flexibility and active involvement in treatment are probably most disputed by Carers and are again questions we ask during assessment.

We do often hear that Carers feel 'there is no point' as they feel, or have heard/been told, there will not be any benefits to doing so. Some Carers have reported that they have tried but have been put off by reception staff, e.g.

- *They don't know how to register them as a Carer.*
- *Tell them they already know and do not need to formalise this.*
- *Tell them there are no benefits other than the flu jab due to capacity within the Practice.*

Other Carers feel it's good enough for them that practice staff 'know'. We are also aware that Carers often say they will do something but don't due to other priorities.

Whereas we do endeavour to engage as actively as we can with GP Practice staff and raise awareness of Carer issues and support with staff, we can rarely reach past reception staff. Each of our team have two or three Practices allocated to them to support.

We ensure that our literature is available for Carers and our hub staff visit every practice in Cheshire East to ensure our information is up to date and to encourage up to date Carers boards. At the moment we are actively requesting that GP Practices add our information to their envisage screens. As far as I am aware, five have done so.

Each Practice has been provided with expression of interest pads which staff can fill in with a Carer looking for support, they can be sent back to us via freepost. We have noticed a slight increase in these being returned enabling us to contact that Carer. Those staff members who actively refer have often had experience of a caring role personally.

I have worked with Carers for 12 years and one thing that is very clear is that there is one place that every one of the estimated 40,000 carers will go to and that's the GP Practice. Often it is for the person they care for of course, but they will go for themselves at some point. It's therefore essential that Carers are identified and supported at the Practice and that Practice staff are aware and actively signpost and refer to other areas of support."

Appendix - Survey Questions

Below is a copy of the survey used for this research.

Carers' Rights Day Survey

Healthwatch Cheshire West and Healthwatch Cheshire East are the local independent consumer champions for Health and Social Care services in Cheshire West and Chester and Cheshire East.

You may have seen one of our team or volunteers out and about around Cheshire trying to gain people's views and experiences of the Health and Social Care services they receive, in order to help inform the priorities and quality of services commissioned by the NHS and local authorities.

Through our conversations with people, we have heard about the process of people registering as a carer with their GP. The Carers Trust defines a carer as: "anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support." We want to gain a better understanding of unpaid carers' experiences of GP Practices and use our findings to produce a report that can be presented to service providers highlighting the issues that you tell us about.

We would really appreciate if you could please take a few minutes to answer this brief survey.

We work across Cheshire West and Cheshire East and so providing us with the first part of your postcode can help us to identify if there are issues particular to certain areas.

1. Please can we have the first part of your postcode: ☐

2. Are you registered as an unpaid carer with your GP?

   ☐ Yes ☐ No

   If the answer is no, please go to question 4 over the page.

3. If you are registered as an unpaid carer with your GP, have you experienced any of these benefits?

Benefit	Yes	No
Providing appointments at convenient times		
Many GP practices now have a designated 'Carers Champion' which you can access		
Practice staff will be aware of your caring role		

healthwatch Cheshire West

healthwatch Cheshire East

Signposting to useful information and support		
Providing free annual health checks and flu vaccinations for you		
Asking the person you look after permission to share appropriate information with you		
Involving you in the care planning of this person		
You may be invited to join the practice patient participation group (PPG) so you can have your say about services		
Being kept up to date about relevant events via SMS messaging		

4. If you aren't registered as an unpaid carer with your GP, were you aware that you can register?

   □ Yes □ No

   If the answer is no, please go to question 6 over the page.

5. If yes, did you know that you could gain these benefits by registering as an unpaid carer?

Benefit	Yes	No
Providing appointments at convenient times		
Many GP practices now have a designated 'Carers Champion' which you can access		
Practice staff will be aware of your caring role		
Signposting to useful information and support		
Providing free annual health checks and flu vaccinations for you		
Asking the person you look after permission to share appropriate information with you		
Involving you in the care planning of this person		
You may be invited to join the practice patient participation group (PPG) so you can have your say about services		
Being kept up to date about relevant events via SMS messaging		

6. Would you like to provide any further feedback on health and care services?

7. What is the name of your GP Practice?