

CARERS NEEDS ASSESSMENT

Warwickshire Joint Strategic Needs Assessment 2015



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APPROVALS

This document requires the following approvals.

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SCLT		Strategic Commissioning Leadership Team	05-Nov-15	1.0

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EXECUTIVE SUMMARY

The existing contract for the delivery of Warwickshire's Carers Support Services will be re-commissioned and the Warwickshire's Joint Carers Strategy refreshed. Carers (both young and adult carers) are one of the eleven identified priority topics and forms part of the JSNA's three year programme of work.

This needs assessment is intended to provide insight into the unpaid care provision across Warwickshire and the extent and nature of local support services. It will also support in planning to meet future demand as a result of the Care Act. Unpaid carers make an important contribution to the overall supply of care services.

The Carers Trust describes the role of 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.'¹

Current number of carers known in Warwickshire

The 2011 Census provides a valuable update on the picture of unpaid care provision in Warwickshire. This section provides the overarching messages from the 2011 Census, more detail on the characteristics of carers in terms of age, gender and health can be found in the chapter, 'characteristics of carers.'

The Census indicates that Warwickshire has 59,240 people or 11% of the population providing some form of unpaid care each week in 2011.

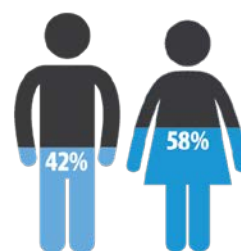
In Warwickshire, 59,240 people or 11% of the population are unpaid carers



Around one in five of these carers provide over fifty hours of care each week



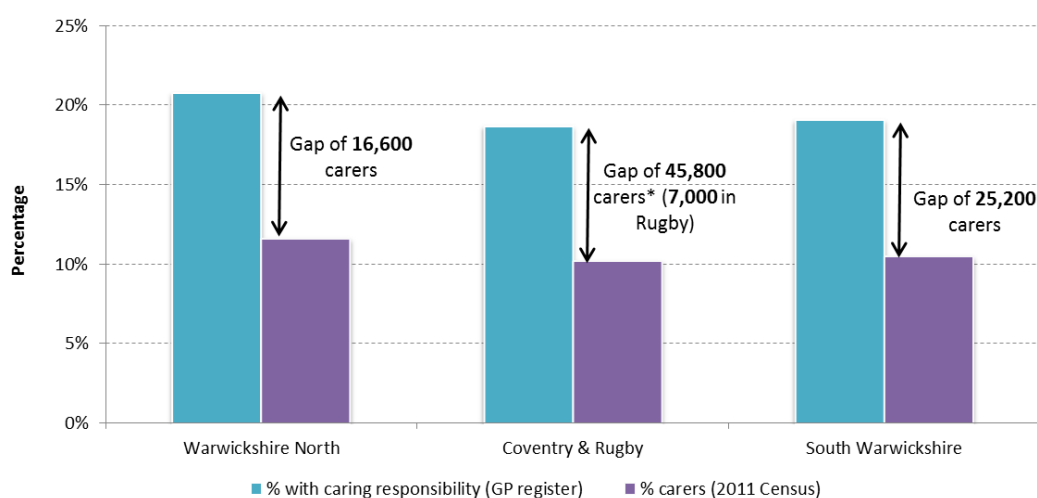
Women are more likely to be unpaid carers than men



Hidden carers - gap between GP patients and 2011 Census - An estimated **108,000** patients registered with a Warwickshire GP had some form of caring responsibility in 2013/14. This represents a significant difference when compared with the 2011 Census, with GP practices effectively identifying nearly **twice** as many carers in Warwickshire than the 2011 Census. This represents an estimated 48,700 more carers registered with a caring responsibility with a Warwickshire GP.

¹ Carers Trust: <http://www.carers.org/role-carer>

Difference in numbers and proportions of carers at CCG level



Source: GP Profiles and 2011 Census

* includes both Coventry & Rugby GP practices

Although there will be significant duplication across these different data sources, in summary Warwickshire identifies:

- **59,240** carers in Warwickshire or **11%** of the resident population (2011 Census) of which:
 - **1,124** are aged 0-15 years
 - **2,562** are aged 16-24 years
 - **41,315** are aged 25-64 years
 - **14,239** are aged 65 years and over
- **108,000** carers in Warwickshire registered with a GP as having some form of caring responsibility or **19.3%** of the registered GP population in Warwickshire (GP registers)
- Just over **5,500** adult carers are known to WCC Commissioned Guideposts service
- **1,002** young carers aged 8-17 years are known to Warwickshire Young Carers Project, plus **330** young adult carers aged 18 to 23 years referred to adult carer services.
- **839** Carers Assessment Events started between April 2014 and March 2015 (*a carer can have more than one assessment*) (see Carers Assessments chapter)
- **4,930** carers in receipt of Carers Allowance as at February 2015 (see separate chapter)

Who's caring for who in Warwickshire,² it is estimated that:

- **30,000** Warwickshire carers care for someone aged over 75 years
- **4,700** Warwickshire carers care for someone under the age of 16 years

² Applying proportions from NHS survey of carers in households to Warwickshire's caring population, according to the 2011 Census

- Nearly **20,000** carers in Warwickshire are caring for their parent and just under **8,000** are caring for their child
- **34,000** carers in Warwickshire are caring for someone with a physical disability
- Over **6,500** carers in Warwickshire caring for someone with a learning disability
- Just under **6,000** carers in Warwickshire are caring for someone with dementia
- Over **7,700** carers in Warwickshire care for someone with a mental health disorder
- Just under **2,500** people in Warwickshire care for someone with a terminal illness

Hidden from view - Many carers do not recognise themselves as carers³. Research suggests they simply see themselves as husband, wife, parent, son, daughter or friend and as a result do not access formal services; this is identified as a particular problem with black and minority ethnic (BME) carers⁴. Identifying these hidden carers is not only a local authority duty under the prevention element of the 2014 Care Act,⁵ it is essential in identifying the full extent of vulnerability in the county and the levels of unpaid care across Warwickshire that is currently hidden from view.

‘Sandwich Generation’ – the term ‘sandwich generation’ is often used to refer to those looking after young children at the same time as caring for older parents. However, it can also be used much more broadly to describe a variety of multiple caring responsibilities for people in different generations. With an ageing population, and where people are starting families later, ‘sandwich caring’ responsibilities are increasing and it is women who are more likely to face the pressure of simultaneously shouldering responsibility for young and old. Research by Employers for Carers and Carers UK found that, without support, the pressure of combined caring responsibilities can take a serious toll on families’ health, finances, careers and relationships. It is therefore important that sandwich carers are identified in Warwickshire and are offered an assessment in order to receive appropriate support.

Future Numbers and the Care ‘Gap’ - Carers UK research suggests that demographic change, coupled with the direction of community care policy mean that the number of carers could increase by 40% by 2037⁶. Over the next 20 years the number of people aged over 85 is expected to double⁷.

There is also a continuing shift away from institutional care to care provided at home and in the community. It is important to recognise this pressure on families to care in their own homes, particularly for spouses and partners, is growing significantly and is predicted to double over the next 30 years⁸. Families provide the majority of care in the UK and it is clear this trend is likely to

³ Heron, C. (1998) 'Working with carers', London: Jessica Kingsley

⁴ National Assembly for Wales (2003) '[Challenging the myth "They look after their own": Carers services - access issues for black and minority ethnic carers in Wales](#)'

⁵ **Care Act 2014**: Part 1 Section 2 Clause 2 (c) places a duty on local authorities to identify carers in their area with needs for support.

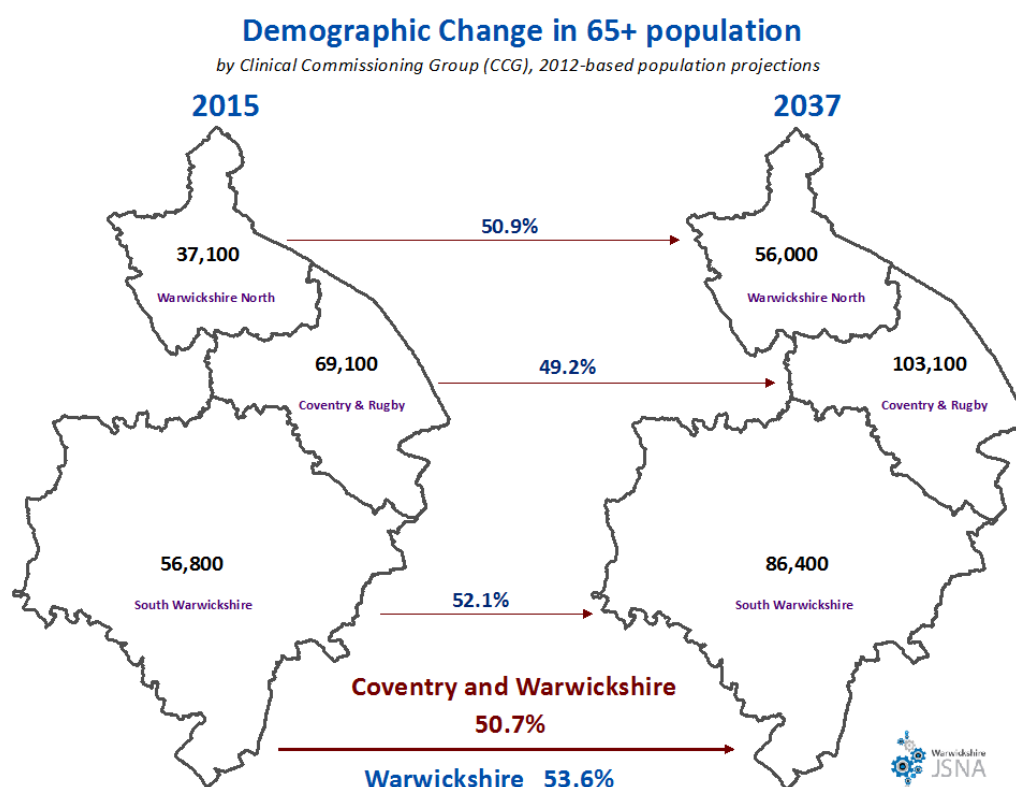
⁶ Carers UK (2012): Facts About Carers

⁷ Office for National Statistics Population Projections: <http://www.ons.gov.uk/ons/rel/npp/national-population-projections/2012-based-projections/stb-2012-based-npp-principal-and-key-variants.html>

⁸ Personal Social Services Research Unit, 'Informal Care for Older People provided by their adult children: Projections of Supply & Demand to 2041 in England:' <http://www.pssru.ac.uk/archive/pdf/dp2515.pdf>

continue. This contribution is worth an estimated £119 billion a year to the UK economy – more than the total cost of the NHS⁹.

The number of older people in need of care is predicted to outstrip the number of family members able to provide it for the first time in 2017. By 2032, there is predicted to be an increase of 60% in the number of older people needing care from their families but the number of people able to care for older parents will have increased by only 20 per cent, creating a shortfall in capacity to care for older generations¹⁰.



Increases in life expectancy are currently outstripping increases in 'healthy life expectancy'¹¹ which means that as people live for longer they are also likely to need care and support for a larger proportion of their lives. For males born in Warwickshire between 2011 and 2013, healthy life expectancy is 67.0 years compared with a life expectancy of 80.0 years, meaning that they are expected to be in poor health for 16.2% of their lives. For females, healthy life expectancy in Warwickshire is 66.3 years compared with a life expectancy of 83.8 years, so although women are expected to live longer, they are also expected to live over one fifth (21%) of their lives in poor health.

⁹ Valuing carers – Calculating the value of unpaid care, 2007. Carers UK, ACE and the University of Leeds.

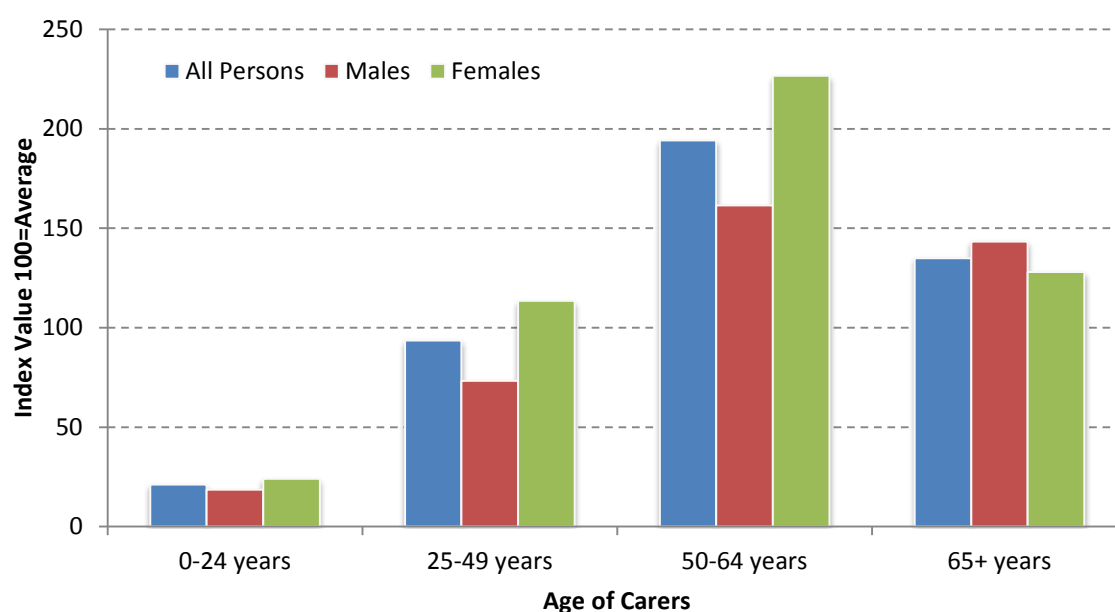
¹⁰ Pickard L (2013) 'A growing care gap? The supply of unpaid care for older people by their adult children in England to 2032', Ageing and Society, DOI: 10.1017/S0144686X13000512. <http://eprints.lse.ac.uk/51955/>

¹¹ Life spent in good or very good health (the amount of time that a person is expected to live free from significant health issues)

Applying population projections to the number of carers identified in the 2011 Census means that the number of carers is estimated to increase by just under **5,000** by 2021 to **64,120** carers in Warwickshire, with the majority of these (over four in five) expected to be aged 65 years and over (**3,930**).

Gender gap in unpaid care provision - women are much more likely than men to provide unpaid care (58% and 42% respectively). This gender difference remains broadly similar irrespective of the number of hours of care undertaken each week. Unsurprisingly, rates of unpaid care provision increase with age among both men and women, up to the age of 65. The data indicates that the share of unpaid care provision is highest for women aged 50-64 years. One in four women in this age group provides some level of unpaid care. The gender difference appears to diminish among those aged 65 plus with men slightly more likely to provide unpaid care than women. Due to this, evidence¹² shows women are more likely to experience strain in providing such care in middle-age as they balance the multiple roles of work, care and social and leisure activities (as referred to in the 'sandwich generation key message).

Likelihood of unpaid care by age and gender in Warwickshire, 2011



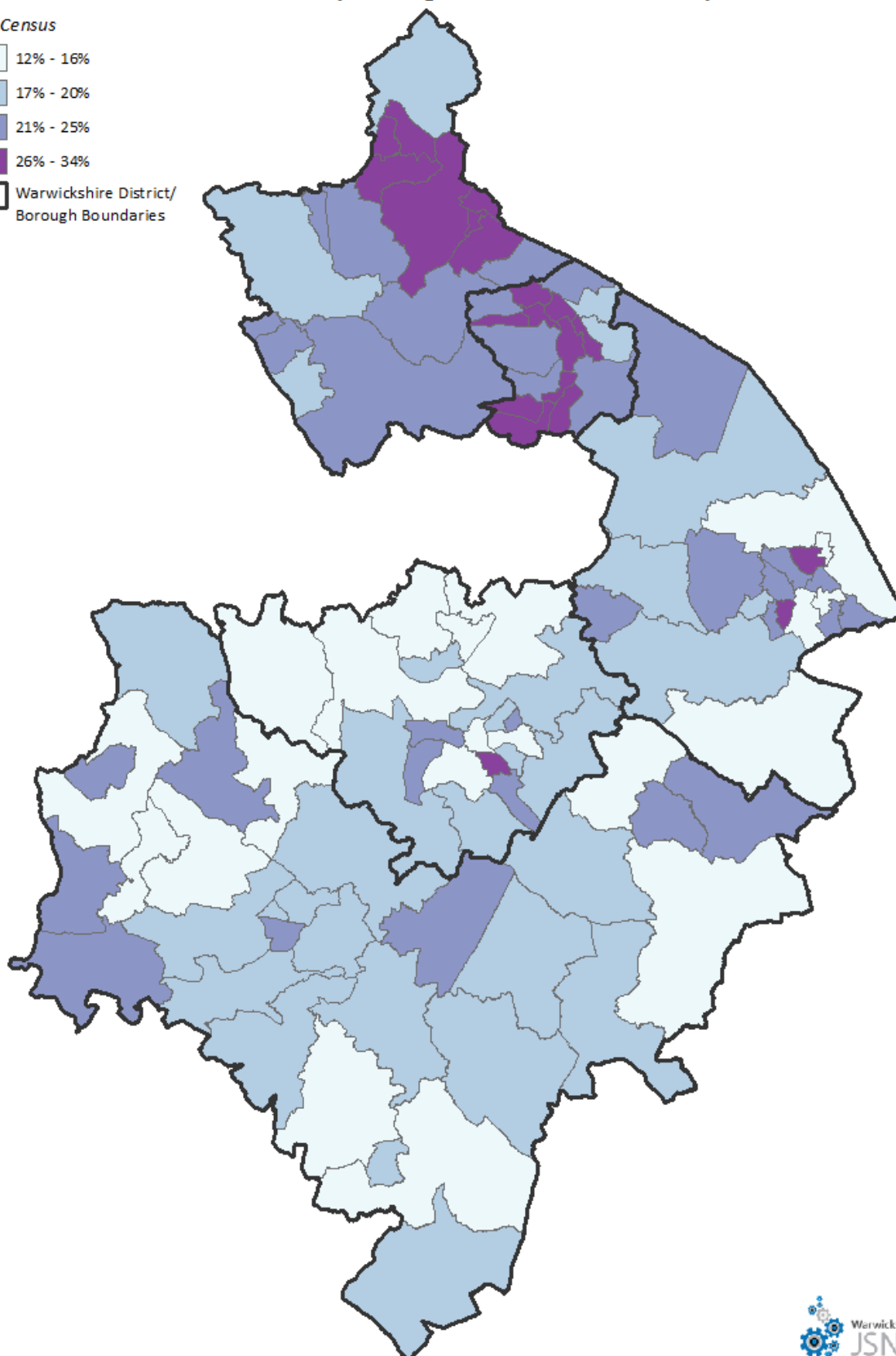
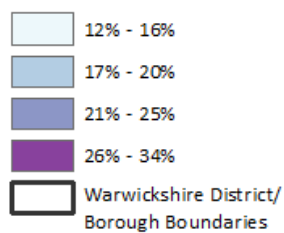
Source: 2011 Census, Office for National Statistics <http://www.ons.gov.uk/ons/guide-method/census/index.html>

Deteriorating health with rising levels of care – there is a uniform pattern of deteriorating general health with rising levels of unpaid care provision. There is a clear relationship between poor health and caring that increases with the duration and intensity of the caring role. Those caring for 50 hours or more per week are at far greater risk of poor health than those caring for fewer hours. Just over 12% of carers in Warwickshire who provide 50 or more hours of care a week state that their health is either 'bad or very bad' compared to 4.6% among those who provide no care and 4.0% of other carers. This additional health risk attached to those who provide 50 hours or more

¹² 2007 study entitled 'Age and gender of informal carers : a population-based study in the UK' <http://dro.dur.ac.uk/5202/>

Proportion of cares in Warwickshire providing 50 or more hours of care per week

2011 Census



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care when compared with both non-carers and those who care for less than 50 hours is evident among all age groups in both Warwickshire and England.

There is national evidence to suggest that a significant number of hospital admissions are due to problems associated with the carer rather than the person admitted. One study found that problems associated with the carer contributed to readmission in 62% of cases¹³. A national study tracking a sample of people over 75 years old who had entered the health and social care system, found that 20% of those needing care were admitted to hospital because of the breakdown of a single carer on whom the person was mainly dependent.

Economy & Employment – a range of evidence shows that caring can significantly impact on the ability of carers to take up or remain in employment. Surprisingly though, those who provide low levels of care (1-19 hours) have a higher economic activity rate than residents who have no identified caring responsibilities. In 2011 in Warwickshire, over 1,300 men and 870 women were in full-time employment while providing 50 hours or more unpaid care per week. Economically active women (in full-time and part-time employment) provided a greater share of the unpaid care burden than men. Unpaid care is more common among part-time workers than full-time workers, suggesting part-time work provides a greater opportunity to balance work and care commitments, but gender inequalities are present in each with women contributing more unpaid care than men.

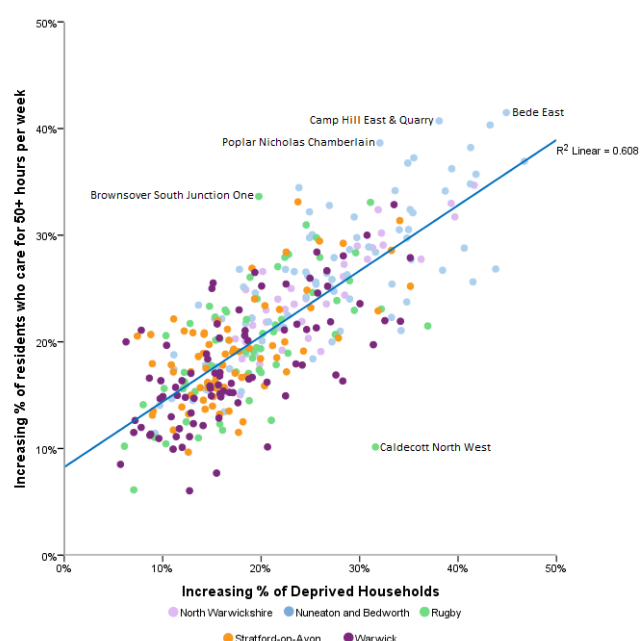
If we applied national proportions to the Warwickshire population of carers from the 2011 Census, this would equate to:

- **15,400** Warwickshire carers who's caring role is affecting their ability to take up or stay in employment
- Of those, it's likely that over **6,100** carers across the county may have left employment because of their caring responsibilities and **4,900** carers have reduced their working hours as a result of their caring responsibility.

Link between care and deprivation

There is a positive relationship between those providing more care in the more deprived areas of the county i.e. those areas that are relatively more deprived are more likely to have more residents providing 50 or more hours of care per week.

Providing 50 or more hours of unpaid care per week and deprived households Source: 2011 Census, Office for National Statistics
<http://www.ons.gov.uk/ons/guide-method/census/index.html>



¹³ Williams, E, Fitton, F (1991), 'Survey of carers of elderly patients discharged from hospital'. British Journal of General Practice, 41, 105-108.

Young Carers – caring has a significant long-term impact on a child’s life¹⁴. The effects include problems at school, health problems, emotional difficulties, isolation, lack of time for leisure, feeling different, pressure from keeping family problems secret, difficulties with transition to adulthood, feeling they are not being listened to and lack of recognition. Young carers are one and a half times more likely to have a long-standing illness or disability or special educational need than their peers.

The 2011 Census shows 1,124 children aged 0-15 years and 2,562 young people aged 16 to 24 years are providing unpaid care in Warwickshire, approximately 2.3% of all children and young people in the county. However, many young carers remain ‘hidden’ from health, social care and education services – partly as a result of those services needing to do more to identify them but also because of family fears that they will be taken into care or because the young people themselves are concerned about the reactions of others and bullying by their peers.

Young carers have significantly lower educational attainment at GCSE level, the equivalent to nine grades lower overall than their peers. The difference between the health status of those providing unpaid care and those who do not is most pronounced among those aged 0-24 years. Nationally, young carers are twice as likely to report that their health is ‘not good’ compared with their peers who provide no care. This difference increases with young carers who care for 50 hours or more per week; they are five times more likely to report their health as ‘not good’ compared to those of the same age providing no care. This implies that high levels of unpaid care have a greater adverse effect on the health of young people.

North Warwickshire, despite having the fewest young carers in the county, has the highest proportion of young carers providing 50 or more hours of unpaid care per week. This is a significant commitment to make at a time when these young carers might otherwise be doing their homework, studying for exams, moving into employment, further education and training, achieving greater independence, developing their own relationships and starting their own families.

Significant and strong associations of factors affecting young carers

Factor	Relationship
Family income	The median family income for families including a young carer was £5,000 less than families without a young carer
Adults in the household in work	Young carers are over four times more likely to live in a household where no adults are in work
Maternal education levels	Young carers are 1.6 times more likely to have a mother who has no educational qualifications
Adults with a limiting disability	Young carers are over twice as likely to live in households where at least one adult has a limiting disability
Number of children in the family	Young carers are 1.6 times as likely to live in households where there are three or more other children living

¹⁴ Hidden From View, the experience of young carers in England, The Children’s Society, 2013
http://www.childrenssociety.org.uk/sites/default/files/tcs/report_hidden-from-view_young-carers_final.pdf

Service provision - there are just over 5,500 carers across Warwickshire that are currently known to Guideposts, in that they have made contact with Guideposts and accessed some level of service. Over the last two years, the service has fallen short of its targets for new referrals, instances of support, training sessions and the majority of peer-led support groups. The Guideposts annual service evaluation has shown that for both peer-led groups and training sessions accessibility of services is an issue for many carers. The main barriers to attendance identified are the inability to leave the cared-for person, time of day, location and transport.

The number of carer assessments started has doubled from an average of 70 per month in 2014/15 to 115 per month so far (Apr-Aug 15) in 2015/16, largely associated with the introduction of the Care Act legislation from April 2015 which entitles carers to an assessment where the carer *appears* to have a need for support. So far in 2015/16, an average of 38 carer support plans have been started per month as the result of an assessment.

What carers told us including gaps and overall satisfaction with services

A range of methods of engagement were used to gain carer views, including a dedicated engagement week and a number of potential gaps were identified as part of this engagement.

Nearly half of all respondents believe that their GP is well placed to advise about relevant services for carers. Three in ten carers identified other informal carers as the next most appropriate group, highlighting the importance of informal networks in supporting carers. Interestingly, the proportion of respondents that considered social workers to be well placed to advise what services and support are available was low at 20%.

Many carers are spending a great deal of time trying to navigate complex systems in order to co-ordinate care and support services for the cared for person. Carers tell us that they feel frustrated with the amount of time they have to spend and difficulties they face trying to navigate and negotiate a complex health and social care system with multiple points of contact, a lack of communication between different parts of the system, barriers to access and often long waiting times. Carers told us that they need support to ensure that they are able to effectively navigate systems in order to co-ordinate care and support of the cared for person.

Carers felt that *breaks from caring or replacement care* was most important to them (57%). Over half (55%) of carers identified that support services for the cared for person would help them in their caring role, with an equivalent percentage identifying information and advice. Again over half (51%) of respondents felt that planning for future care and support needs would be helpful to them. A number of respondents identified that they would prefer to access face-to-face support during the daytime but they would prefer this support to be available in the home (65%).

'Respite care at a centre or preferably in own home would enable carers who cannot easily go out on their own to do so. A known specialist agency who could provide such care either privately or via the system of financial support would be a bonus'.

Warwickshire's statistical neighbours¹⁵ offer a wide range of services to carers who reside in their area. The majority of councils offer some form of information and advice, guide-posting, emergency support/cards/helplines, support groups and training. An example is Carers Gloucestershire, a local Gloucestershire based charity which runs a Carers' Hospital Support service which aims to ensure that carers of people admitted into hospital have good experiences, are respected, involved and supported throughout their stay.

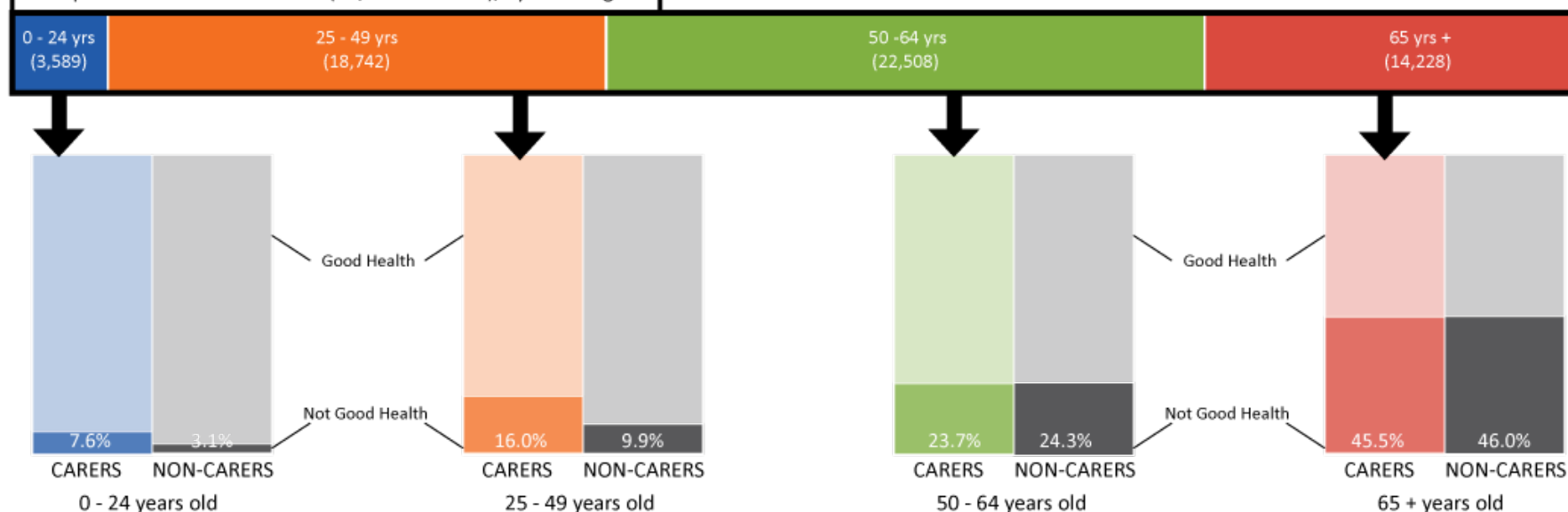
The main headline measure from the Warwickshire 2014/15 carers survey relates to the overall satisfaction with services provided. Overall satisfaction levels for carers has fallen in 2014/15, from 51.4% in 2012/13 to 35% in the most recent survey; a fall of over 30%. The equivalent survey for the cared for identifies that the cared for customer appears to be nearly twice as likely to be satisfied with the care and support they receive than the carer.

¹⁵ Councils which are similar to Warwickshire in terms of population and demography

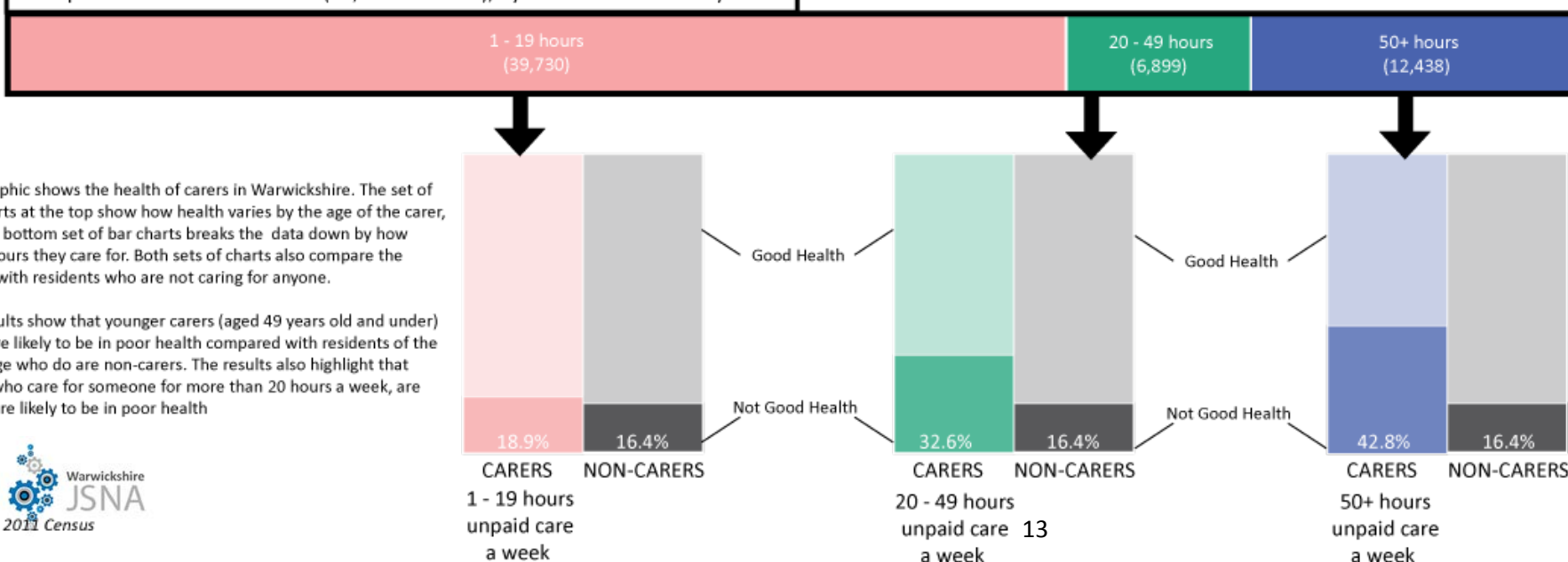
Who's caring for the carers ?

Note: The overall numbers of carers differs in this visualisation as this shows the number of carers by age and number of hours cross-tabulated with their health condition. Not all of those answering one question will have answered the other, which explains the small variation in overall reported numbers (59,240, compared to 59,067) in this visualisation. However, the messages from the visualisation remain the same.

All unpaid carers in Warwickshire (59,067 residents), by carers age



All unpaid carers in Warwickshire (59,067 residents), by number of hours they care



This graphic shows the health of carers in Warwickshire. The set of bar charts at the top show how health varies by the age of the carer, and the bottom set of bar charts breaks the data down by how many hours they care for. Both sets of charts also compare the results with residents who are not caring for anyone.

The results show that younger carers (aged 49 years old and under) are more likely to be in poor health compared with residents of the same age who do are non-carers. The results also highlight that carers who care for someone for more than 20 hours a week, are also more likely to be in poor health

RECOMMENDATIONS

Identifying, signposting and referring (hidden) carers early

- GPs and pharmacies are in a key position to make contact with hidden carers. Every GP should be identifying carers in their practice areas. Working in partnership across the public sector with health services when identifying hidden carers is key.
- Develop a sample referral form that can be used to identify hidden carers within a locally agreed protocol.
- Develop a local Carer Assessment Identification Tool to prompt appropriate assessment, identification and ongoing review to enable support for carers.
- Hospitals should routinely provide mechanisms to identify and support new carers, centring their efforts on wards where patients have received a new diagnosis or are due to be discharged and on out-patient clinics where patients are likely to be accompanied by those who care for them.
- Ensure information is available for carers in hospitals before discharge of the cared for person. Discharge teams should focus on the carer as well as the cared-for patient and provide them with relevant personalised information and advice.
- Carer support information needs to be available in out-patients and clinics as well as on the wards. Hospitals need to have links with carer support organisations, this may be via volunteers from these organisations in hospitals providing the required support.
- When trying to identify carers, illustrative questions should be asked, such as 'Do you look after or support someone?' rather than 'are you a carer' which can often elicit a negative response.
- Clearly identify 'sandwich carers' who have multiple caring responsibilities for people in different generations.
- Further work to try to identify carers in Warwickshire who are at high risk of reaching crisis point by acting as a second unpaid carer when two people have been required to carry out a caring role or who reduce the number of visits by paid carers in order to try to keep their costs down.

Health recommendations – GPs and health professionals have a key role to play

- Raise awareness of carers' needs with General Practice Nursing and District Nursing services. Ensure training includes cultural awareness, sensitivity and competence relevant to local communities.
- GP practices should offer flexibility with appointment times for carers, offering appointments outside clinic times or offering a home visit for those carers who cannot leave the person for whom they care.
- Every GP practice should be encouraged to identify a lead worker for carer support, who can assist in carer identification, help in referring carers to suitable local services, and ensure carers' access to health appointments and treatments is not impeded by their caring circumstances (*also an identification recommendation*).

- Develop, encourage and support older adults to make healthy living choices and/or to access local mental health and/or wellbeing services.
- All public sector agencies to have an awareness of the particular challenges when a carer is bereaved and loses what is often their key purpose in life.
- GP practices in rural areas are likely to be the most accessible place for many carers living in Warwickshire's countryside. These practices in particular must act as a gateway to support for these carers.
- Develop a mechanism within existing systems to capture the numbers of hospital admissions in Warwickshire that are due to carer breakdown in order to quantify potential savings across acute care by improving support to carers.

Commissioning and service recommendations

- Carers need to be fully involved in shaping the services that support them. New models of services meeting their needs should be designed at a local level and carers should be engaged in the commissioning process.
- The identification of carers should be part of the assurance process in contracts with all services commissioned by Warwickshire County Council and wider partners across Health & Social Care.
- Further support based intervention tools to be designed and developed, including self-help guides.
- Identify the needs of carers in the context of family context and work/education, ensuring that design and delivery of these services takes all identified needs into account.
- Further work to consider the impact on services when the carer goes into hospital themselves (could be carer breakdown) and the cared for has to be supported.
- Consider shaping future support offered to carers to have the option to support couples.
- Psychological support should be offered to carers adjusting to the decline of a loved one with a progressive condition nearing the end of life. This could include access to palliative care services that can offer counselling support both before and after bereavement.
- Assessing the particular needs of carers with multiple caring roles, who may benefit from support with household or other activities of their choosing in order to enable them to spend quality time as a family. Age appropriate psycho-social support for children in the family may also be needed.
- Facilitate self-help support groups in which families can share their experiences and learn from each other, while also recognising the balance between peer-led support and carers requiring support from workers at the commissioned service provider.
- Design and development a range of affordable respite care services, delivered at home or in the community, that provide age and condition appropriate activities delivered by social care professionals.
- Guidance for carers to help them find the support and services that they need in order to keep the person they care for as independent as possible and for those carers who do not want the person they care for to be moved into a residential care setting.

- NHS Continuing Healthcare assessments should, where possible, take place in conjunction with social care assessments.

Engagement recommendations

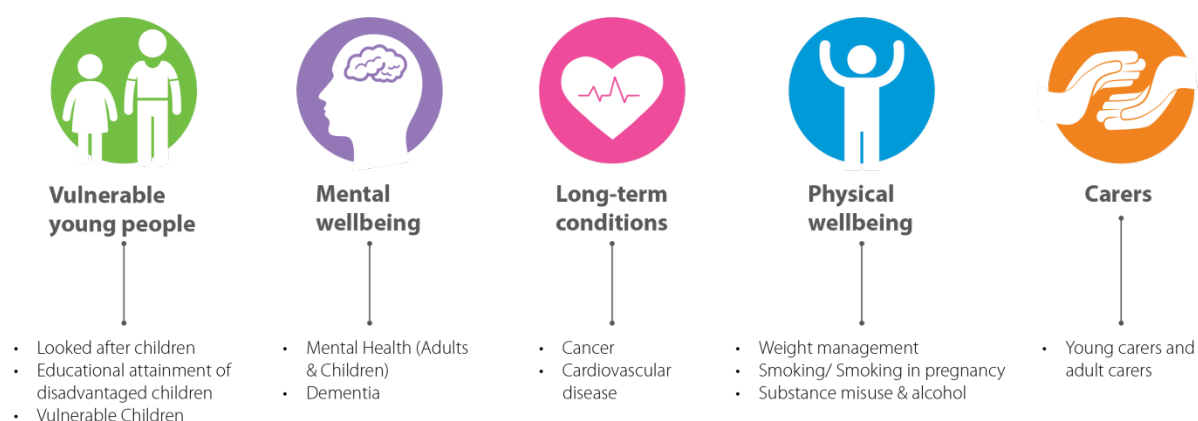
- Building on the recent engagement week in Warwickshire, further engagement specifically targeted at carers in Warwickshire to better inform our knowledge in commissioning services for this socially and demographically diverse group across Warwickshire.
- Raise carer awareness of their rights to an assessment and information and advice.
- Encourage carers to record their social 'goals' and help them work towards them to improve their wellbeing. Encourage carers to get involved with local carers groups and meetings to help combat social isolation and loneliness.
- Encourage employers to adopt family friendly working policies to make it easier for carers to maintain their working lives.
- Engage with carers to try to ascertain the range of support groups that are most wanted and when/where they should be held. Peer-led support groups are not appropriate for all carers, especially those who do not want to organise things themselves or have limited access to support staff.

Data recommendations

- An additional question to be added to Warwickshire's Carers Survey in order to better understand whether falling carer satisfaction levels relates more to the services they receive or the processes involved.
- More routine performance reporting from Warwickshire commissioned services related to carers and inclusion of a data sharing agreement in any future specifications for future commissioned services.
- Record the number of young carers who have dual caring responsibilities (caring for a parent and a sibling/other) and assess the young carer for their needs relating to each person they care for.
- Further work to look into detail at Warwickshire's domiciliary care providers, including the areas of Warwickshire they cover, their charging policies, additional charges and minimum call-out times.
- Access to NHS Continuing Healthcare assessments data to try and gain an understanding of solely health-funded packages of care and the carer support offered in these scenarios.

INTRODUCTION

Every three years, the Joint Strategic Needs Assessment (JSNA) reviews its priorities to ensure it is focused on key health and wellbeing issues facing the local population. This involves analysing and reviewing the latest data and evidence to highlight the most significant health and wellbeing issues in Warwickshire, both now and in the future. Carers (both young and adult carers) are one of the eleven identified priority topics and forms part of the JSNA's three year programme of work.



The existing contract for the delivery of Warwickshire's Carers Support Services will be re-commissioned and the Warwickshire's Joint Carers Strategy refreshed. The outcome of the carers services review indicates that there is a need to redesign the provision of support services to carers in order to develop an approach that is fit for purpose, offers real and accessible support to informal carers, ensures that we deliver on our duties under the Care Act, and prepare Warwickshire for the increasing 'care gap'.

This needs assessment will support the development of Warwickshire's Joint Carer's Strategy refresh and inform the targeting of resources and activities in order to drive improvements across carers support infrastructure, specifically in terms of:

- Early identification of carers – effective signposting to right support
- Increased numbers of carers accessing commissioned support services
- Increased numbers of carers accessing a Carers Assessment
- Carers are able to access services/support they need at the right time in the right place

This needs assessment is intended to provide insight into the unpaid care provision across Warwickshire and the extent and nature of local support services. It will also support in planning to meet future demand as a result of the Care Act. Unpaid carers make an important contribution to the overall supply of care services. As the population grows and ages, an increasing number of people are likely to continue to provide significant levels of care. The value of unpaid care in Warwickshire is estimated to be between £575m and £1.24bn per year¹⁶. As such, it is important to recognise the potential impact that providing many hours of care each week may have on carers'

¹⁶ Using Warwickshire's average homecare fee rate as a proxy indicator of the value of unpaid care.

own quality of life – their physical and mental health, employment opportunities and social and leisure activities.

Carers are a socially and demographically diverse group and as the demand for care is projected to grow, people are increasingly likely to become providers of care at some point in their lives. Consideration is given in this report to the personal situations of carers in terms of who they care for, the amount and type of care they provide and the impact that their caring role has on their health, employment situation, finances, quality of life and social relationships. Particular attention is paid to certain groups of carers who face challenging circumstances including young carers, older carers and those caring for people with specific conditions.

This report also looks at the increasing burden of care in the community, largely driven by Warwickshire's ageing population and seeks to assess the impact of this in terms of likely increases in the number of carers across the county over the next five to ten years.

No one data source provides a definitive picture of the number of carers locally or their personal circumstances. Self-reported Census data from 2011 provides the most comprehensive picture, particularly when used in conjunction with local service data from Guideposts and the Young Carers Project (Warwickshire's current commissioned carers support services) and intelligence from Social Care and Support within Warwickshire County Council on carer's assessments. A range of research literature, particularly from Carers UK and local and national surveys are also considered and provide much of the qualitative background for this report. A brief summary of each data source is provided below:

- **Warwickshire Carers Survey** - the statutory requirement to complete the carers survey is biennial but Warwickshire has committed to completing it annually. The last survey was carried out between October and November 2014. A total of 1,015 carers were chosen at random to participate in the survey, with 368 carers completing the survey, a response rate of 36%.
- **Survey of Carers in Households** - a detailed survey of carers in households in 2009/10, commissioned by the Department of Health as part of the Government's Carers' Strategy programme. Carers were identified via a short screening questionnaire at addresses which were randomly selected from the Postcode Address File (PAF). Carers were defined as those people who identified themselves as having extra responsibilities of looking after someone who has a long-term physical or mental ill health or disability, or problem related to old age. People providing care in a professional capacity were excluded.
- **GP Patient Survey** – a national survey conducted by an independent survey agency. Questionnaires are sent out twice a year to a randomly selected group of patients aged 18 or over who have been continuously registered with a general practice in England for at least six months. The latest survey results were published in July 2015. Carers are identified within the GPPS by responses to the question, 'Do you look after, or give any help or support to family members, friends, neighbours or others because of either: a long-term physical or mental ill health/disability or; problems related to old age?'
- **Osiris MR Customer Engagement report for Warwickshire** - between May and July 2015 Warwickshire County Council arranged a dedicated week of engagement, part of which

included obtaining carers' views on the quality of care and support services in Warwickshire. In total there were 149 combined responses to the survey (although not all questions were answered) including 96 online responses and 53 paper copies.

It is strongly suspected that most data sources under-estimate the size of the cohort. This is likely due to a number of factors including a carer not identifying themselves as a provider of care and support, particularly if this support is offered to a family member, and a reluctance to engage with service providers or the local authority in some circumstances. This needs assessment focuses on carers themselves rather than the person they care for, despite the strong links between the two. Further work relating more to the cared for has been added to the list of recommendations.

What is a carer?

Although there is no single definition of 'carer', a carer is generally described as a person of any age providing unpaid care to an ill, frail or disabled family member, friend or partner. This may include physical care or emotional support, advice and advocacy. It is important to note that a carer is not a volunteer who has been placed in a caring role by a voluntary organisation, nor someone who is paid as a care worker or personal assistant.

Clause 10 of the 2014 Care Act defines a carer as: 'an adult who provides or intends to provide care for another adult ('adult needing care')'¹⁷. The Carers Trust builds on this further and describes the role of 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'¹⁸. The Carers Trust goes on to say that:

Each carer's experience is unique to their own circumstances. The causes of someone taking on caring responsibilities are varied but can include:

- Serious physical illness
- Long-term physical disability
- Long-term neurological conditions
- Mental health problems
- Dementia
- Addiction
- Learning disabilities
- Sight/hearing loss
- Frailty/ageing
- Terminal illness

The provision of unpaid care in England and Wales is becoming increasingly common as the population ages, with an expectation that the demand for care provided by spouses and adult children will more than double over the next thirty years¹⁹.

Government Policy

In 2014, the Government published '[Carers strategy: actions for 2014 to 2016](#)'²⁰ which is the second national action plan, identifying the main actions for the next two years to support carers. This builds on the [national Carers Strategy of 2008](#)²¹ and the [next steps update of 2010](#)²².

¹⁷ Care Act 2014: http://www.legislation.gov.uk/ukpga/2014/23/pdfs/ukpga_20140023_en.pdf

¹⁸ Carers Trust: <http://www.carers.org/role-carer>

¹⁹ [Informal Care for Older People Provided by Their Adult Children: Projections of Supply and Demand to 2041 in England](#), Personal Social Services Research Unit.

The national carers strategy, 'Carers at the heart of 21st century families and communities' sets out the vision that by 2018, carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be based on individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring.

This strategy identifies a carer as:

"A carer spends a significant proportion of their life providing unpaid support to family or friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems."

The strategy sets out the ten year vision for improving support for carers, which is a shared responsibility between central and local government, the NHS, the third sector, families and communities. The principles outlined in the ten year vision are that by 2018:

- carers will be treated with dignity and respect as expert care partners;
- carers will have access to the services they need to support them in their caring role;
- carers will be able to have a life of their own;
- carers will not be forced into financial hardship by their caring role;
- carers will be supported to stay mentally and physically well;
- children and young people will be protected from inappropriate caring roles.

The strategy also aimed to protect children and young people from inappropriate caring and to support them to learn, develop and thrive and enjoy positive childhoods. In order to support the ten year vision, the strategy includes a set of commitments, including better collection of data about carers' lives and to the continued inclusion of a question about carers in the Census.

The Coalition Government refreshed this strategy in 'Recognised, valued and supported: next steps for the Carers Strategy 2010' retaining these aims and including a series of actions necessary to support the best possible outcomes for carers and care recipients, including:

- Supporting early self-identification and involvement in local care planning and individual care planning;
- Enabling carers to fulfil their educational and employment potential;
- Personalised support for carers and those receiving care;
- Support carers to remain healthy.

²⁰ https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/368478/Carers_Strategy_-_Second_National_Action_Plan_2014_-_2016.pdf

²¹ Carers at the heart of 21st-century families and communities:
<https://www.gov.uk/government/publications/the-national-carers-strategy>

²² Recognised, Valued and Supported: next steps for the carers strategy:
<https://www.gov.uk/government/publications/recognised-valued-and-supported-next-steps-for-the-carers-strategy>

The second national action plan in 2014 identifies the steps taken to improve awareness about the significant contribution that carers make and to improve support for carers in many spheres, including through Government legislation. Both the Care Act and Children and Families Act 2014 have set out improvements for assessing and supporting carers of all ages. The extension of the right to request flexible working to all employees introduced from 30 June 2014, will also help carers who wish to stay in paid employment alongside caring responsibilities. This action plan focuses on implementing the reforms set out in legislation, ensuring good outcomes for carers of all ages both in terms of their own health and well-being and quality of life.

Care Act 2014

With the implementation of Part One of the Care Act from April 2015, carers are now placed on an equal footing to those that they support, given the same recognition in law and a legal right to support in their caring role. The Act gives local authorities a responsibility to assess a carer's needs for support, where the carer *appears* to have such needs. This replaces the existing law, which says that the carer must be providing 'a substantial amount of care on a regular basis' in order to qualify for an assessment. This will mean more carers are able to have an assessment, comparable to the right of the people they care for. This assessment will consider the impact of caring on the carer and their wellbeing. The Care Act does not cover the assessment of people under the age of 18 who care for others. However, they can be supported under the law relating to children. The Children and Families Act gives young carers (and parent carers) similar rights to assessment as other carers have under the Care Act.

2011 Census

While the 2011 Census²³ found that 5.4 million people in England were providing unpaid care (the same proportion of the population as reported in 2001), over a third were providing 20 or more hours care a week, an increase of 5% on 2001 figures.

The Census also found that there were over 166,000 young carers aged 5-17 in England – an increase of over 26,000 since 2001. The majority were providing 1 to 19 hours care but over 8% were providing 50 or more hours of care per week. Significantly, more women than men in the age group 50-64 were providing care²⁴. However, there has been a shift in the age group of 65 and above – more men were providing care than women in 2011.

It is clear from the 2011 Census that the general health of carers deteriorates incrementally with the increasing hours of care provided. Over 5% of carers reported their own health as 'not good' and this rose to almost 16% among those caring for more than 50 hours a week.

While 55% of female adult carers and 45% of male adult carers reported they were economically active, only 12% of women and 9% of men were working full-time alongside caring responsibilities

²³ Office for National Statistics: http://www.ons.gov.uk/ons/dcp171778_290685.pdf

²⁴ Office for National Statistics: http://www.ons.gov.uk/ons/dcp171776_310295.pdf

and only 1.2% of women and 1% of men reported they were in full-time employment while providing 50 hours or more care a week.

National Evidence

Research from Carers UK suggests that that every year over 2.3 million adults in the UK become carers and that three in five people will be carers at some point in their lives²⁵. However, it should be recognised that nearly a third of carers do not recognise themselves as being a carer for up to five years. The Government publication in 2010, 'Recognised, Valued and Supported' outlines some of the reasons why this may be the case:

"A significant number of people with caring responsibilities do not readily identify themselves as carers. They understandably see themselves primarily as a parent, spouse, son, daughter, partner, friend or neighbour. In addition, the concept of caring is assumed but not recognised in some families in ethnic minority communities.

Many carers do not identify themselves as such until they have been caring for a number of years. This is understandable when the caring role develops gradually, for example with the onset of dementia. And when a family member or friend is suddenly in need of support, such as after a stroke, it can be difficult to find the time and energy to think through what the future may hold in terms of a caring role."

Carers UK research suggests that demographic change, coupled with the direction of community care policy the number of carers could increase by 40% by 2037²⁶. Over the next 20 years the number of people aged over 85 is expected to double²⁷. There is also a continuing shift away from institutional care to care provided at home and in the community. The majority of people with dementia, for example, are now cared for at home by a relative or friend. While this shift is welcome, it is important to recognise that the pressure on families to care in their own homes, particularly for spouses and partners, is growing significantly and is predicted to double over the next 30 years²⁸. Families provide the majority of care in the UK and it's clear this trend is likely to continue. This contribution is worth an estimated £119 billion a year to the UK economy – more than the total cost of the NHS²⁹.

²⁵ Carers UK (2001) It Could Be You – A report on the chances of becoming a carer

²⁶ Carers UK (2012): Facts About Carers

²⁷ Office for National Statistics Population Projections: <http://www.ons.gov.uk/ons/rel/npp/national-population-projections/2012-based-projections/stb-2012-based-npp-principal-and-key-variants.html>

²⁸ Personal Social Services Research Unit, 'Informal Care for Older People provided by their adult children: Projections of Supply & Demand to 2041 in England:' <http://www.pssru.ac.uk/archive/pdf/dp2515.pdf>

²⁹ Valuing carers – Calculating the value of unpaid care, 2007. Carers UK, ACE and the University of Leeds.

Carers Week³⁰ is an annual awareness campaign to celebrate and recognise the vital contribution made by the UK's 6.5 million carers. The below graphic summarises the national picture of caring in 2015:



³⁰ <http://www.carersweek.org/>

Health & Wellbeing

Carers UK's State of Caring Survey 2014³¹, found that eight in ten carers have felt lonely or socially isolated as a result of their caring responsibilities. Over 57% of carers have lost touch with friends and family as a result of caring and just under half (49%) of carers say they have experienced difficulties in their relationship with their partner because of their caring role. Carers who have reached breaking point as a result of caring are twice as likely to say that they are socially isolated because they are unable to leave the house and are also more likely to have experienced depression as a result of caring.

Caring for an older or disabled loved one can take a serious toll on carers' mental and physical health, their personal relationships and family finances. Without the support they need, this can lead to exhaustion, suffering physical injury or becoming overwhelmed by stress and anxiety. The UK Census showed that carers caring for 50 or more hours a week are more than twice as likely to be in bad-health than non-carers. The GP Patient Survey in 2013 highlighted the impact of caring on carer health; with 60% of all carers having a long-standing health condition rising to 70% of all carers caring for 50 or more hours a week. The survey showed significantly higher levels of arthritis, high blood pressure, long-term back problems, diabetes, mobility problems, anxiety and depression amongst carers.

Without time to recover or seek treatment, these problems can escalate, resulting in a health crisis and the carer either being hospitalised or emergency care services having to step in for the older or disabled person as the carer recovers.

Caring can result in a range of complex and often conflicting emotions – alongside feelings of love and duty, carers report feeling trapped, desperate and angry at their situation but then guilty about these feelings. With degenerative conditions like Motor Neurone Disease or Parkinson's, carers may also feel they are already grieving for the person and the relationship they feel they have lost. Many worry constantly about the future, particularly parents of disabled children or of partners who know their caring responsibilities will be life-long.

Young Carers

A young carer is a child or young person under the age of 18 who provides regular and ongoing care and emotional support to a family member, friend or neighbour who is physically or mentally ill, disabled or misuses substances. Young carers provide care that is relied upon in maintaining the health, safety or day to day wellbeing of the person receiving support or care and do not include children and young people who provide occasional or daily help that may occur in most families. Young carers may routinely be involved in domestic chores, giving medication, assisting with mobility, personal care and emotional support. In some families, in addition to undertaking one or more of these tasks, young carers will also provide child care for younger siblings.

³¹ Carers UK (2014) State of Caring Survey

Research conducted by The Children's Society³² reveals that young carers are one and a half times more likely to have a long-standing illness or disability or special educational need than their peers. More than 2,000 young carers from the Census 2011 data were reported to have 'bad' or 'very bad' health in Warwickshire. The report highlights that caring has a significant long-term impact on a child's life. The effects include problems at school, health problems, emotional difficulties, isolation, lack of time for leisure, feeling different, pressure from keeping family problems secret, difficulties with transition to adulthood, feeling they are not being listened to and lack of recognition.

Research carried out into young carers of school age found that the impact was significant in all age groups, with 28% of the 5-15 age group experiencing educational difficulties or missing school. Young carers have significantly lower educational attainment at GCSE level, the equivalent to nine grades lower overall than their peers.

Research by the Audit Commission in 2010 found that young carers between the ages of 16 and 18 had a much greater chance of being not in education, employment and training (NEET). Of these, 75% had been NEET at least once (compared with 25% of all young people) and 42% had been NEET for six months or more (compared with 10% of all young people).

In their report, 'Hidden From View', The Children's Society used data from the Longitudinal Survey of Young People in England (LSYPE) to look at household economic factors, parental characteristics, family structure, and young carers' contact with different agencies, to understand the circumstances affecting the daily lives of young carers. Figure X below shows the factors that have a significant and strong association with being a young carer, in comparison with their peers.

Figure 1: Significant and strong associations of factors affecting young carers

Factor	Relationship
Family income	The median family income for families including a young carer was £5000 less than families without a young carer
Adults in the household in work	Young carers are over four times more likely to live in a household where no adults are in work
Maternal education levels	Young carers are 1.6 times more likely to have a mother who has no educational qualifications
Adults with a limiting disability	Young carers are over twice as likely to live in households where at least one adult has a limiting disability
Number of children in the family	Young carers are 1.6 times as likely to live in households where there are three or more other children living

³² Hidden From View, the experience of young carers in England, The Children's Society, 2013
http://www.childrenssociety.org.uk/sites/default/files/tcs/report_hidden-from-view_young-carers_final.pdf

IDENTIFYING CARERS IN WARWICKSHIRE

2011 Census

The 2011 Census provides a valuable update on the picture of unpaid care provision in Warwickshire. This section provides the overarching messages from the 2011 Census, more detail on the characteristics of carers in terms of age, gender and health can be found in the chapter, 'characteristics of carers.'

The Census indicates that Warwickshire has **59,240** people or **11%** of the population providing some form of unpaid care each week in 2011. At District/Borough level, North Warwickshire residents report the highest rate of unpaid carers (12.1%) followed by Nuneaton & Bedworth and Stratford-on-Avon (11.4% and 11.3% respectively). Rugby (10.4%) and Warwick (9.8%) residents are least likely to be unpaid carers.

The release of 2011 Census data allows us to assess changes in the levels of unpaid care being provided over the last ten years. While rates of unpaid care provision are similar to those in 2001 across Warwickshire, absolute numbers have increased by 11% with an increase of over 6,000 carers in the county over the ten year period. A third of this increase was in Stratford-on-Avon District, with an 18.4% increase between the two Censuses. It's likely this is largely due to the older age profile of the District although it's worth highlighting the continued effect the ageing population will have on the numbers of carers across the county in future years which is particularly relevant for Stratford-on-Avon District.

At Clinical Commissioning Group³³ (CCG) level, while Coventry & Rugby has the largest volumes of unpaid carers (although three quarters of these carers are Coventry residents), Warwickshire North has the highest rate of unpaid carers at 12%. South Warwickshire CCG has seen the largest percentage change over the period with over 3,200 more carers in 2011 compared with 2001.

Figure 2: Provision of unpaid care in Warwickshire by District/Borough and CCG, 2001 and 2011

	Provides any unpaid care (2001)		Provides any unpaid care (2011)		Change over time (2001 – 2011)	
	Number	%	Number	%	Number	%
England	4,877,060	9.9%	5,430,016	10.2%	+552,956	11.3%
Warwickshire	53,221	10.5%	59,240	10.9%	+6,019	11.3%
North Warwickshire	7,070	11.4%	7,519	12.1%	+449	6.4%
Nuneaton & Bedworth	13,212	11.1%	14,232	11.4%	+1,020	7.7%
Rugby	9,059	10.4%	10,391	10.4%	+1,332	14.7%
Stratford-on-Avon	11,532	10.3%	13,651	11.3%	+2,119	18.4%
Warwick	12,348	9.8%	13,447	9.8%	+1,099	8.9%

³³ Clinical Commissioning Groups (CCGs) are NHS organisations set up by the Health and Social Care Act 2012 to organise the delivery of NHS services in England.

Warwickshire Clinical Commissioning Groups:

	Provides any unpaid care (2001)		Provides any unpaid care (2011)		Change over time (2001 – 2011)	
	Number	%	Number	%	Number	%
Warwickshire North	20,282	11.2%	21,751	11.6%	+1,469	7.2%
Coventry & Rugby	39,106	10.1%	42,492	10.2%	+3,386	8.7%
South Warwickshire	23,880	10.1%	27,098	10.5%	+3,218	13.5%

Source: 2001 and 2011 Census, Office for National Statistics

Carers known to GPs

Clinical Commissioning Group (CCG) GP Patient Register

GP surgeries record what proportion of their registered patients have a caring responsibility and this is reported at Clinical Commissioning Group level, although it is worth highlighting that the extent this is uniformly applied and maintained across all practices is unknown. In addition, this data covers all patients registered with a GP practice across the three Warwickshire CCGs (which includes Coventry) covering significant populations who are resident outside of the county.

This variation between the resident population and the GP registered patients is highlighted in the table below. For both, Coventry & Rugby and South Warwickshire CCGs, the GP populations are higher than the equivalent reported resident population projections for 2015. This will likely include a considerable numbers of people who are resident in Warwickshire's neighbouring authorities; nevertheless, this represents the population the three Warwickshire CCGs cover and as a result is worth consideration when considering service provision and commissioning of services across these areas. Interestingly, Warwickshire North's CCG GP population is slightly lower than the 2015 population projection perhaps reflecting the fairly static population in this area over recent years.

Figure 3: Difference in patient and resident population at CCG level

Clinical Commissioning Group	CCG GP patient population (2015)*	Resident population (2015)**	Variation
Warwickshire North	185,800	190,300	-4,500
Coventry & Rugby~	483,500	440,100	+43,400
South Warwickshire	276,200	262,300	+13,900

* Numbers of patients registered with GPs at CCG level, July 2015, rounded to nearest 100, Health & Social Care Information Centre (HSCIC), <http://www.hscic.gov.uk/catalogue/PUB17927>

**2015 population projection from 2012 subnational population projections, Office for National Statistics, <http://www.ons.gov.uk/ons/rel/snpp/sub-national-population-projections/2012-based-projections/stb-2012-based-snpp.html>

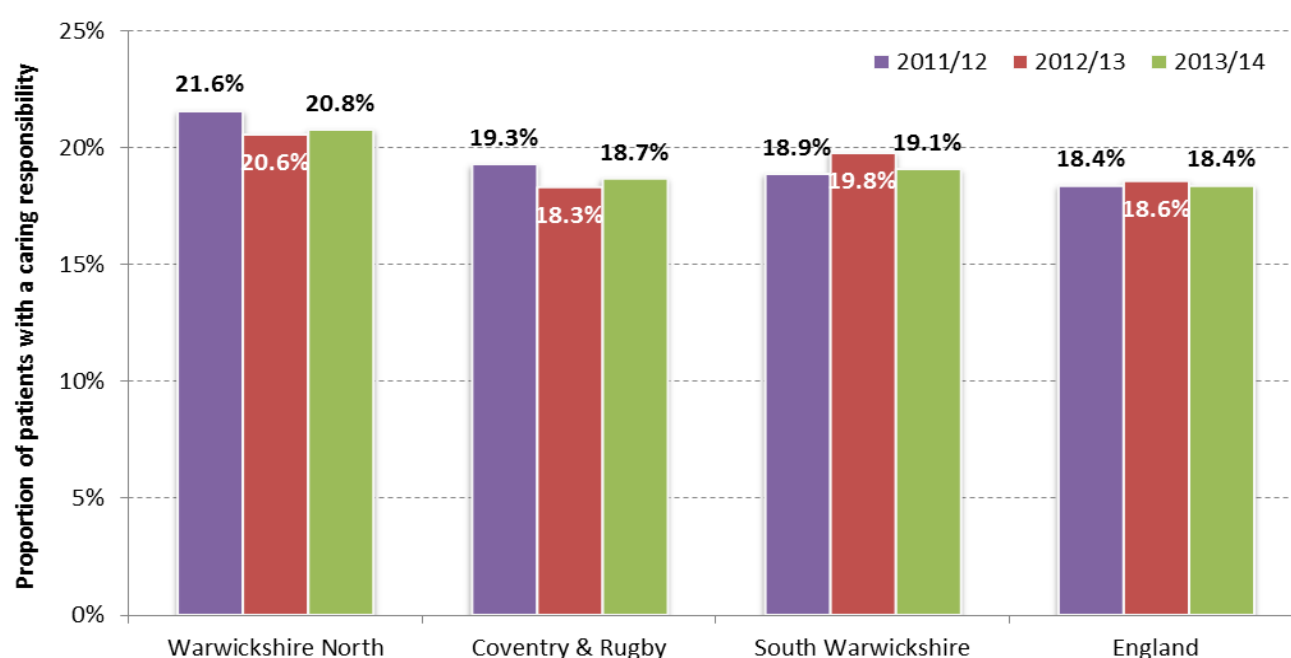
~Unable to breakdown for Rugby Borough specifically as reported at CCG level.

Warwickshire North CCG has the highest proportion of residents with a caring responsibility at 20.8%; one in five registered patients in 2013/14. This varies from 18.7% in Coventry & Rugby CCG and 19.1% in South Warwickshire CCG. All three CCGs are above the equivalent national proportion of 18.4%. Looking at trends over time in the proportion of patients with caring responsibilities, it

appears that proportions have stayed relatively stable when comparing 2011/12 and 2013/14 with a blip in 2012/13 in some CCG areas.

However, there is significant variation within each CCG at GP practice level. This is illustrated best in Nuneaton & Bedworth Borough (part of Warwickshire North CCG). A GP practice in Bedworth has nearly one in three registered patients with a caring responsibility compared to a practice in Attleborough in Nuneaton that has less than one in ten patients (9.8%) with a caring responsibility; three times less than the Bedworth GP practice. As a result, there is very little pattern discernible which may be linked to the variation in recording of this at GP practice level.

Figure 4: Proportion of registered GP patients with caring responsibility, by CCG, 2011-12-2013/14



Source: GP Patient survey, 2011/12 – 2013/14, Department of Health, <http://www.gp-patient.co.uk>

WCC Support to Adult Carers

The current carers' strategy identifies the following four priorities:

1. Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages.
2. Enabling those with caring responsibilities to fulfil their educational and employment potential.
3. Personalised support both for carers and those they support, enabling them to have a family and community life.
4. Supporting carers to remain mentally and physically well.

Guideposts Carers Support Services (GCSS) are commissioned to provide support services for adult carers in Warwickshire in line with this strategy. The value of this contract is £355,000 and includes:

- Information and advice on all aspects of the caring role;
- 1-to-1 and peer-led support;
- Practical and emotional support, including training sessions.

Referrals and Instances of support

There are just over 5,500 carers across Warwickshire that are currently known to Guideposts, in that they have made contact with Guideposts and accessed some level of service. Over the last two years the service has fallen short of its targets for numbers of new referrals and number of instances of support, as illustrated in the table below.

	Target	2013/14 ³⁴	2014/15 ³⁵
Number of new referrals per year	1,000	710	639
Number of instances of support per year	12,000	9,305	7,910

Source: Guideposts Carers Support Service Performance Reporting

A more detailed breakdown of services offered to carers is covered in the service provision chapter for adult carers and the young carers chapter for those carers under the age of 18 years.

In summary:

- **59,240** carers in Warwickshire or **11%** of the resident population of which:
 - **1,124** are aged 0-15 years
 - **2,562** are aged 16-24 years
 - **41,315** are aged 25-64 years
 - **14,239** are aged 65 years and over (*2011 Census*)
- Number of carers in Warwickshire registered with a GP:
 - Warwickshire North CCG – **38,319** carers (estimated)
 - Coventry & Rugby CCG – **88,278** carers (estimated)
of which: Rugby estimated at **17,358** carers
(registered at GP practice with a Rugby Borough postcode)
 - South Warwickshire CCG – **52,295** carers (estimated)

Giving a total Warwickshire figure (excluding Coventry) of: **107,972 estimated to have some form of caring responsibility or 19.3% of the registered GP population in Warwickshire**
- Just over **5,500** adult carers are known to WCC Commissioned Guideposts service
- **1,002** young carers aged 8-17 years are known to Warwickshire Young Carers Project, plus **330** young adult carers aged 18 to 23 years referred to adult carer services.
- **839** Carers Assessment Events started between April 2014 and March 2015 (*a carer can have more than one assessment*) (see Carers Assessments chapter)
- **4,930** carers in receipt of Carers Allowance as at February 2015 (see separate chapter)

³⁴ Contractual Year July 2013–June 2014

³⁵ Contractual Year July 2014–June 2015

HIDDEN CARERS

‘Hidden’ can have a number of different implications in the context of carers. The two that this chapter focuses on are:

- The ‘gap’ between those identified on GP patient registers and numbers recorded in the 2011 Census.
- Hidden in the respect that many do not view themselves as carers i.e. even the above figures are likely to represent an underestimate.

Gap between GP patients and 2011 Census

As highlighted in the previous section, the 2011 Census identified over 54,200 carers in Warwickshire. This compares with an estimated 108,000 patients registered with a Warwickshire GP who have some form of caring responsibility in 2013/14. Although it’s worth reiterating that a proportion of these carers are likely to live outside of Warwickshire despite being registered to a GP practice within Warwickshire, this still represents a significant difference, with GP practices effectively identifying nearly **twice** as many carers in Warwickshire than the 2011 Census, with an estimated 48,700 more carers registered with a caring responsibility with a Warwickshire GP. This seems to reflect the national picture, with a similar difference between Census reporting and GP registers.

Figure 5: Difference in numbers and proportions of carers, CCG level

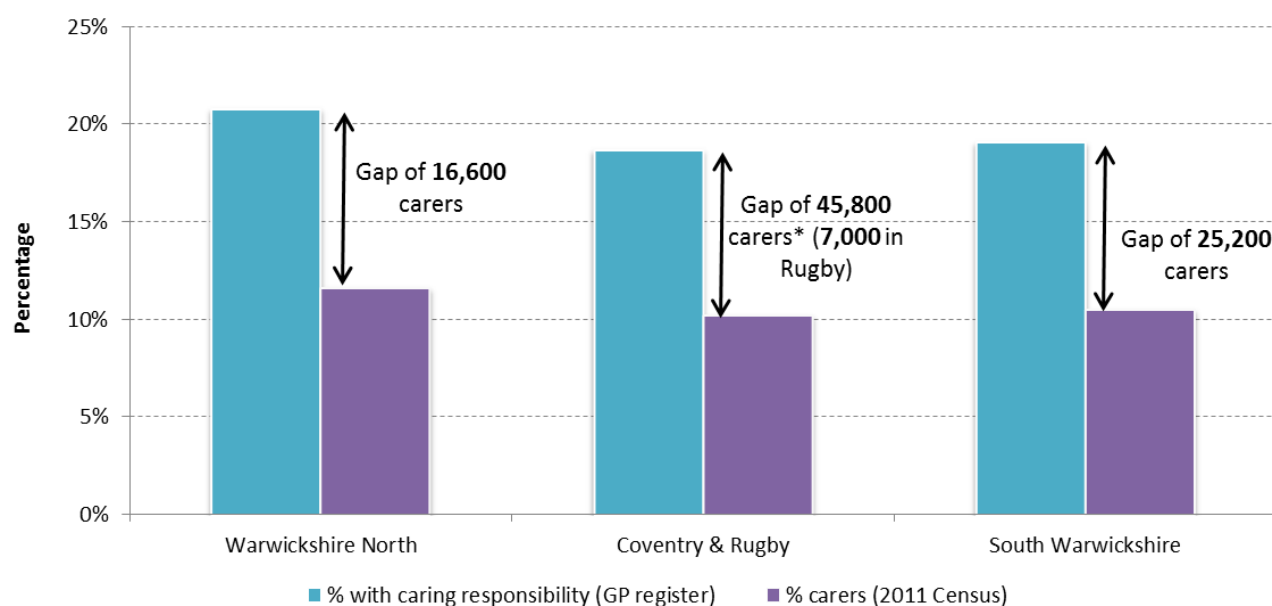
Clinical Commissioning Groups	Census carers (2011)		Patients with caring responsibilities* (GP register, 2013/14)		Gap
	Number	%	Number**	%	Number*
England	5,430,016	10.2%	10,352,152	18.6%	4,922,136
Warwickshire	59,240	10.9%	107,972	19.3%	48,732
Warwickshire North	21,751	11.6%	38,319	20.8%	16,568
Coventry & Rugby	42,492	10.2%	88,278	18.7%	45,786
South Warwickshire	27,098	10.5%	52,295	19.1%	25,197

Source: GP Practice Profiles and 2011 Census * only available at CCG level, not available for Districts/Boroughs

**estimated numbers based on percentages

The gap for Warwickshire’s three CCGs is illustrated in Figure X. Including Coventry, the ‘gap’ for the CCG areas covering Warwickshire rises to 87,600 between the numbers of patients with a caring responsibility with a GP compared with the 2011 Census numbers. Unsurprisingly, Coventry’s ‘gap’ makes up the majority of the difference in the Coventry and Rugby CCG area, accounting for 38,800 or 85% of the total.

Figure 6: Difference in numbers and proportions of carers at CCG level



Source: GP Profiles and 2011 Census

* includes both Coventry & Rugby GP practices

Hidden from view

Many carers do not recognise themselves as carers³⁶. Research suggests they simply see themselves as husband, wife, parent, son, daughter or friend and as a result do not access formal services. This is identified as a particular problem with black and minority ethnic (BME) carers³⁷. Identifying these hidden carers is not only a local authority duty under the prevention duty of the 2014 Care Act,³⁸ it is essential in identifying the full extent of vulnerability in the county and the levels of unpaid care across Warwickshire that is currently hidden from view.

*'I do not automatically think I am a carer;
in the first instance I am a wife.*

*Perhaps the word caregiver should be
used instead.'*^{*}

Twinned with this, there is reluctance among some carers to make their needs known. Carers of people with stigmatised conditions (for example, mental health problems, and drug and alcohol problems) may be reluctant to make their needs known³⁹. Some carers may view the assessment

³⁶ Heron, C. (1998) 'Working with carers', London: Jessica Kingsley

³⁷ National Assembly for Wales (2003) '[Challenging the myth "They look after their own": Carers services - access issues for black and minority ethnic carers in Wales](#)'

³⁸ [Care Act 2014](#): Part 1 Section 2 Clause 2 (c) places a duty on local authorities to identify carers in their area with needs for support.

³⁹ Identifying hidden carers, Implementing the Carers Act 2004:
<http://www.scie.org.uk/publications/guides/guide09/section1/hidden.asp>

*From Warwickshire engagement with carers

process as a way of checking up on their ability to care⁴⁰ and this may discourage them from approaching services.

Many carers are likely to have first contact with the health service⁴¹. GPs and pharmacies are in a key position to make contact with hidden carers. This highlights the importance for local authorities of working in partnership with health services when identifying hidden carers. The Princess Royal Trust for Carers has published a good practice guide⁴² that outlines methods for involving local health professionals in the identification of hidden carers.

The same is true for young carers. Many young carers remain 'hidden' from health, social care and education services – partly because of family fears that they will be taken into care or because the young people themselves are concerned about the reactions of others and bullying by their peers. Similarly, parents of children with long-term conditions or a disability often feel 'invisible' and that they are just seen as parents.

⁴⁰ Wood, J. and Watson, P. (2000) 'Working with family carers: A guide to good practice', London: Age Concern.

⁴¹ Department of Health (1999) 'Caring about carers: A National Strategy for carers', London

⁴² The Princess Royal Trust (2003) 'Focus on carers and the NHS: Identifying and supporting hidden carers.'

CHARACTERISTICS OF CARERS IN WARWICKSHIRE

The 2011 Census provides a valuable update on the picture of unpaid care provision in Warwickshire. It indicates that Warwickshire has 59,240 people or 11% of the population providing some form of unpaid care each week. Rates of unpaid care provision are similar to those in 2001 (although absolute numbers have increased by 11%), but the data suggests that carers are providing more hours of care each week than ten years ago.

Number of hours of unpaid care provided

While overall rates of unpaid care provision remain broadly similar to those ten years ago, the data indicates a rise in the proportion of carers who are caring for more hours, especially those in the category who provide 50 hours or more each week. In 2011, one in five carers (12,452 people or 21%) provided 50 or more hours of care each week compared with 18% of carers in 2001. A similar pattern, as demonstrated in Figure X, is evident across the county. Nuneaton & Bedworth Borough has the highest numbers and proportion of carers who do so for more than 50 hours per week.

Figure 7: Number of hours of care provided

	Provides 1-19 hours of unpaid care		Provides 20-49 hours of unpaid care		Provides 50+ hours of unpaid care	
	Number	%	Number	%	Number	%
England	3,452,636	6.5	721,143	1.4	1,256,237	2.4
Warwickshire	39,871	7.3	6,917	1.3	12,452	2.3
North Warwickshire	4,797	7.7	924	1.5	1,798	2.9
Nuneaton & Bedworth	8,557	6.8	1,995	1.6	3,680	2.9
Rugby	7,118	7.1	1,211	1.2	2,062	2.1
Stratford-on-Avon	9,685	8.0	1,413	1.2	2,553	2.1
Warwick	9,714	7.1	1,374	1.0	2,359	1.7
Warwickshire Clinical Commissioning Groups:						
Warwickshire North	13,354	7.1	2,919	1.6	5,478	2.9
Coventry & Rugby	26,574	6.4	5,918	1.4	10,000	2.4
South Warwickshire	19,399	7.5	2,787	1.1	4,912	1.9

Source: 2011 Census, Office for National Statistics <http://www.ons.gov.uk/ons/guide-method/census/index.html>

The south of the county has a higher proportion of carers providing lower levels of care with 7.5% of South Warwickshire residents providing 1-19 hours per week. While Warwickshire falls broadly in line with national equivalents for those providing higher hours of care in 2011, the proportion of unpaid carers providing 1-19 hours of unpaid care is higher than the England average of 6.5%. This is worth noting as the population ages, this may translate into an increased number of hours of care for this particular group.

Figure 8: Proportion of carers providing unpaid care for 50 or more hours per week, 2001-2011



Source: 2001 and 2011 Census, Office for National Statistics <http://www.ons.gov.uk/ons/guide-method/census/index.html>

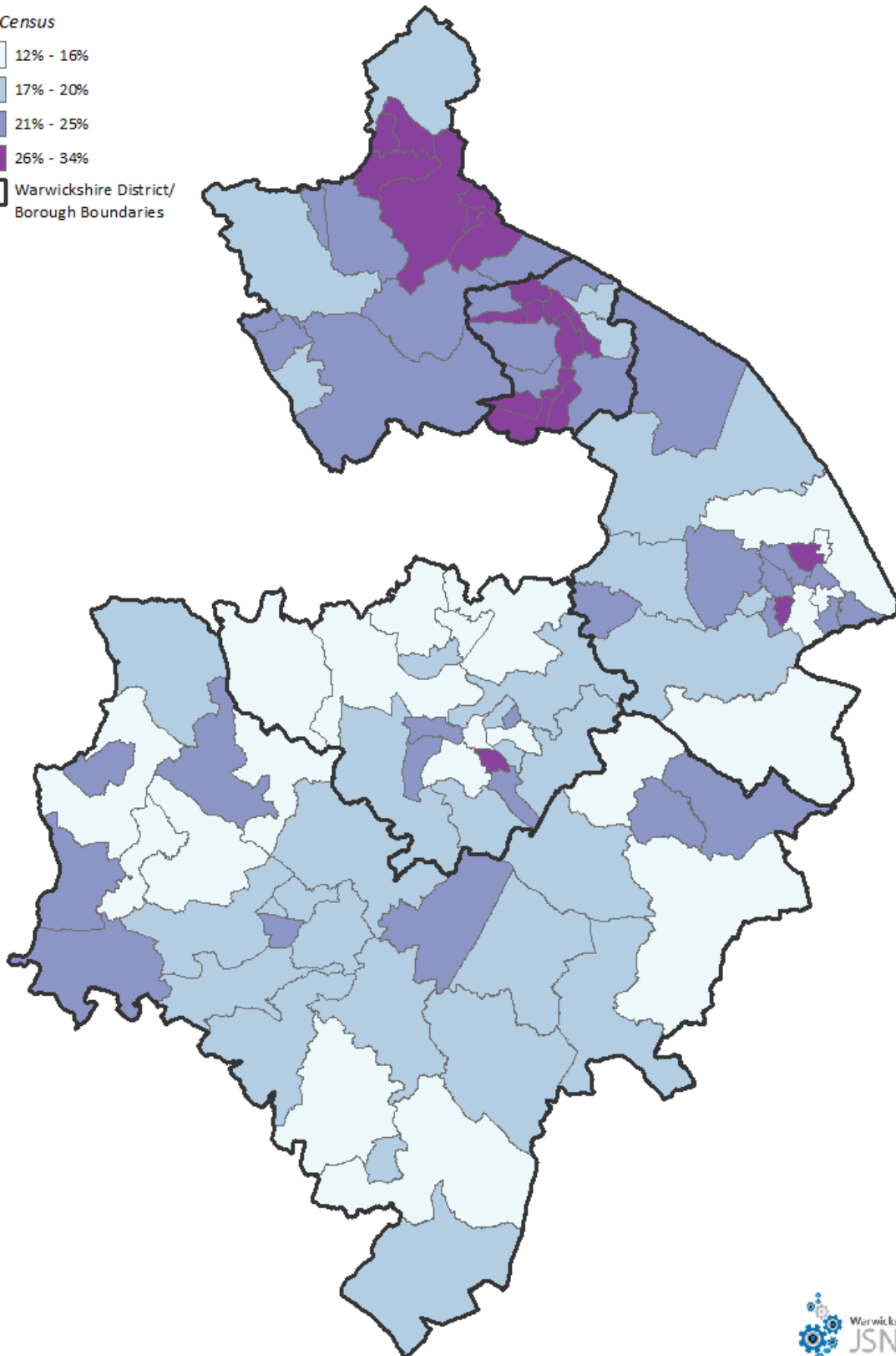
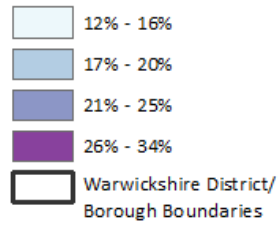
The Census does not break down further the number of hours of care provided over 50 hours per week. This is potentially masking the full extent and intensity of care provided by carers. Carers UK 2015 annual survey revealed that over half (56%) of respondents care for 90 or more hours every week, while 17% care for 50-89 hours, 20% for 20-49 hours and 8% care for 1-19 hours a week. This national research further highlights the full-time nature of many caring roles, particularly for individuals who live in the same household as the cared for person.

There is significant variation at ward level when looking at those providing some form of unpaid care across Warwickshire. Nearly 15% of residents in Bulkington ward in Nuneaton & Bedworth Borough provided some form of care in 2011, this is over twice the proportion of residents in Clarendon ward in Leamington Spa where 6.7% of residents provide some care according to the 2011 Census. This variation increases when you consider the proportion of residents that care for 50 or more hours per week. Similarly, Clarendon ward has the lowest proportions of carers providing high levels of care (0.9%) and Exhall ward in Nuneaton & Bedworth Borough has over four times the proportion of carers providing 50+ hours of care at 3.9%.

The map overleaf highlights those wards in Warwickshire by the proportion of their caring residents that provides the highest number of hours care per week (50 or more hours). Those wards with the highest proportions (the areas in red) are primarily in the north of the county. Over a third (34%) of carers in Camp Hill ward in Nuneaton & Bedworth Borough care for 50 or more hours per week. The top five wards in the county are all in the Borough (Camp Hill, Kingswood, Bede, Wem Brook, and Exhall) with Dordon ward in North Warwickshire Borough the highest outside of Nuneaton & Bedworth Borough, with 31% of the caring population in the ward providing the highest hours of care. Two wards in Rugby Borough (Brownsover South and Overslade wards) and one in Warwick District (Brunswick ward) are also wards where over a quarter of carers care for 50 or more hours a week.

Proportion of cares in Warwickshire providing 50 or more hours of care per week

2011 Census

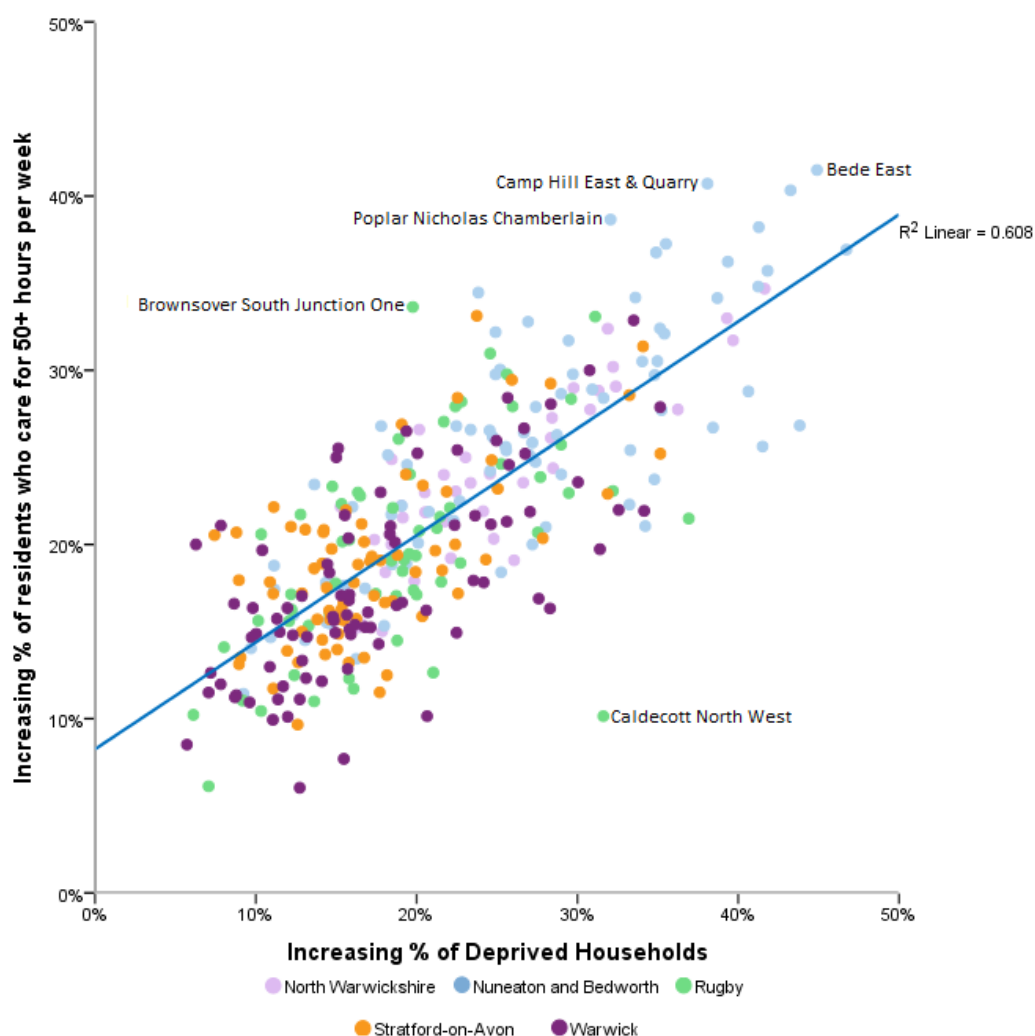


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Unpaid care and deprivation

In order to identify whether a relationship exists between providing unpaid care and deprivation, the 2011 Census allows a comparison between the relative level of disadvantage and those providing unpaid care and this is shown in Figure X below. There is a positive relationship between those providing more care in the more deprived areas of the county. The graph below shows the proportion of households in a Lower Super Output Area⁴³ (LSOA) that meet two or more of the Office for National Statistics (ONS) deprivation criteria against the proportion of carers who provide 50 or more hours of care.

Figure 9: Providing 50 or more hours of unpaid care per week and deprived households



Source: 2011 Census, Office for National Statistics <http://www.ons.gov.uk/ons/guide-method/census/index.html>

⁴³ Lower Super Output Areas (LSOAs) are a statistical geography designed to improve the reporting of small area data. LSOAs typically vary from between 400 households to 1,200 households.

A large number of those nearest the top of the graph i.e. those areas that are relatively more deprived and those areas that have proportional more residents providing 50 or more hours of care per week are in Nuneaton & Bedworth Borough.

Caring by gender and age

Women are more likely to be unpaid carers than men (58% and 42% respectively). This gender difference remains broadly similar irrespective of the number of hours of care undertaken each week. Unsurprisingly, rates of unpaid care provision increase with age among both men and women, up to the age of 65. The data indicates that the share of unpaid care provision is highest for women aged 50-64 years. Indeed, one in four women in this age group provides some level of unpaid care. The gender difference appears to diminish among those aged 65 plus with men slightly more likely to provide unpaid care than women.

Figure 10: Likelihood of undertaking unpaid care by age and gender in Warwickshire, 2011



Source: 2011 Census, Office for National Statistics <http://www.ons.gov.uk/ons/guide-method/census/index.html>

Guideposts Warwickshire identified a total of 747 carers in 2014/15, which represents less than 2% of carers identified in the 2011 Census. The gender split of those registered with Guideposts (67% female, 33% male) is considerably more skewed towards females than among those identified in the Census.

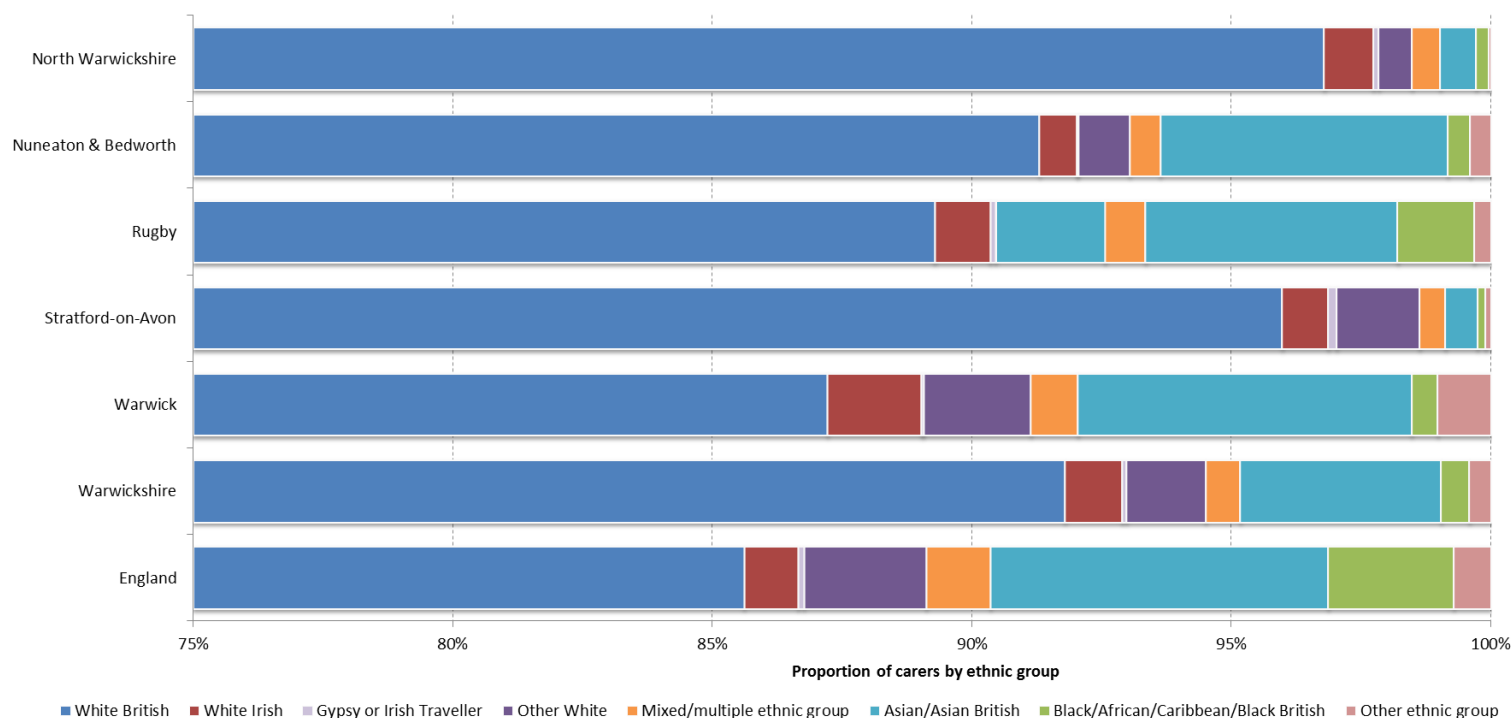
In general, the category of 1 to 19 hours per week is the most common level of care provision among all age groups. However, the proportion of those caring for more than 50 hours or more per week rises notably in those aged 65 and over where around a third of carers do so for more than 50 hours per week. On average, one in five (20%) carers in Warwickshire provide unpaid care for more than 50 hours per week.

Younger carers (aged between 0 and 24 years) are identified as of particular concern because of the potential impact of caring responsibilities on educational outcomes and wider social opportunities. They warrant further analysis in their own right and this is included in the next chapter.

Caring by ethnic group

The ethnic profile of carers is similar to Warwickshire's overall ethnic profile. According to the 2011 Census, over nine in ten (92%) Warwickshire carers classify themselves as White British a total of 54,383 carers. In part, the variations in caring proportions among different ethnic groups are likely to be a result of the differences in their respective age profiles. Warwickshire's white population tends to be older when compared with other ethnic groups and the overall Warwickshire age profile often masks considerable variation when considering individual ethnic groups. This is best shown by the following [graphic](#) produced as a result of the 2011 Census showing age profiles by ethnic group.

Figure 11: Unpaid carers by ethnic group, 2011



Source: 2011 Census, Office for National Statistics <http://www.ons.gov.uk/ons/guide-method/census/index.html>

The Indian ethnic group (part of the Asian/Asian British ethnic group in Figure X) has the largest proportion and volume of unpaid carers outside of the White British group with nearly 1,700 carers in the county at the time of the Census (or 2.8%). At District/Borough level, Warwick District and Nuneaton & Bedworth Borough have higher proportions of carers from the Indian ethnic group than the county average, 4.9% and 4.2% respectively. Again this falls in line with Warwickshire's overall ethnicity profile. The White Other ethnic group is also notable, particularly in Rugby Borough and Warwick Districts (2.1%). For all ethnic groups, the most common length of time spent providing unpaid care was 1 to 19 hours per week.

YOUNG CARERS

A young carer is a child or young person under the age of 18 who provides regular and ongoing care and emotional support to a family member, friend or neighbour who is physically or mentally ill, disabled or misuses substances.

The 2011 Census shows 1,124 children aged 0-15 years and 2,562 young people aged 16 to 24 years are providing unpaid care in Warwickshire, approximately 2.3% of all children and young people in the county. This rate is broadly in line with the national average of 2.6%. However, this number is likely to be an underestimate of the true number of children and young carers given that Census questionnaires are completed by parents and not children, and made no mention of conditions such as mental health or substance misuse.

According to 'Hidden from View', a report published by The Children's Society on the experiences of young carers in England, caring has a significant long-term impact on a child's life. The effects include problems at school, health problems, emotional difficulties, isolation, lack of time for leisure, feeling different, pressure from keeping family problems secret, difficulties with transition to adulthood, feeling they are not being listened to and lack of recognition.

Research conducted by the University of Nottingham and the BBC in 2010 showed that one in 12 children interviewed for their study (of over 4,000 school children) had caring responsibilities. If the same methodology is applied to Warwickshire's population, it would suggest that there are approximately 4,880 young carers in the county, an increase of over a third compared to the number identified by the 2011 Census.

A range of research^{44,45} highlights some of the risks of under-estimating the number of young carers, attributing the difficulties of identification to a range of family related causes. This is summarised in the Government report Recognised, Valued and Supported⁴⁶:

Many young carers remain 'hidden' from health, social care and education services – partly as a result of those services needing to do more to identify them but also because of family fears that they will be taken into care or because the young people themselves are concerned about the reactions of others and bullying by their peers.

The number of young carers aged from 8 to 17 years of age known to the Warwickshire Young Carers Project at the end of 2014/15 financial year was 1,002, up from 801 the previous year. 6% of these young carers in Warwickshire were from BME groups. A slightly higher number of young carers were identified in the north of the county compared to the south (401 in the north compared with 380 in the south). A further 202 young carers were identified in Rugby Borough. Warwickshire

⁴⁴ The Children's Society (2013) Hidden from View: The Experience of Young Carers in England

⁴⁵ Clarkson, Frank, Lucantoni, Fox (2008) Emotional Support for Young Carers: Briefing Paper for Royal College of Psychiatrists

⁴⁶ Recognised, Valued and Supported: next steps for the carers strategy:

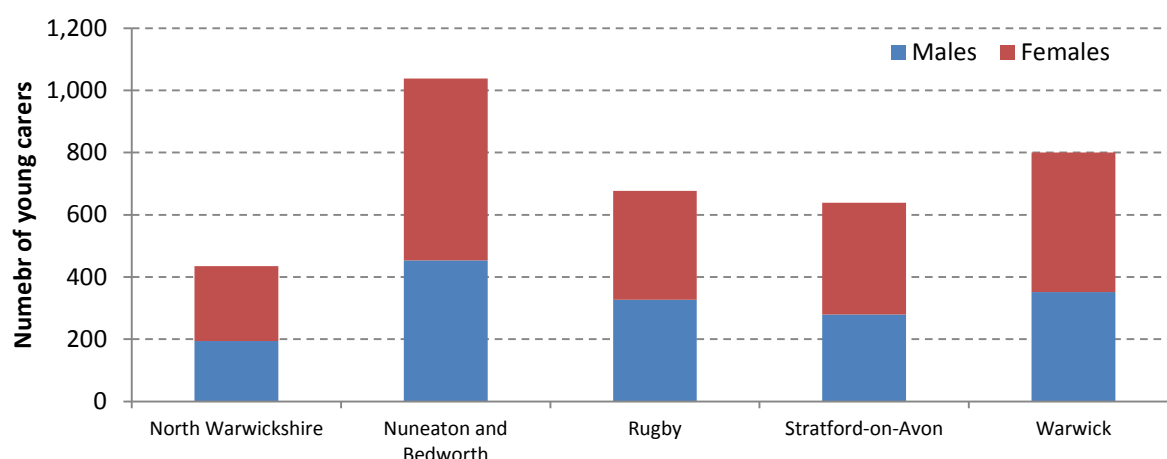
<https://www.gov.uk/government/publications/recognised-valued-and-supported-next-steps-for-the-carers-strategy>

Young Carers Project also referred a further 330 young adult carers aged 18 to 23 years to adult carer services in Warwickshire.

2011 Census

Of the 3,686 children and young people aged 0 to 24 years recorded by the Census 2011 as providing unpaid care in Warwickshire, just under half (45%) were males with the remaining 55% females. Nuneaton & Bedworth Borough has the highest number of young carers (1,038) and North Warwickshire the fewest (435).

Figure 12: Young carers (0-24 year olds) providing unpaid care by District/Borough and sex



Source: 2011 Census, Office for National Statistics <http://www.ons.gov.uk/ons/guide-method/census/index.html>

Age breakdowns within the 0-15 year and 16-24 age category providing unpaid care are not available at local level. However, if the national age specific rates for providing unpaid care are applied in Warwickshire the following estimates of levels of unpaid care among young carers aged 5-17 years might be expected (no carers under the age of 5 were identified nationally).

Figure 13: Estimated number of unpaid carers by age in Warwickshire

Age Group	Number of unpaid carers
Total 0-15 years	1,124
Total 16-24 years	2,562
Estimated 5-17 years	1,482

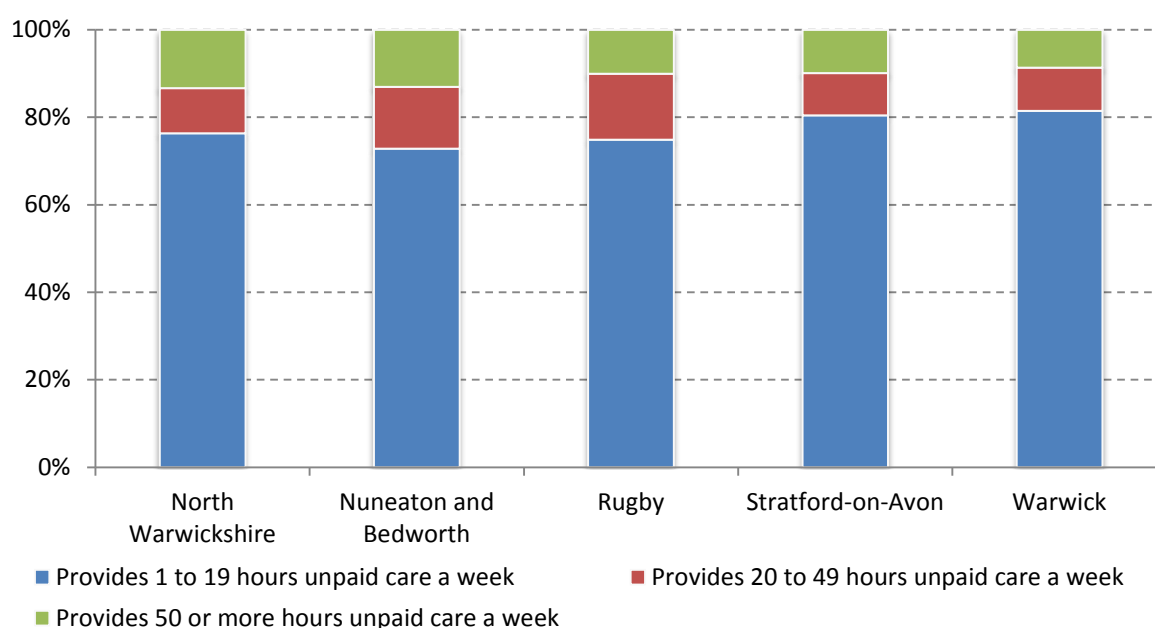
2011 Census data shows that 82% of children aged 0-15 years and 75% of young people aged 16-24 years who provide unpaid care in Warwickshire, provide between 1 to 19 hours of care per week. 398 children and young people (11%) were recorded as providing 50 or more hours of care per week, of whom 108 were aged under 16 years. North Warwickshire, despite having the fewest young carers in the county, has the highest proportion of young carers providing 50 or more hours of unpaid care per week. This is a significant commitment to make at a time when these young carers might otherwise be doing their homework, studying for exams, moving into employment, further education and training, achieving greater independence, developing their own relationships and starting their own families.

Figure 14: Provision of unpaid care in Warwickshire by young carers (aged 0 – 24 years)

Carers	North Warwickshire	Nuneaton & Bedworth	Rugby	Stratford-on-Avon	Warwick
Provides 1-19 hours unpaid care a week	332	756	507	514	652
Provides 20-49 hours unpaid care a week	45	147	102	62	79
Provides 50+ hours unpaid care a week	58	135	68	63	69
Provides unpaid care: Total	435	1,038	677	639	800

Source: 2011 Census, Office for National Statistics <http://www.ons.gov.uk/ons/guide-method/census/index.html>

Figure 15: Young carers (0-24 year olds) providing unpaid care and hours of unpaid care



Source: 2011 Census, Office for National Statistics <http://www.ons.gov.uk/ons/guide-method/census/index.html>

The difference between the health status of those providing unpaid care and those who do not is most pronounced among those aged 0-24 years. Nationally, young carers are twice as likely to report that their health is 'not good' compared with their peers who provide no care. This difference increases with young carers who care for 50 hours or more per week; they are five times more likely to report their health as 'not good' compared to those of the same age providing no care. This implies that high levels of unpaid care have a greater adverse effect on the health of young people.

In Warwickshire, 4.8% of young carers and young adult carers who provide more than 50 hours care a week reported that their health is 'bad or very bad' compared with only 0.6% of their peers who provide no care. The effect of caring on the health status of those who provide less than 50 hours of unpaid care per week is less pronounced, but the proportion of these young and young adult carers reporting their health is 'bad or very bad' is still higher, at 0.9%, than their peers who provide no care.

The Warwickshire Young Carers' Project is commissioned by Warwickshire County Council to provide free and confidential support to young carers and young adult carers aged 8 years up to 25 years.

The project provides young carers with an opportunity to relax and have a break from their caring roles, to make new friends, support their educational needs and access help from other agencies and service providers, as well as a range of other emotional support and practical advice. The project also works with the young carers' family, conducting home visits and providing advocacy on available services that the whole family may benefit from.

Young carers can contact the service directly or can be referred by their parents or someone who knows them, such as a school teacher, social worker or health professional. The project employs a designated project worker for each of the Warwickshire Districts/Boroughs.

All young carers under the age of 18 have a right to an assessment regardless of who they care for, what type of care they provide or how often they provide it, in accordance with the Children and Families Act 2014. When this assessment is undertaken it is imperative that the child's emotional needs are taken into consideration as well as their care-giving responsibilities, especially if the physical or mental condition of the person being cared for results in a lack of, or neglectful, parenting. From 1st October 2015, the statutory responsibility to carry out formal young carers assessments was passed from Warwickshire County Council to Warwickshire Young Carers Project. Although no new assessments have been formerly completed under the new legislation yet, for each young carer that is newly identified (new referrals), Warwickshire Young Carers Project meets with the young carer and completes an assessment of their caring situation. This examines their responsibilities as well as how they feel about their situation and looks to identify any possible additional needs. The number of young carers identified by area and financial year are as follows:

Figure 16: Newly identified young carers by Warwickshire area by financial year

Area	2013/14	2014/15
North (Nuneaton and Bedworth & North Warwickshire Boroughs)	78	73
Rugby	38	42
South (Stratford-on-Avon & Warwick Districts)	66	78
Out of County	1	8
Total	183	201

The Warwickshire Young Carers' Project recognises that young carers can often underachieve in the education system and the organisation therefore works closely with a number of schools and educational professionals to help raise awareness of the needs of young carers and to support individual needs to help reduce the impact of caring responsibilities on their education.

Project staff support schools to help raise awareness of the needs of young carers through information sessions and assemblies as well as staff meetings and CAF meetings. The project runs the Warwickshire Young Carers Schools Awards, which aims to encourage and support schools to work towards provision of a high standard of support for young carers attending their school. The award programme has been developed in line with the objectives detailed in the Warwickshire Joint Carers' Strategy 2012-2015. There are three levels for this award; Bronze, Silver and Gold, with standards that must be met in order for a school to achieve that level. So far, 11 out of 36 secondary schools in Warwickshire have achieved these standards; 7 at Bronze level, 3 at Silver level and 1 at

Gold level. By completing this award it is hoped that schools will be better equipped to support students with caring responsibilities to reach their potential.

Figure 17: Schools in Warwickshire which have completed the Young Carers Schools Award

Schools that have reached **GOLD** level:

Kineton High School – Stratford-on-Avon District Council

Schools that have reached **SILVER** level:

Bilton Junior School – Rugby Borough Council

Camp Hill Primary School - Nuneaton & Bedworth Borough Council

George Eliot School – Nuneaton & Bedworth Borough Council

Myton School – Warwick District Council

Nicholas Chamberlain Technology College – Nuneaton & Bedworth Borough Council

Schools that have reached **BRONZE** level:

Ash Green School – Nuneaton & Bedworth Borough Council

Bilton School – Rugby Borough Council

Etone Community School and Technology College – Nuneaton & Bedworth Borough Council

Hartshill School – Nuneaton & Bedworth Borough Council

Michael Drayton Junior School - Nuneaton & Bedworth Borough Council

Milverton Primary School - Warwick District Council

North Leamington Community School and Arts College – Warwick District Council

Queen Elizabeth School and Sports College – North Warwickshire Borough Council

Shipston High School - Stratford-on-Avon District Council

St Michael's C of E Primary School - Nuneaton & Bedworth Borough Council

Welford on Avon Primary School - Stratford-on-Avon District Council

WHO IS CARING FOR WHO?

The NHS Survey of Carers in Households in 2009/10 was commissioned by the Department of Health as part of the Governments' Carers' Strategy programme. Carers were identified for the survey via a short questionnaire at addresses which were randomly selected across the country. Carers were defined as those people who identified themselves as having extra responsibilities of looking after someone who has a long-term physical or mental ill health or disability, or problem related to old age. People providing care in a professional capacity were excluded. This remains the most comprehensive survey of carers in England, unlike the HSCIC Survey of Adult Carers in England which focusses on carers already known to the local authority.

Around half of all those surveyed cared for someone aged 75 years and over, with children aged 16 and under representing just 8% of the total. Applying this to Warwickshire's carers population (according to the Census 2011) suggests that almost 30,000 people in Warwickshire care for someone aged 75+ and over 4,700 people care for someone under 16 years of age.

Figure 18: Estimate of the number of carers in Warwickshire according to Census 2011, by the age of the person they are caring for

	Age of cared for person							Total
	<16 years	16 - 34 years	35 - 44 years	45 - 54 years	55 - 64 years	65 - 74 years	75+ years	
Warwickshire	4,739	4,147	2,962	4,147	6,516	7,701	29,620	59,832
North Warwickshire	602	526	376	526	827	977	3,760	7,594
Nuneaton & Bedworth	1,139	996	712	996	1,566	1,850	7,116	14,374
Rugby	831	727	520	727	1,143	1,351	5,196	10,495
Stratford-on-Avon	1,092	956	683	956	1,502	1,775	6,826	13,788
Warwick	1,076	941	672	941	1,479	1,748	6,724	13,581
Warwickshire Clinical Commissioning Groups:								
NHS Coventry & Rugby CCG	3,399	2,974	2,125	2,974	4,674	5,524	21,246	42,917
NHS South Warwickshire CCG	2,168	1,897	1,355	1,897	2,981	3,523	13,549	27,369
NHS Warwickshire North CCG	1,740	1,523	1,088	1,523	2,393	2,828	10,876	21,969

Source: Estimated from NHS Survey of Carers in Households

The respondents of Warwickshire's 2014/15 Carer's Survey showed a similar age profile to that of the NHS survey in terms of the age of the person cared for, although Warwickshire's survey was only sent to adults caring for someone over the age of 18 years. Warwickshire's survey had a slightly higher proportion of carers caring for someone over 75, suggestive of Warwickshire's older population profile, compared with the national population.

Figure 19: Comparison of age of the person carers are caring for

Age of Cared for Person	NHS Survey of Carers in Households (2009/10)	HSCIC Survey of Adult Carers in Warwickshire (2014/15)
<16 years	8%	~
16 to 34 years	7%	10%*
35 to 44 years	5%	4%
45 to 54 years	7%	7%
55-64 years	11%	5%
65 to 74 years	13%	15%
75+ years	50%	56%
Unknown	0%	4%

Source: NHS Survey of Carers in Households and Warwickshire survey of adult carers *aged 18-34 years

One third of all people surveyed cared for a parent, followed by a spouse/partner (26%), then child (13%), with other relatives accounting for 18% and friends or neighbours accounting for 9%. Applying this to Warwickshire's carers population (according to the Census 2011) suggests that nearly 20,000 carers in Warwickshire are caring for their parent, and just under 8,000 carers are caring for their child. Unfortunately, very little information is available on parents who are combining looking after young children with caring for older or disabled loved ones, known as 'sandwich caring' or 'dual caring'. Most surveys ask carers who care for more than one person to focus their answers on the person they provide most care for. Research by Employers for Carers and Carers UK⁴⁷ found that, without support, the pressure of combined caring responsibilities can take a serious toll on families' health, finances, careers and relationships. It is therefore important that sandwich carers are identified within Warwickshire and offered an assessment in order to receive appropriate support which they are likely to need.

Figure 20: Relationship of Cared for Person to Carer

Applied to '...' Carers Population	Relationship of cared for person to carer							
	Parent	Spouse/partner	Child	Friend or Neighbour	Parent in Law	Other relative	Grand-parent	Other relative
Warwickshire	19,549	15,402	7,701	5,332	4,147	4,147	2,370	592
North Warwickshire	2,481	1,955	977	677	526	526	301	75
Nuneaton & Bedworth	4,697	3,700	1,850	1,281	996	996	569	142
Rugby	3,429	2,702	1,351	935	727	727	416	104
Stratford-on-Avon	4,505	3,549	1,775	1,229	956	956	546	137
Warwick	4,438	3,496	1,748	1,210	941	941	538	134
Warwickshire Clinical Commissioning Groups:								
NHS Coventry & Rugby CCG	14,022	11,048	5,524	3,824	2,974	2,974	1,700	425
NHS South Warwickshire CCG	8,942	7,045	3,523	2,439	1,897	1,897	1,084	271
NHS Warwickshire North CCG	7,178	5,655	2,828	1,958	1,523	1,523	870	218

Source: Estimated from NHS Survey of Carers in Households

⁴⁷ Employers for Caring & Carers UK (2012) Sandwich Caring: combining childcare with caring for older or disabled relatives

The most common condition of the cared for person according to the survey was physical disability (58%), followed by a long standing illness (37%). 13% of respondents were caring for someone with a mental health problem, 11% with a learning disability & 10% with dementia. Respondents were able to tick more than one box, allowing them to record multiple conditions. Applying these responses to Warwickshire's carers population (according to the Census 2011) suggest that over 34,000 carers in Warwickshire are caring for someone with a physical disability.

Figure 21: Condition of carer for person

Applied to '...' Carers Population	Condition of Cared for Person									
	Physical disability	Long-standing illness	Sight/hearing loss	Problems connected to ageing	Mental health	Learning disability/difficulty	Dementia	Terminal illness	Alcohol/substance misuse	Other
Warwickshire	34,359	21,919	11,848	10,071	7,701	6,516	5,924	2,370	592	592
North Warwickshire	4,361	2,782	1,504	1,278	977	827	752	301	75	75
Nuneaton & Bedworth	8,255	5,266	2,846	2,419	1,850	1,566	1,423	569	142	142
Rugby	6,027	3,845	2,078	1,766	1,351	1,143	1,039	416	104	104
Stratford-on-Avon	7,918	5,051	2,730	2,321	1,775	1,502	1,365	546	137	137
Warwick	7,799	4,975	2,689	2,286	1,748	1,479	1,345	538	134	134
Warwickshire Clinical Commissioning Groups:										
NHS Coventry & Rugby CCG	24,645	15,722	8,498	7,224	5,524	4,674	4,249	1,700	425	425
NHS South Warwickshire CCG	15,717	10,026	5,420	4,607	3,523	2,981	2,710	1,084	271	271
NHS Warwickshire North CCG	12,616	8,048	4,350	3,698	2,828	2,393	2,175	870	218	218

Source: Estimated from NHS Survey of Carers in Households

Caring for someone with a Physical Disability

An estimated 34,000 people in Warwickshire are caring for someone with a physical disability. Getting around can be one of the most important issues facing those with a physical disability. Many people need help with day to day tasks, including getting out of bed and washing and dressing. The provision of suitable and accessible mobility support can in many instances make the role of the carer more manageable, but there is still a physical impact of caring on carers, particularly in terms of manual handling. Carers looking after someone with a physical disability are at potential risk of personal injury, especially if they have not been shown the safe and correct way to lift or move someone.

Caring for someone with Dementia

Applying NHS Survey of Carers in Households in 2009/10 data to Warwickshire's carer population gives an estimate of just under 6,000 carers in Warwickshire caring for someone with dementia. It is recognised that carers of people with dementia face a unique set of challenges, primarily due to the degenerative nature of the condition which has a wide reaching effect on the lives of those with the

condition and those who care for them. The way in which the person with dementia's illness affects them will vary, as will carers' capacity to cope, both physical and emotionally.

Caring for someone with a Mental Health disorder

It is estimated that there are over 7,700 carers in Warwickshire who are caring for someone with a mental health disorder. Carers caring for someone with a mental health disorder face a unique set of issues. Twinned with this, mental health carers are less likely to discuss their caring role with friends, family or professionals and therefore may end up isolated.

Mental health carers often experience problems in obtaining sufficient information about the service users' condition to care effectively. The nature of mental illness often means that carers are faced with unpredictable, occasionally violent behaviour and personality changes in the people they care for. The 'highs' and 'lows' of certain conditions often mean that the physical capabilities of the person may be 'normal' while their mental capabilities and emotional state may vary greatly. There is a lack of specialised respite for people with mental health disorders, with conventional services often inappropriate or unable to offer trained mental health support staff. As a result, mental health carers tend to have less time off caring, which impacts their own physical and mental health and their capacity to care. A survey carried out by The Princess Royal Trust for Carers found that mental health carers spend an average of 60 hours per week on caring tasks⁴⁸. In the same survey, carers of people with mental health disorders were twice as likely to report high levels of neurotic symptoms as those caring for people with physical problems or old age, 28% compared with 14%.

Caring for someone with a Terminal Illness or at the end of life

It is estimated that just under 2,500 people in Warwickshire are caring for someone with a terminal illness. There is often extensive medical care available to people diagnosed with a terminal illness such as cancer, however this medical care can often overlook the emotional support required for patients receiving a terminal diagnosis or their loved ones/carers. People who receive a terminal diagnosis may experience and show emotions that their family and loved ones would describe as out of character. They may become quiet, withdrawn, demanding, angry, frustrated or tearful. These emotions may show only occasionally, come and go frequently and change rapidly. For a carer, trying to alleviate these feelings can be a difficult and daunting task, which is why an increasing number of organisations are being set up to help patients & their carers cope following diagnosis.

Carers who are faced with the deteriorating health of the person they care for on a daily basis can feel frustrated. While keeping hopeful helped some carers cope, the majority of carers felt a need to be honest and accepting about the approaching death of their friend or relative. In terms of end of life care, time is of the essence, with carers needing timely training and support to provide care. For terminally ill people who wish to die at home, it is essential that care planning helps carers to foresee, understand and make decisions about what is likely to happen in order to help them feel as though they remain in control.

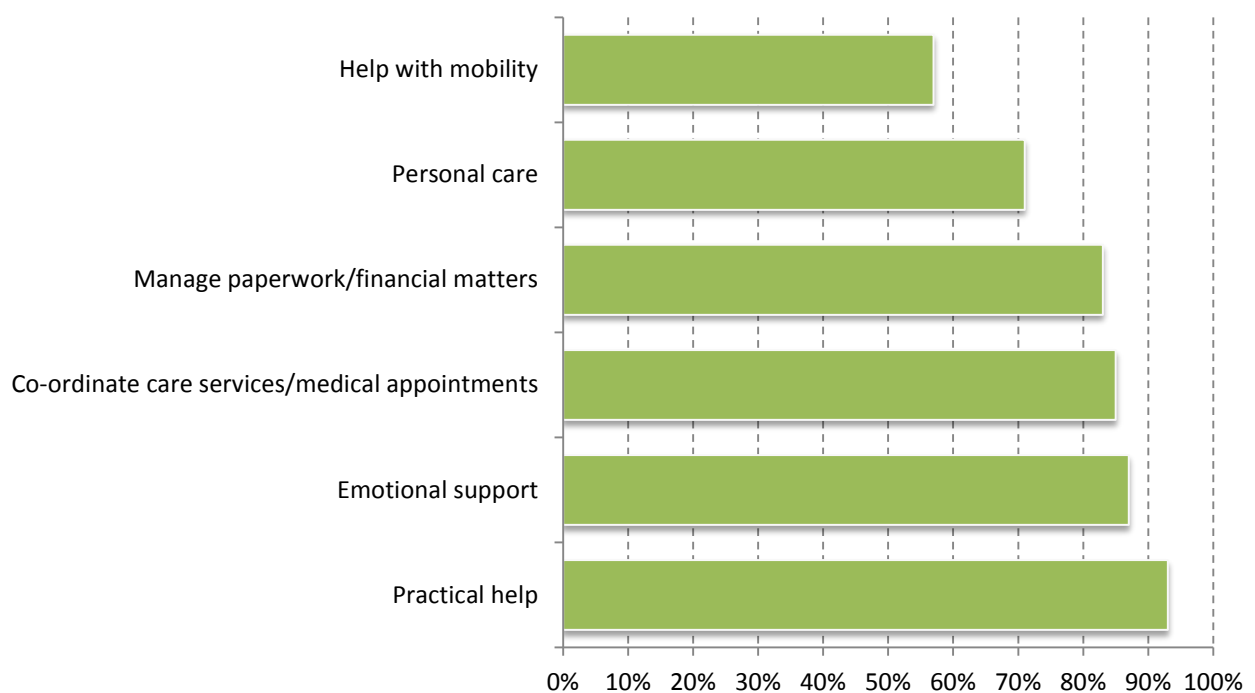
⁴⁸ Survey carried out in September 2007 by The Princess Royal Trust for Carers, undertaken in City and Hackney, Hammersmith and Fulham, Medway, Reading and Central Berkshire, and Suffolk Carers Centres.

Type of Care Provided

Carers provide a wide range of care and support for the people they care for depending on the condition of the cared for person, their own personal circumstances, where the care takes place (in their own household and elsewhere) and the degree of care services accessed. A carer might provide a few hours of care a week; shopping, collecting medication and taking someone to medical appointments, or they may care around the clock. According to Carers UK's State of Caring 2014:

- 93% said they provide practical help such as preparing meals, doing laundry or shopping
- 87% provide emotional support, motivation or keeping an eye on someone either in person or by phone
- 85% said they arranged or co-ordinated care services or medical appointments
- 83% said they manage paperwork or financial matters for the person they care for
- 71% of carers provide personal care like help with washing, dressing, eating or using the toilet
- 57% carers were helping the person they care for with their mobility – getting in and out of bed, moving around or getting out of the house

Figure 22: Type of care provided by carers



Source: Carers UK, State of Caring, 2014

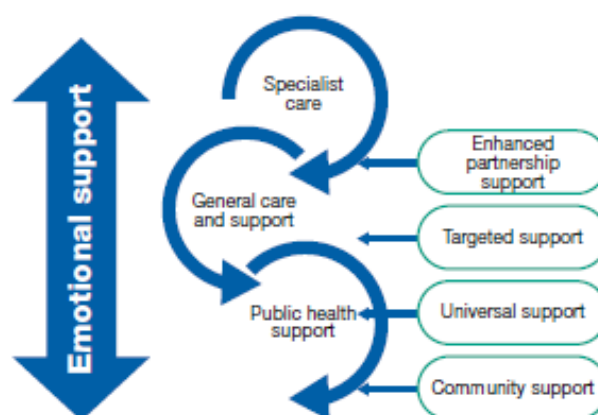
It is clear from these statistics that many carers help with all aspects of the cared for person's life and that many people who are likely to be frail or suffering from ill health themselves are performing physically demanding tasks.

IMPACT OF CARING ON HEALTH & WELLBEING

Caring can be very rewarding and fulfilling but it can also be emotionally and physically draining without recognition and with little practical and/or emotional support. Research shows that carers can often experience diminished quality of life and poorer health outcomes in terms of their physical and mental health as well as their emotional wellbeing⁴⁹.

Carers are at greater risk of developing long-term or chronic conditions such as heart disease and high blood pressure, sometimes attributed to the anxiety associated with caring, as well as being prone to musculoskeletal injuries resulting from inappropriate lifting and moving. Stress and anxiety can be related to concerns about the person who is being cared for, frustration about a lack of information and 'battling' with systems and organisations to obtain help and services.

Much of this ill health is avoidable or can be minimised. Supporting carers to remain physically and mentally well is therefore a key part of the health and social care agenda. There is currently no single profession or organisation that can ensure the best outcomes for carers in term of their health and wellbeing, therefore agencies need to work effectively together to identify, assess and act on issues facing carers and improve support.



Source: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/329867/Carers_Pathway.pdf

Data from the 2011 Census indicates that three-quarters of unpaid carers in Warwickshire self-reported their health to be 'Good' or 'Very good' (75%), slightly higher than the England average of 73%. Less than 6% of unpaid carers in Warwickshire rated their health as 'Bad' or 'Very Bad', slightly less than the England average (6.6%). However, there are variations within the county at District/Borough level and at CCG level.

Nuneaton & Bedworth Borough had the lowest proportion of unpaid carers reporting their health as 'Good' or 'Very Good' (71%) compared with Warwick District where 78% of unpaid carers reported their health as 'Good' or 'Very Good'. Nuneaton & Bedworth also had the highest proportion of unpaid carers describing their health as 'Bad' or 'Very Bad' (7%) compared with Stratford-on-Avon District which had the lowest proportion of unpaid carers describing their health as 'Bad' or 'Very

⁴⁹ <http://circle.leeds.ac.uk/files/2012/08/new-approaches-report-jan-12.pdf>

Bad' (4.9%). NHS South Warwickshire CCG has the highest proportion of unpaid carers reporting their health as 'Good' or 'Very Good' (76.9%) and the lowest proportion of unpaid carers describing their health as 'Bad' or 'Very Bad' (5.0%) compared with NHS Coventry and Warwickshire CCG (72.2% and 6.9% respectively) and NHS Warwickshire North CCG (71.1% and 6.8% respectively).

Figure 23: Self-reported general health of unpaid carers in Warwickshire, Census 2011

	Proportion of unpaid carers with very good or good health	Proportion of unpaid carers with fair health	Proportion of unpaid carers with bad or very bad health
England	72.7	20.7	6.6
Warwickshire	74.5	19.8	5.7
North Warwickshire	72.2	21.4	6.4
Nuneaton & Bedworth	70.6	22.4	7.0
Rugby	75.2	19.4	5.4
Stratford-on-Avon	76.4	18.7	4.9
Warwick	77.4	17.6	5.0
Warwickshire Clinical Commissioning Groups:			
NHS Warwickshire North CCG	71.1	22.1	6.8
NHS Coventry & Rugby CCG	72.2	20.9	6.9
NHS South Warwickshire CCG	76.9	18.2	5.0

* **red** = worst area in the county, **green** = best area in the county Source: 2011 Census, Office for National Statistics <http://www.ons.gov.uk/ons/guide-method/census/index.html>

Unsurprisingly the proportion of unpaid carers who self-reported their health to be 'Good' or 'Very good' decreases with age, with 92.4% of unpaid carers aged 0-24 years reporting their health to be 'Good' or 'Very good' compared with only 54.5% of unpaid carers aged 65 and over.

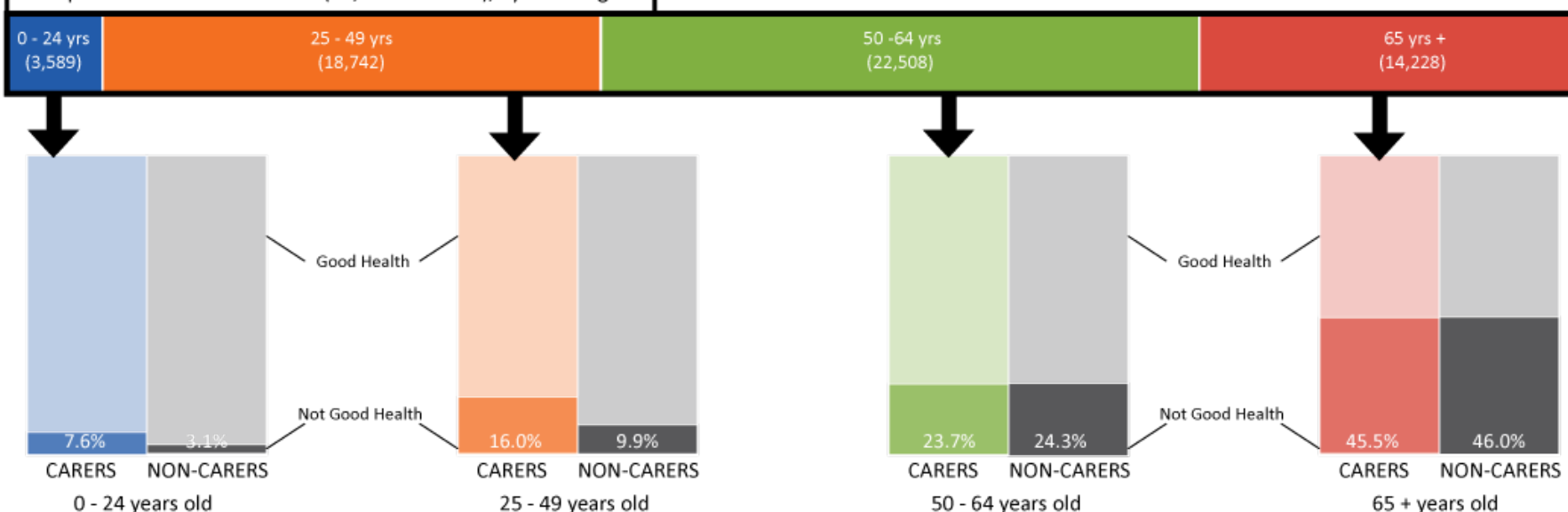
However, it does not appear that the burden of providing care later in life is, in itself, necessarily detrimental to health, as the proportion of carers aged 65+ who say their health is 'bad' or 'very bad' is actually lower than the rest of the population in this age band (10.7% compared to 13.5%). The impact of caring on the health and wellbeing of younger carers is more of a concern, with a higher proportion of children and young people stating that their health is 'bad' or 'very bad' if they are an unpaid carer than the rest of Warwickshire's 0-24 year population. This is consistent with the pattern across England as a whole.

There is a clear relationship between poor health and caring that increases with the duration and intensity of the caring role. Those caring for 50 hours or more per week are at far greater risk of poor health than those caring for fewer hours. Just over 12% of carers in Warwickshire who provide 50 or more hours of care a week state that their health is either 'bad' or 'very bad' compared to 4.6% among those who provide no care and 4.0% of other carers. This additional health risk attached to those who provide 50 hours+ care when compared with both non-carers and those who care for less than 50 hours is evident among all age groups in both Warwickshire and England.

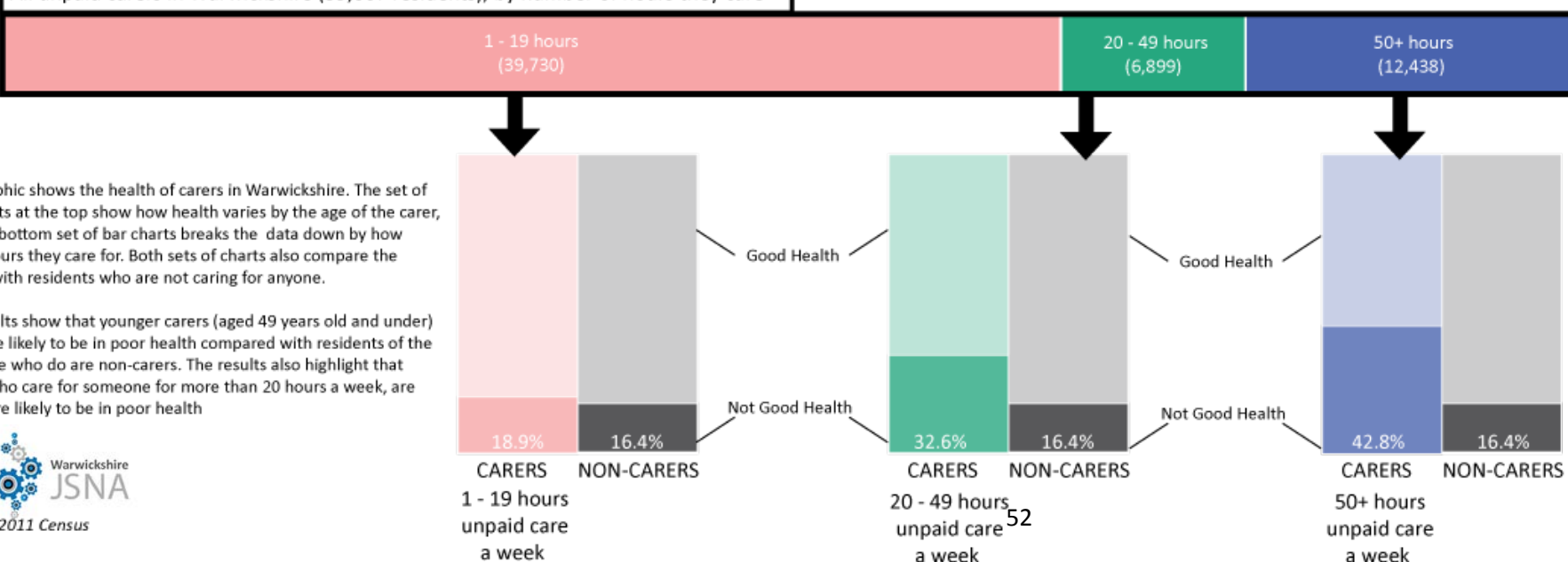
Who's caring for the carers ?

Note: The overall numbers of carers differs in this visualisation as this shows the number of carers by age and number of hours cross-tabulated with their health condition. Not all of those answering one question will have answered the other, which explains the small variation in overall reported numbers (59,240, compared to 59,067) in this visualisation. However, the messages from the visualisation remain the same.

All unpaid carers in Warwickshire (59,067 residents), by carers age



All unpaid carers in Warwickshire (59,067 residents), by number of hours they care



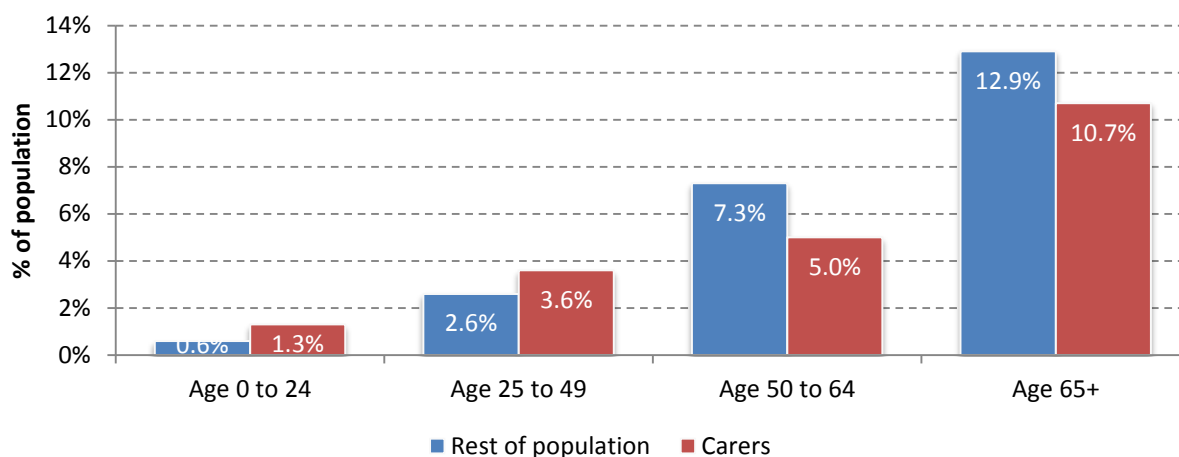
This graphic shows the health of carers in Warwickshire. The set of bar charts at the top show how health varies by the age of the carer, and the bottom set of bar charts breaks the data down by how many hours they care for. Both sets of charts also compare the results with residents who are not caring for anyone.

The results show that younger carers (aged 49 years old and under) are more likely to be in poor health compared with residents of the same age who do not care for anyone. The results also highlight that carers who care for someone for more than 20 hours a week, are also more likely to be in poor health.



Source: 2011 Census

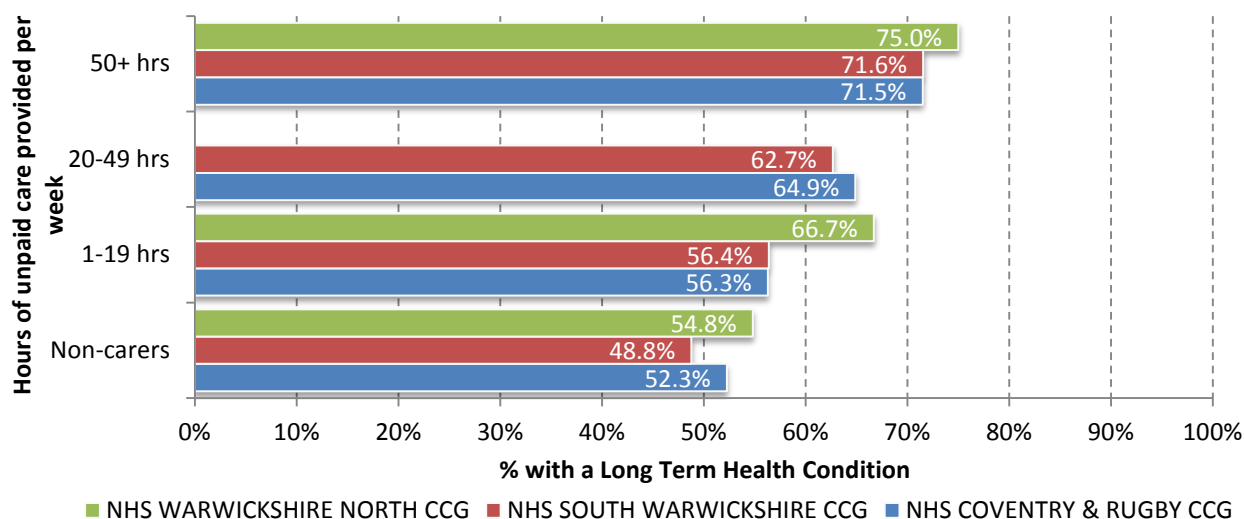
Figure 24: People with self-reported general health of 'Bad' or 'Very Bad' in Warwickshire by age



Source: 2011 Census, Office for National Statistics <http://www.ons.gov.uk/ons/guide-method/census/index.html>

Using data from the General Practice Patient Survey (GPPS), Figure X below shows that the proportion of carers who report a long standing health condition increases as hours of support increases across all CCGs. On average, 52% of non-carers report that they had a long standing health condition whereas 66% of carers reported a long standing health condition. This increased to 73% of carers providing 50+ hours of care a week.

Figure 25: Carers who report a long standing health condition by hours of care provided, by CCG



Source: GPPS Survey Results, July 2015

Caring for someone else can often be demanding and overwhelming at times, leaving carers feeling stressed and isolated. Over time, this can lead to mental health problems. Carers who already live with a mental health problem can find that being a carer can affect their ability to stay well.

Reducing Hospital Admissions and Delayed Transfers of Care

Hospital admissions can be an indication of a breakdown in the caring relationship, because the carer is no longer able to care, often as a result of the strain of caring causing physical or mental ill-health. There is evidence to suggest that a significant number of admissions are due to problems associated with the carer rather than the person admitted. One study found that problems associated with the carer contributed to readmission in 62% of cases⁵⁰.

A whole systems study tracking a sample of people over 75 years old who had entered the health and social care system, found that 20% of those needing care were admitted to hospital because of the breakdown of a single carer on whom the person was mainly dependent. A health professional advised that respiratory distress is often used to admit a patient, when the real reason is because the carer may be in hospital and it is thus unsafe to leave the other person at home. This substantiates the belief that social care services can impact upon demand for health services.

Measuring delayed transfers of care is a good indication of how well health and social care services are interfacing. This is captured as an outcome measure in the Adult Social Care Outcomes Framework. The 2014/15 figures show that Warwickshire has 4.7 delayed transfers of care (for those aged 18 and over) that are attributable to adult social care, per 100,000 population. Delayed transfers are not only expensive but can also be bad for patients, threatening their independence and delaying or impeding rehabilitation.

Carers who do not feel prepared or sufficiently supported are one cause of delays in transfer of care. In 2010, The Princess Royal Trust for Carers published 'Out of Hospital'⁵¹ to help hospitals improve their discharge processes by involving carers. This guide refers to lessons learnt from pilots in The Great Western Hospital, Swindon and Barnet and Chase Farm Hospital. Key recommendations from this guide were:

- Include identification, recording and referral of carers in hospital discharge policy
- Collect clinical audit data on the numbers of carers identified and the impact of providing carer support on patients and hospital, e.g. improved patient experience of discharge, increased hospital efficiency
- CCGs should agree carers' standards as part of the contract with hospital trusts
- CCGs should actively participate in local strategic and developmental work on carers issues, e.g. local carers' strategy

The evidence that increasing support for carers can reduce hospital and residential care admissions is important for CCGs and councils in relation to measuring performance against the NHS Outcomes Framework and for quantifying the savings to acute services through investment in social care and support for carers.

⁵⁰ Williams, E, Fitton, F (1991), 'Survey of carers of elderly patients discharged from hospital'. British Journal of General Practice, 41, 105-108.

⁵¹ Newbrunner, L (2010), 'The Princess Royal Trust for Carers Out of Hospital Project – Learning from the Pilot Projects'. London: Acton Shapiro Ltd. Available at: <http://professionals.carers.org/health/hospitals,806,PP.html>.

The Better Care Fund⁵² was announced by the Government in June 2013. It creates a local, single pooled budget to incentivise the NHS and local government to work more closely together around people, placing their wellbeing as the focus of health and care services, and shifting resources into social care and community services for the benefit of the people, communities and health and care systems. This is known locally in Warwickshire as 'Warwickshire Cares – Better Together'. Nationally the pooled fund is worth £3.8bn which equates to £36m in Warwickshire. This will be used to roll out a number of projects to improve access to services and people's experiences of using them. Better Together is a five year programme of work, grouped under five main themes or priorities⁵³:

- **Community resilience:** helping people to stay independent for longer by providing services close to home and enabling communities to support themselves.
- **Integrated care:** providing joint health and social care services, including social care and other professionals working from GP practices, and moving towards joint assessments across health, social care, public health and housing.
- **Care at home:** a shift in resources from hospital care to care at home, focussing on reducing non-essential hospital admissions and supporting people and carers to receive and give care in the home environment.
- **Accommodation with care:** focuses on services and support available at residential and care homes, to look to introduce new quality standards, develop ways to help people rehabilitate more quickly and create services to meet the needs of older and frailer populations.
- **Improvements to long term care:** considering how to provide early support to people with long term conditions so they can be as healthy as possible and manage their own care for longer.

⁵² Department of Health (2014), 'Better Care Fun Policy Framework'. London. Available at:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/381848/BCF.pdf

⁵³ <http://news.warwickshire.gov.uk/blog/2015/04/21/health-and-social-care-services-are-better-together/>

IMPACT OF CARING ON THE ECONOMY & EMPLOYMENT

The value of unpaid care in Warwickshire is estimated to be between £575m and £1.24bn per year⁵⁴. As such, it is important to recognise the potential impact that providing many hours of care each week may have on carers' own quality of life, including employment opportunities as well as the saving this represents to the economy i.e. the right support for carers is an effective way of preventing or delaying more costly interventions.

As previously identified, there is a considerable gender gap⁵⁵ in unpaid care provision. Women are much more likely than men to supply unpaid care and according to national research, more likely to experience strain in providing such care in middle-age as they balance the multiple roles of work, care and social and leisure activities. The burden and extent of unpaid care delivered by people of working age is important, as it can constrain their participation in the labour market; for example, by working part-time rather than full-time, or becoming economically inactive themselves to look after family members who are sick or disabled. The 2011 Census provides the opportunity to examine this inequality in more detail and better understand the relationship between the extent unpaid care provision has on economic positions.

Economic activity relates to whether or not a person was working or looking for work in the week before the census. It provides a measure of whether or not a person was an active participant in the labour market. Those who are active participants are referred to as 'economically active' and those who are not as 'economically inactive'⁵⁶.

There are 34,705 economically active carers aged 16-74 years in Warwickshire, equating to an economic activity rate of 60% or more simply, three in five carers were active in the labour market at the time of the 2011 Census. This is less than the rate among non-carers in the county (66%), but higher than that for carers across England (58%). Perhaps unsurprisingly, the economic activity rate falls as the number of hours of care provided increases, although it's worth highlighting that the age of those caring for 50 or more hours a week is made up of a large proportion of residents who are likely to be retired (and therefore classified as inactive). Nevertheless, the trend remains valid.

⁵⁴ Using Warwickshire's average homecare fee rate as a proxy indicator of the value of unpaid care.

⁵⁵ 'Age and gender of informal carers : a population-based study in the UK, 2007' <http://dro.dur.ac.uk/5202/>

⁵⁶ To be economically active a person must be either in paid employment working full-time or part-time, be a full-time student in employment or be seeking work (unemployed) or ready to take up a job offered in the next two weeks. A person is economically inactive if he or she is retired, long-term sick or disabled, looking after the home or family, a student not in employment or for other reasons.

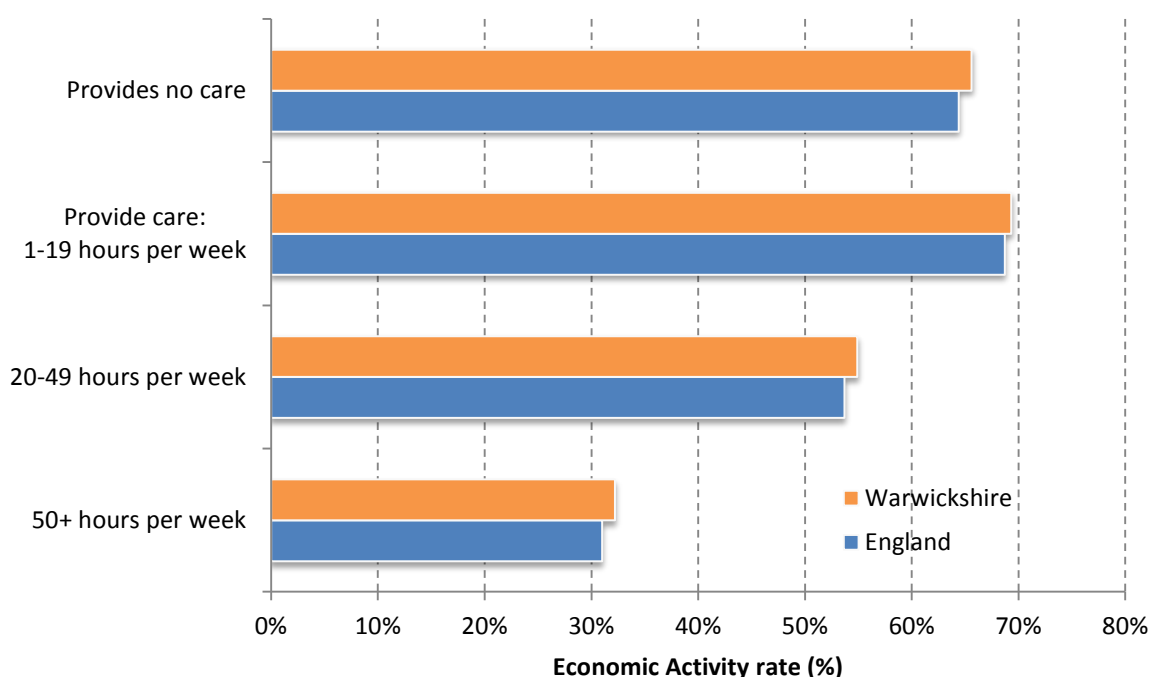
Figure 26: Economic Activity Rate by unpaid care provision

	Economic Activity rate (%)				
	Provides no care	Provides care	Provides care:		
			1-19 hours per week	20-49 hours per week	50+ hours per week
England	64.4%	57.9%	68.7%	53.7%	31.0%
Warwickshire	65.6%	59.7%	69.3%	54.9%	32.2%
North Warwickshire	66.2%	59.8%	71.6%	56.2%	30.5%
Nuneaton & Bedworth	65.6%	58.2%	70.7%	56.5%	30.9%
Rugby	67.4%	60.4%	69.4%	56.3%	32.3%
Stratford-on-Avon	64.6%	58.7%	66.4%	50.9%	33.7%
Warwick	65.1%	61.8%	69.7%	54.5%	33.9%

Source: 2011 Census, Office for National Statistics <http://www.ons.gov.uk/ons/guide-method/census/index.html>

A breakdown of Warwickshire's economically active population shows that the economic activity rate is actually higher for those caring for 1-19 hours per week than for those who provide no care (see Figure X). This mirrors the national trend and Warwickshire's economic activity rates are slightly above the national average across those who provide care and those who provide no care.

Figure 27: Economic Activity rates and unpaid care provision



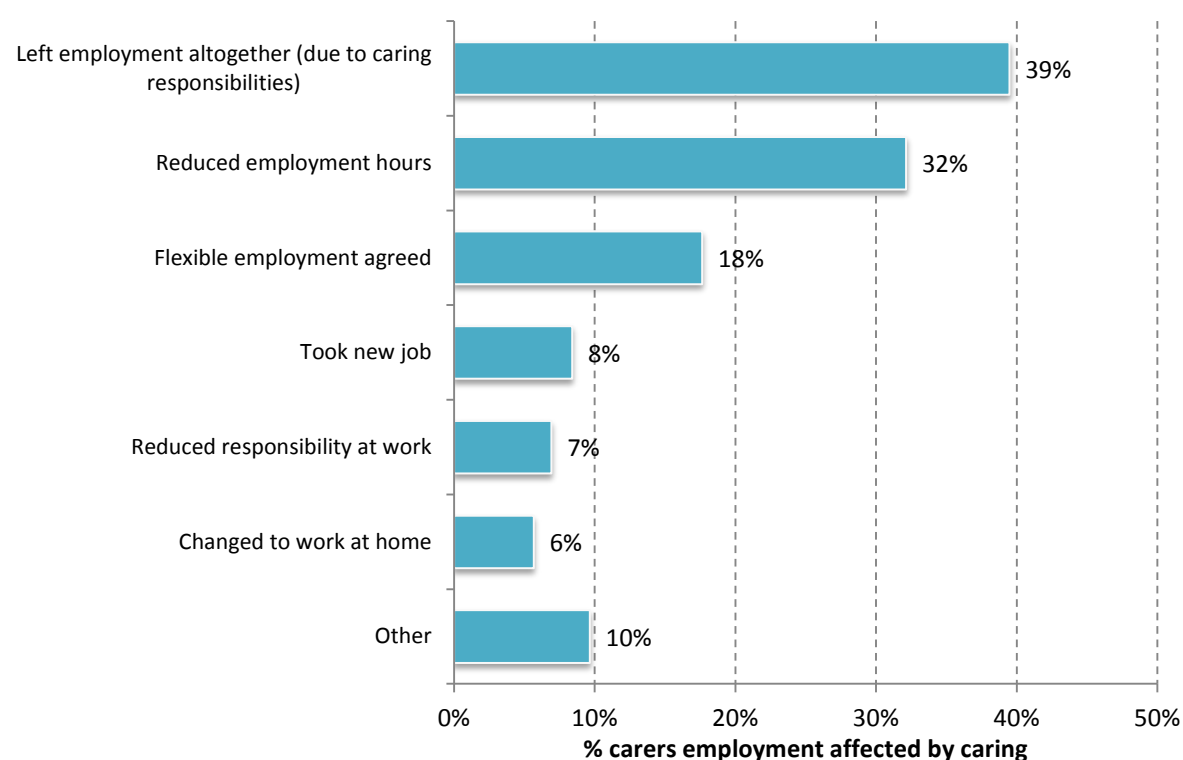
Source: 2011 Census, Office for National Statistics <http://www.ons.gov.uk/ons/guide-method/census/index.html>

In 2011 in Warwickshire, over 1,300 men and 870 women were in full-time employment while providing 50 hours or more unpaid care per week. Economically active women (in full-time and part-time employment) provided a greater share of the unpaid care burden than men; in Warwickshire

8.4% of women were economically active and providing unpaid care compared to 7.1% of men in 2011. Unpaid care is more common among part-time workers than full-time workers, suggesting part-time work provides a greater opportunity to balance work and care commitments, but gender inequalities are present in each with women contributing more unpaid care than men.

A uniform pattern of deteriorating general health with rising levels of unpaid care provision was present across all economic positions; men and women working full-time in Warwickshire and providing 50 hours or more unpaid care per week were more likely to report their general health as 'Not Good' compared with those providing no unpaid care. A marked health divide is also present between full-time workers providing 50 hours or more unpaid care and those providing no unpaid care, suggesting providing unpaid care to this extent is affecting the health related well-being of both men and women living under these circumstances.

Figure 28: The impact of caring upon carers' ability to take up or stay in employment for those carers whose employment prospects had been affected



Source: Survey of Carers in Households – NHS Information Centre for Health & Social Care

A range of evidence shows that caring can significantly impact on the ability of carers to take up or remain in employment. The State of Caring Report (2015)⁵⁷ identifies some of the barriers carers face when juggling their caring and work responsibilities. When there is a lack of support to help with caring at home or a lack of understanding and flexibility at work, it can lead to stress and

⁵⁷ Carers UK (2015) State of Caring [report](#)

anxiety, absence, tiredness, isolation and loneliness.⁵⁸ Of full-time or part-time employees responding to the survey, over two thirds (68%) have used their annual leave to care and 46% have worked overtime to make up hours spent caring. Half (51%) of carers responding to the survey have given up work to care and 12% have retired early to care. A fifth (21%) reduced their working hours while 13% have had to take a less qualified job or turned down promotion to fit around caring. Worryingly, six in ten (60%) working carers are worried about their ability to remain in work over the next year.

Over a quarter (26%) of respondents to the NHS Survey of Carers in Households 2009/10⁵⁹ aged 70 and under said that their caring role had affected their ability to take up or stay in employment, with this proportion rising significantly among those caring for 20 hours or more a week (40%), those who live in the same household as the cared for person (38%) and those working part-time (35%). Among those whose employment had been affected, two in five carers (39%) said that they had left employment because of their caring responsibilities and a further 32% had reduced their employment hours. The most commonly cited barrier to employment cited by respondents was the lack of available job opportunities (63%), although issues directly relating to caring responsibilities were also prominent: unable to work regularly (40%), can't work because of caring (37%).

If we applied these proportions to the Warwickshire population of carers (59,240) from the 2011 Census, this would equate to:

- **15,400** Warwickshire carers who's caring role is affecting their ability to take up or stay in employment
- Of those, it's likely that over **6,100** carers across the county may have left employment because of their caring responsibilities and **4,900** carers have reduced their working hours as a result of their caring responsibility.

While caring responsibilities undoubtedly present a challenge for carers in terms of labour market participation, research suggests that there are some positive trends relating to increasing job opportunities for carers. For instance, a survey by Employers for Carers conducted on behalf of Carers UK⁶⁰ suggests that employers are increasingly recognising caring as a key issue for workforce recruitment and retention showing that:

- The majority of employers considered that supporting carers in their workforce had advantages in both attracting and retaining staff, reducing recruitment and training costs, reducing sick leave and absenteeism, increasing productivity and improving service delivery, producing cost savings and increasing staff morale, improving staff engagement, people management and team working;

⁵⁸ Carers UK and Employers for Carers (2015) Caring and isolation in the workplace: Impact report and recommendations

⁵⁹ <http://www.hscic.gov.uk/pubs/carerssurvey0910>

⁶⁰ Carers UK (2013): Employers Business Benefits Survey

- 56% of employers said that they address carer support on a case-by-case basis and 44% through organisation wide policies, however, many of these suggested that most of the times they use a mix of these methods;
- Flexible working (94%), flexible/special leave (83%) and remote working (50%) were among the most popular ways employers used to support carers in their workforce, followed by in-house information/signposting (40%) and other workplace support/employee benefits (29%).

Similarly, work by Sheffield Hallam University's Centre for Social Exclusion⁶¹ points to the fact that more inclusive employment legislation is being supported by underlying changes in the structure of the labour market. Although written at a time of economic prosperity, the report suggests that an ageing workforce should provide job opportunities for working age carers and other excluded groups. This is particularly the case as employers become more attuned to the needs of flexible working and technology driven alternatives such as home working become more viable.

Financial Hardship

Carers UK's Caring & Family Finances Inquiry found that carers can face higher utility bills, higher transport costs, higher shopping bills, spending on care services and even the cost of home adaptations.⁶² A recent survey by Carers UK⁶³ highlights many of the financial pressures faced by carers as a result of their caring role, with 48% of carers surveyed saying they were struggling to make ends meet. In addition 45% say that financial concerns are affecting their health. In part this is likely because carers have a reduced capacity to earn compared with non-carers, however, they also incur substantial costs as a result of the illness or disability of the person they care for. A separate report details many of the extra costs faced by carers⁶⁴:

- Higher heating and electricity bills: as families are at home all day and disabled, ill and older people need to be kept warm.
- Higher basic household costs: incontinence can mean washing bed sheets several times a week or even every day.
- Specialist equipment, foods and medicines: these range from everyday costs of food and incontinence pads, to big costs for aids and adaptations.
- If families do not qualify for social care support, they may face bills of hundreds of pounds for replacement care if they want to take a few days off from caring.
- Big travel and parking charges from frequent trips to hospital and GPs.

Financial difficulties have resulted in many carers surveyed in the State of Caring cutting back on essentials:

- 41% of those struggling are cutting back on essentials like food and heating;

⁶¹ Yeandle et al (2006): Who Cares Wins the Social and Business Benefits of Supporting Working Carers

⁶² Carers UK (2014) Caring & Family Finances Inquiry: UK Report

⁶³ Carers UK (2015) State of Caring [report](#)

⁶⁴ Carers UK (2011) The Cost of Caring: How Money Worries Are Pushing Carers to Breaking Point

- 26% are borrowing from friends and family
- 38% are using their savings to get by

Fuel poverty also appears to be a significant issue, with 58% of carers surveyed saying that they spent at least 10% of their income on energy bills⁶⁵. Although the statistics are not directly comparable as they are based on households rather than individuals, figures from the Office for National Statistics (ONS) from 2013 provide some context, showing that on average one in ten (10%) households in England are considered to be fuel poor.

A report by Carers UK⁶⁶ based on a national survey conducted as part of the Carers, Employment and Services study (University of Leeds) argues that while affluence does not solve all carers' problems and difficulties, poverty undoubtedly causes some carers additional stress and worry. In addition, it notes that within the survey those carers who identified themselves as financially struggling to make ends meet represent a distinct and significant sub-group of the carers' population and are more likely to be:

- in poor health (34%);
- unqualified (21% have no formal qualifications);
- caring for 20 or more hours per week (88%, with 66% caring 50+ hours per week);
- caring for a child aged 19 or under (37%);
- caring for someone with a learning disability (42%);
- caring for someone with a mental health problem (27%);
- receiving some free services (as a carer or as services to the person cared for).

⁶⁵ Carers UK (2013) The State of Caring 2013

⁶⁶ Yeandle et al (University of Leeds 2007): Diversity in Caring: Towards Equality for Carers

IMPACT OF CARING ON SOCIAL ISOLATION & LONELINESS

Isolation and loneliness is something that many people face as a result of their caring responsibilities. Contrary to popular belief, loneliness is not all about being alone; it is subjective; a feeling, and refers to how individuals evaluate their level and quality of social contact. Loneliness can be a transient feeling which comes and goes, or only occurs at certain times, or it can be chronic, where someone feels lonely all or most of the time.

Loneliness is linked to social isolation but it is not the same thing. Social isolation is a measurable, objective state whereby the number of social contacts or interactions a person has can be counted. For some people, solitude is a way of life which temperamentally suits them and they may not feel lonely even if they have no visitors. However for most people, reduced social contact, being alone, isolation and feelings of loneliness are associated with reduced quality of life and are harmful to health. Lacking social connections is as comparable a risk factor for early death as smoking 15 cigarettes a day, and is worse than well-known risk factors such as obesity and physical inactivity⁶⁷.

Research published in January 2015 by Carers UK⁶⁸ suggested that 8 out of 10 carers have felt lonely or isolated as a result of caring and over a third feel uncomfortable talking to friends about being a carer. Carers may feel isolated or lonely because, by putting the person they look after first, they can no longer have the time to see other friends and family. The extra costs of caring and potential fall in income many carers face may mean that they can no longer afford social activities. Some aspects of caring can be difficult for carers to share with others, even when talking to someone who partially understands, out of respect and dignity for the person being cared for.

Talking about caring may be especially hard for Black and Minority Ethnic (BME) carers, who, in the Carers UK study, were more likely to say that they were not comfortable talking to their friends about caring which has made them feel lonely and socially isolated. This could be because for some carers from BME backgrounds there is a cultural barrier to discussing disability openly or a stigma around particular conditions.

Carers living in rural parts of Warwickshire face unique difficulties as a result of isolation. For those without access to a private vehicle or are no longer able to drive, public transport is often inadequate to enable them to access community resources. This is coupled with the inability for carers to be able to leave the person they care for in order for them to travel and attend a meeting or community-led centre, which would often mean leaving the house for well over a couple of hours if travelling from a rural location. Some carers report that care agencies will not go out to rural locations, or charge mileage rates that make trips out of the house unaffordable.

Carers responding to the statutory Warwickshire Carer's Survey, 58/368 (16%) respondents said that 'I have little social contact with people and feel socially isolated'. 151/368 (41%) people said 'I have some social contact with people but not enough'. This means that 57% of all respondents to the questionnaire are not satisfied with their social situation.

⁶⁷ Luanaigh CO, Lawlor BA; Loneliness and the health of older people. *Int J Geriatr Psychiatry*. 2008 Dec;23(12):1213-21. doi: 10.1002/gps.2054.

⁶⁸ <http://www.carersuk.org/for-professionals/policy/policy-library/alone-caring>

A new measure regarding social contact for carers has been included within the 2014/15 Adult Social Care Outcomes Framework (ASCOF), which will enable local authorities to see how they compare against their comparators and nationally in terms of carers receiving as much social contact as they would like. National and comparator group data is not due to be released until the end of 2015, but provisional Warwickshire data shows that only 40.8% of responders reported that they had as much social contact as they would like.

A range of support options need to be available for carers facing loneliness and social isolation, as all carers have different needs and require support in different ways. Peer support from people who understand can help many carers feel less alone. Others may not feel comfortable to open up or are unable to attend in such settings, preferring online support through social media, forums or helplines.

Crossroads Care Coventry & Warwickshire is an independent local charity which offers a personalised service to carers in Warwickshire, enabling them to access the community and social activities of their choice. The service has been designed in order to support carers who feel lonely or who may otherwise be isolated at home due to their caring responsibilities. Crossroads support staff also provide friendship, reassurance and companionship in the home.

Guideposts Carers support service run peer-led support groups which meet on a monthly basis across Warwickshire. These groups provide carers with an opportunity to meet other carers in a relaxed, informal setting. Some groups are location based, others are more specialised, tailored towards carers of people with Learning Disabilities, Autistic Spectrum Disorder and Mental Health.

Carers 4 Carers is a self-help group run by carers for carers and was started specifically to support carers who live in a rural area in and around South Warwickshire. The group meets once a month in Kineton, Stratford-on-Avon District for coffee and an opportunity to chat to others who experience isolation because of their caring role. A Companionship Group is run alongside the carers' meeting which enables the carer to bring the person they care for with them where they are looked after by a qualified care worker. The group was recently nominated for local Charity of the Year at a local supermarket in Stratford-on-Avon District.

PROJECTING FUTURE NUMBERS OF CARERS AND THE CARE 'GAP'

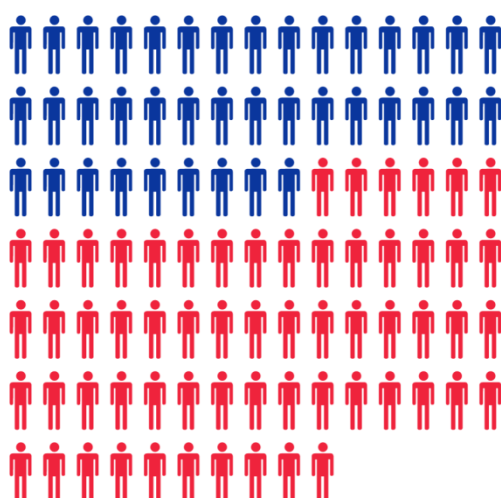
According to the latest ONS sub-national population projections, Warwickshire has an ageing population, with the highest rates of projected population growth in the groups aged 65 years and over. The rate of growth increases with age with the eldest age group, those aged 90 and over, projected to increase by 116% over the next 15 years from 2015 to 2030.

Figure 29: Projected population change (in 000's) in Warwickshire by age and sex, 2015-2030

Age group	2015		2020		2025		2030		% change from 2015 - 2030	
	Males	Females	Males	Females	Males	Females	Males	Females	Males	Females
65-69 years	17.1	17.7	15.6	16.1	16.8	17.0	19.4	19.9	13.5	12.4
70-74 years	13.6	14.4	16.0	17.0	14.7	15.5	16.0	16.5	17.6	14.6
75-79 years	9.6	11.0	12.1	13.4	14.4	15.9	13.4	14.6	39.6	32.7
80-84 years	6.4	8.4	7.7	9.6	9.9	11.8	12.0	14.2	87.5	69.0
85-89 years	3.6	5.9	4.4	6.5	5.5	7.7	7.3	9.6	102.8	62.7
90+ years	1.6	4.1	2.3	5.0	3.2	6.2	4.4	7.9	175.0	92.7
Total	51.9	61.5	58.1	67.6	64.5	74.1	72.5	82.7	39.7	34.5

Based on a three year moving average from 2011 to 2013, overall life expectancy in Warwickshire is slightly higher than the national average, at 80.0 years for males and 83.8 years for females. Nearly two-thirds (62%) of Warwickshire's population aged over 80 years are women.

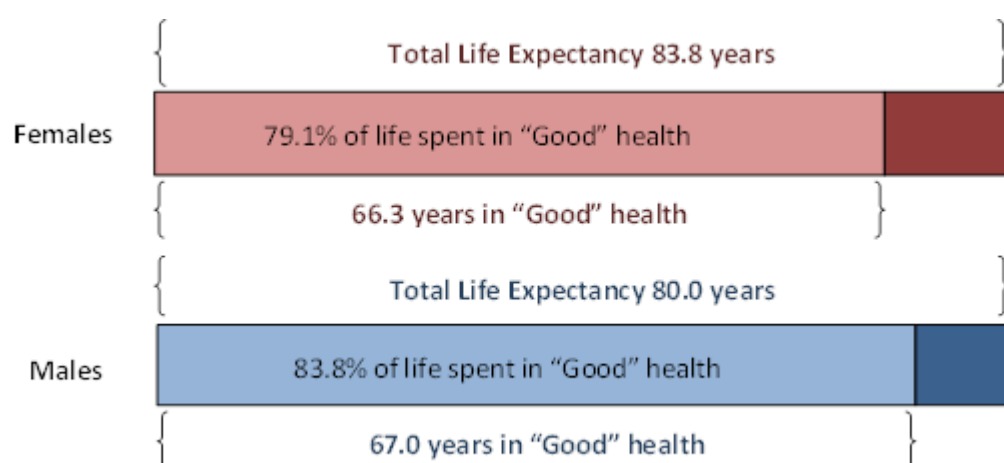
Figure 30: Proportion of males and females aged 80+ years in Warwickshire



Increases in life expectancy are currently outstripping increases in 'healthy life expectancy'⁶⁹ which means that as people live for longer they are also likely to need care and support for a larger proportion of their lives. For males born in Warwickshire between 2011 and 2013, healthy life expectancy is 67.0 years compared with a life expectancy of 80.0 years, meaning that they are expected to be in poor health for 16.2% of their lives. For females, healthy life expectancy in Warwickshire is 66.3 years compared with a life expectancy of 83.8 years, so although women are expected to live longer, they are also expected to live over one fifth (21%) of their lives in poor health.

⁶⁹ Life spent in good or very good health (the amount of time that a person is expected to live free from significant health issues)

Figure 31: Healthy life expectancy in Warwickshire, 2011-13



As the UK population ages and people live longer, family members will find themselves under increasing pressure to provide more support, for longer. Changes in family formation with, for example, higher rates of divorce and more lone parent families, plus increasing geographical mobility within families, could result in fewer people being available, able and willing to be carers. The pressure on individuals to become carers may increase substantially. This could have a significant effect on how families manage to maintain paid employment, how they provide for their pensions, the time they have to spend with their children or other family members and the time they have for social activities; with significant economic and social consequences for individuals and local communities.

The number of older people in need of care is predicted to outstrip the number of family members able to provide it for the first time in 2017. By 2032 there is predicted to be an increase of 60% in the number of older people needing care from their families but the number of people able to care for older parents will have increased by only 20 per cent, creating a shortfall in capacity to care for older generations⁷⁰.

Having no carer is a major precipitant of admission to long-term residential and nursing care. A study⁷¹ found that there was a 20-fold protective effect of having a co-resident carer on the likelihood of an adult moving into long-term residential care. Carer-related reasons for admission to nursing or residential care are common, with carer stress the reason for admission in 38% of cases⁷². This suggests that giving carers extra support to manage their caring role more effectively and maintain good health could reduce unwanted residential care admissions.

The number of older carers is growing at a fast rate. In England, the number of carers aged 65 and over has increased by 35% in ten years (from 2001 to 2011). In Warwickshire, the increase over the same time frame is even higher at 45%. Stratford-on-Avon District has seen the highest increase in

⁷⁰ Pickard L (2013) 'A growing care gap? The supply of unpaid care for older people by their adult children in England to 2032', Ageing and Society, DOI: 10.1017/S0144686X13000512. <http://eprints.lse.ac.uk/51955/>

⁷¹ Banerjee et al, 2003 'Predictors of Institutionalisation in People with Dementia'

⁷² Bebbington, A, Darton, A, Netten, A (2001), 'Care Homes for Older People: Volume 2. Admissions, needs and outcomes'. University of Kent, Personal Social Services Research Unit.

the number of carers over the age of 65 between 2001 and 2011; an increase of over 60%. Warwick District has seen the smallest increase, of under 30%; lower than the national average.

Figure 32: The number of unpaid carers aged 65 and over, 2001 and 2011

Area	2001	2011	% change
North Warwickshire	1,152	1,747	51.6
Nuneaton & Bedworth	2,205	3,143	42.5
Rugby	1,691	2,510	48.4
Stratford-on-Avon	2,287	3,712	62.3
Warwick	2,440	3,116	27.7

Source: 2011 Census, Office for National Statistics <http://www.ons.gov.uk/ons/guide-method/census/index.html>

By 2021, Warwickshire's population is projected to have increased by 5.4%, although this varies widely by age group, with the number of older people aged 75+ projected to increase by 27.6% compared to the working age population (between 16 and 64 years) which is projected to decrease.

Applying population projections to the number of carers in each age group identified in the 2011 Census means that the number of carers is estimated to increase by just under 5,000 people by 2021, with the majority of these aged 65 years and over (3,930).

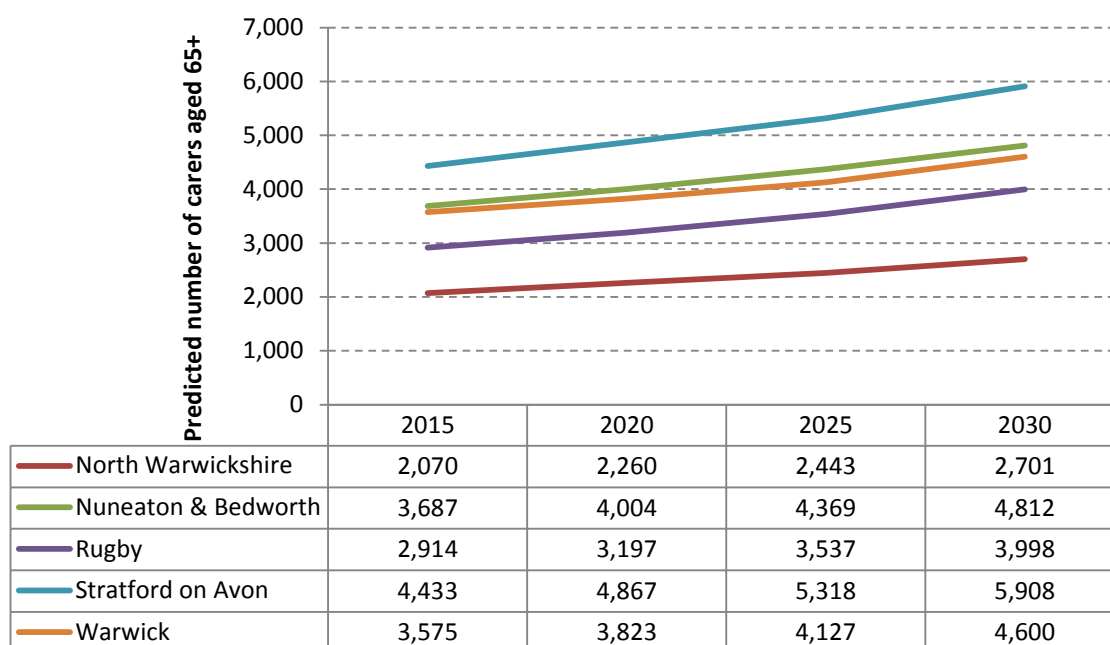
Figure 33: Estimated future number of carers in Warwickshire by 2021

Age group	2011 Population	2021 Population Projection	Population Change from 2011-2021	Number of Carers in 2011	Projected Number of Carers in 2021	Projected Increase in Number of Carers from 2011-2021
Age 0 to 15	98,388	104,869	6.6%	1,124	1,198	74
Age 16 to 24	58,839	51,287	-12.8%	2,562	2,234	-327
Age 25 to 34	64,485	69,037	7.1%	4,121	4,414	293
Age 35 to 49	118,489	104,852	-11.5%	14,659	12,973	-1686
Age 50 to 64	106,053	118,215	11.5%	22,535	25,127	2,592
Age 65+	100,300	128,026	27.6%	14,239	18,169	3,930
Total	46,554	576,286	5.4%	59,240	64,115	4,875

Source: 2011 Census and sub-national population projections, Office for National Statistics

Projecting Older People Population Information System (POPPI) has projections for carers over the age of 65 in Warwickshire by District/Borough up to 2030. They estimate that there will be 18,147 carers over the age of 65 in Warwickshire by 2020, similar to the projections above (18,169 carers over 65 in 2021). POPPI predicts that by 2030, the number of carers over the age of 65 years will have increased by nearly a further 4,000 people, to just under 22,000. At District/Borough level, Stratford-on-Avon is predicted to have the highest number of carers aged over 65 years, reflective of the District's ageing population. However, Rugby Borough is predicted to have the greatest increase in the number of carers over 65 years of over 37% from 2015 to 2030.

Figure 34: Projected number of people aged 65 and over providing unpaid care, 2015-2030



Source: Projecting Older People Population Information System (POPPI)

Learning Disability

Individuals with a learning disability are described in the 2001 Government White Paper '*Valuing People*' as having a significantly reduced ability to understand new or complex information and learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood and had a lasting effect on their development. In Warwickshire in 2014, there are estimated to be approximately 10,916 people with a learning disability

People with learning disabilities have an increasing life expectancy and growing numbers of children and young people with more complex disabilities are now surviving into adulthood. The table below shows the estimated predicted prevalence of learning disabilities in Warwick from 2014 to 2024 by age group. The most pronounced rise is predicted to be in those who are over the age of 65, with an 11% rise in the 5 years from 2014 to 2019 and an 21% rise from 2014 to 2024.

Figure 35: Predicted Future Prevalence of Learning Disabilities in Warwickshire

Age Group	2014	2019	% change from 2014	2024	% change from 2014
0-17	1,546	1,103	-28.6%	1,140	-26.3%
18-64	7,569	8,057	6.4%	8,119	7.3%
65+	1,802	2,001	11.0%	2,183	21.1%
All Ages	10,916	11,161	2.2%	11,442	4.8%

Source: Emerson & Hatton 2010, ONS mid-2014 population estimates

Dementia

Dementia is a degenerative disease of the brain which over time can result in gradual loss of mental awareness, memory, general communication and skills to carry out daily activities, as well as personality change. The speed of progression is variable but typically develops slowly over a number of years. In Warwickshire, there are 4,143 registered patients diagnosed with dementia, however, there are an estimated 3,491 individuals in Warwickshire living with dementia but who are undiagnosed, a total of 7,634 people. Over the next five years (2015-2020), the prevalence of dementia is projected to increase by 18.1% in those aged 65 and over.

Figure 36: Predicted Future Prevalence of Dementia in Warwickshire

Age Group	2015	2020	2025	2030	% change from 2015 to 2030
65-69 years	434	395	422	490	12.9
70-74 years	767	904	828	892	16.3
75-79 years	1,205	1,488	1,768	1,632	35.4
80-84 years	1,770	2,062	2,579	3,113	75.9
85-89 years	1,911	2,178	2,628	3,350	75.3
90 years+	1,705	2,177	2,796	3,653	114.3
Total population aged 65+	7,791	9,204	11,021	13,130	68.5

Source: POPPI

The changes for local authorities in identifying and supporting carers informed by the Children and Families Act 2014 and the Care Act 2014 came into effect April 2015. As awareness increases, more agencies may identify carers and young carers and more families may recognise when a family member is deemed a carer or young carer. Councils, for the first time, have a duty to meet carers' assessed eligible needs.

CURRENT SERVICE PROVISION

Guideposts Carers Support Services (GCSS) are commissioned to provide support services for adult carers in Warwickshire in line with the Warwickshire Joint Carers strategy. The value of this contract is £355,000 and includes:

- Information and advice on all aspects of the caring role;
- 1-to-1 and peer-led support;
- Practical and emotional support, including training sessions.

The current service provision provided for young carers by the Young Carers Project is covered in the Young Carers chapter.

Guideposts Carers Support Services

Referrals and Instances of support

There are just over 5,500 carers across Warwickshire that are currently known to Guideposts, in that they have made contact with Guideposts and accessed some level of service. Over the last two years, the service has fallen short of its targets for numbers of new referrals and number of instances of support, as illustrated in the table below.

Figure 37: Number of referrals and instances of support provided by Guideposts

	Target	2013/14 ¹	2014/15 ²
Number of new referrals per year	1,000	710	639
Number of instances of support per year	12,000	9,305	7,910

Source: Guideposts Carers Support Service Performance Reporting

Training sessions

Guideposts have provided 51 training sessions in 2014/15, falling short of the annual target of 75 sessions. Attendance at these events has been consistently low. The table below summarises the targets for each specified training session, along with the actual number delivered and average levels of attendance for 2013/14.

Figure 38: Number of training sessions by type provided by Guideposts

	Target	2013/14 ¹	2014/15 ²	Average attendance (2013/14) ¹
Caring with Confidence	20	18	17	3
Moving and handling	10	10	6	2
Dementia	10	18	7	3
Mental Health	10	10	5	5
Stroke	10	10	6	3
Reablement	10	10	6	2
Bills to Wills	5	6	4	5

Source: Guideposts Carers Support Service Performance Reporting

Peer-led support groups

In 2014/15, Guideposts provided 139 peer-led support groups. In 2013/14, targets for some peer-led support groups were met (Mental Health, Generic/Older People) and in the case of Dementia this was exceeded. However, in 2014/15, two out of the six targets identified below were met (Mental Health and Generic/Older People) but for all others, the number of groups is significantly under the specified target and as a result, the 200 target for numbers of peer-led support groups was not met in the most recent contractual year. Figure X summarises the targets for peer-led support groups, along with numbers delivered.

Figure 39: Number of peer-led support groups provided by Guideposts

	Target	2013/14 ¹	2014/15 ²
Mental Health	30	30	33
Dementia	30	75	21
Learning Disability	30	12	12
Generic/Older People	60	60	60
Autism	30	9	13
Workplace sessions	20	7	0

Source: Guideposts Carers Support Service Performance Reporting

Again attendance has generally been low (with the exception of Stratford, Southam & Warwick). Figure X provides a snap shot of the average levels of attendance across the groups.

Figure 40: Number of carers attending each support group provided by Guideposts

Group	Average attendance (2013/14 ¹)	Average attendance (2014/15 ²)
Leamington - Generic/Older People	5	2
Stratford - Generic/Older People	19	16
Studley - Generic/Older People	6	2
Southam - Generic/Older People	7	9
Rugby - Generic/Older People	7	4
Rugby - Mental Health	4	2
Stratford - Mental Health	6	6
North Warwickshire - Mental Health	2	1
Warwick - Learning Disability	9	12

Source: Guideposts Carers Support Service Performance Reporting

The Guideposts annual service evaluation has shown that for both peer-led groups and training sessions accessibility of services is an issue for many carers. The main barriers to attendance are:

- Unable to leave the cared-for person
- Time of day
- Location
- Transport

It is important to consider whether peer-led support groups are the most suitable type of support group for all carers. For some carers, they spend the majority of their time and lives organising and doing things for the person they care for, they do not necessarily then want to have to organise anything else. For these carers, a support group should feel like an opportunity for respite, where they have the time to talk to others in a similar position, sit quietly, read a book, listen to an outside speaker or direct questions to the support staff. It is therefore important that Warwickshire County Council commissions a range of different types of support services or engages and signposts carers to existing community groups/networks.

Carer Emergency Cards

Warwickshire County Council, NHS Warwickshire and Guideposts introduced a Carer Emergency Card for carers to carry in their purse or wallet to identify them as a carer should they be caught up in an emergency situation such as a medical emergency. The card has room on the back for the details of up to three people that could be contacted to quickly arrange support for the person the carer looks after, giving peace of mind to the carer and the person cared for. The service has received 344 applications for the Emergency Card in the last contractual year, July 2014 to June 2015.

Respite

Respite from a caring role enables the carer to rest, catch up with other tasks or take part in activities that they may not normally be able to do. There are different forms of respite; it can be residential, domiciliary or activity based. In certain situations, respite care may be provided by Warwickshire adult services after a carer's assessment as part of a support plan.

Many services provided to customers are provided to support both the cared for and the carer; primarily respite, homecare, day care and direct payments. Respite provides a valuable break for full time carers, providing breaks that are essential for carers to maintain wellbeing and carry on in their caring role. The table below shows that there has been a decrease in the number and proportion of adult social care customers accessing traditional respite services from 495 people in 2012/13 to 189 people in 2014/15. The proportion of customers receiving respite has halved in this time. However the number of nights stay has increased, suggesting that the service is targeted to those with more complex needs who need longer periods of respite.

Indicator	2012/13	2013/14	2014/15
Number of ASC Customers receiving respite	495	195	189
% of ASC Customers receiving respite	3.40%	1.35%	1.45%
Total respite night's stay	13,675	7,483	7,215
Average nights per customer	28	38	38

Direct payments provide carers with funds to purchase support on an ongoing basis, alternatively one-off direct payments to make a one-off purchase to support them in their caring role (for

example to purchase a washing machine). The number of people receiving a direct payment is low but is increasing with awareness and legislation regarding personalisation. At 31st September 2015, there were 96 adult social care customers in Warwickshire in receipt of an ongoing direct payment, up from 33 in January 2015. Between July and September 2015 one-off direct payments were made to 24 customers. However, the figures above are for all customers receiving a direct payment and not specifically for Carer's due to recording issues.

Carers Support Models – Warwickshire's Statistical Neighbours

Warwickshire's statistical neighbours⁷³ offer a wide range of services to carers who reside in their area. The majority of councils offer some form of information and advice, guide-posting, emergency support/cards/helplines, support groups and training. Some counties offer more specific support to their carers, such as Dorset's Carers caseworkers, who cover specific geographical areas of Dorset and provide assistance and support to family carers.

Most services for carers are provided by external providers, but some councils provide services from internal teams, such as Worcestershire County Council, who provides an emergency help service for Carers known as 'Back me up', and Gloucestershire County Council's 'Positive Caring Programme'; a series of free sessions enabling carers to gain knowledge and skills and to find out about services/sources of support.

Carers Gloucestershire is a locally based charity which provides information, support and advice to carers whilst the person they care for is in hospital. A Hospital Liaison Officer works closely with hospital staff, who identify carers of the patients and the patient themselves if they are a carer. The service won the 'Innovations and Best Practice in Community Hospital's Award' for 2014/15. The specific aim of the work of Carers Gloucestershire within community hospitals is to ensure that carers of people admitted into the hospital have good experiences, are respected, involved and supported throughout their stay⁷⁴.

Carers Gloucestershire is a locally based charity which runs a Carers' Hospital Support service, which aims to ensure that carers of people admitted into the hospital have good experiences, are respected, involved and supported throughout their stay. The service won the 'Innovations and Best Practice in Community Hospital's Award' for 2014/15.

⁷³ Councils which are similar to Warwickshire in terms of population and demography.

⁷⁴ <http://carersgloucestershire.org.uk/wp-content/uploads/2013/09/Carers-Gloucestershire-Service-Guide.pdf>

Carers Assessments

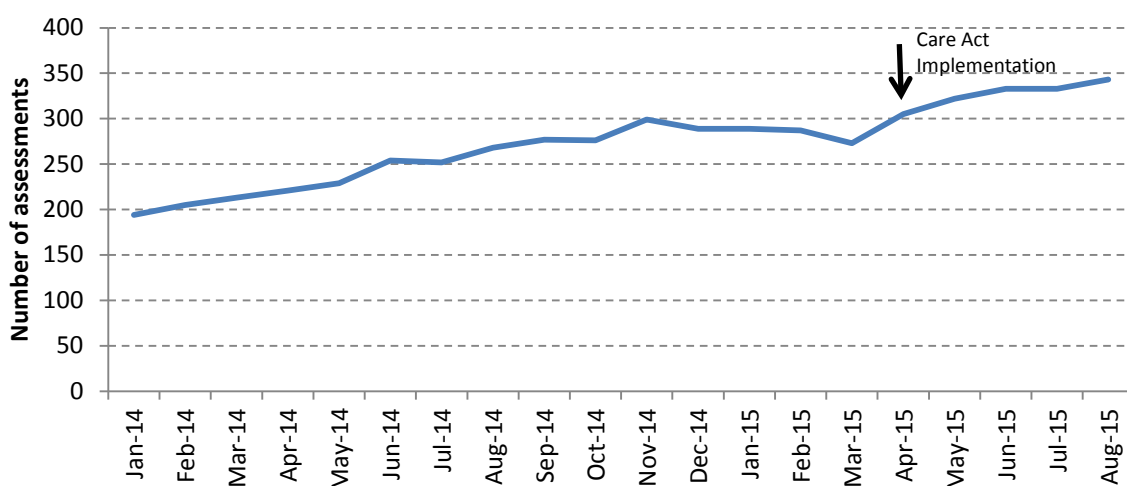
A carer's assessment is a discussion between a carer and the local authority to identify any support needs that the carer may have, to help them in their caring role and/or to continue to do things which are important to them and their family. It covers the carer's caring role, their physical, mental and emotional health as well as how caring affects their work, leisure, education, wider family and relationships.

When the assessment is complete, the local authority will decide whether the carer's needs are 'eligible' for support from the local authority. In accordance with the Care Act 2014, local authorities now have a legal duty to assess any carer who requests one or who appears to need support.

Information on young carer's assessments is found within [Young Carers](#) chapter.

The number of open carer assessments has been steadily increasing from 194 open assessments in January 2014 to 343 in August 2015. The average number of open assessments in 2014/15 was 268 per month. So far in 2015/16, there has been an average of 327 per month.

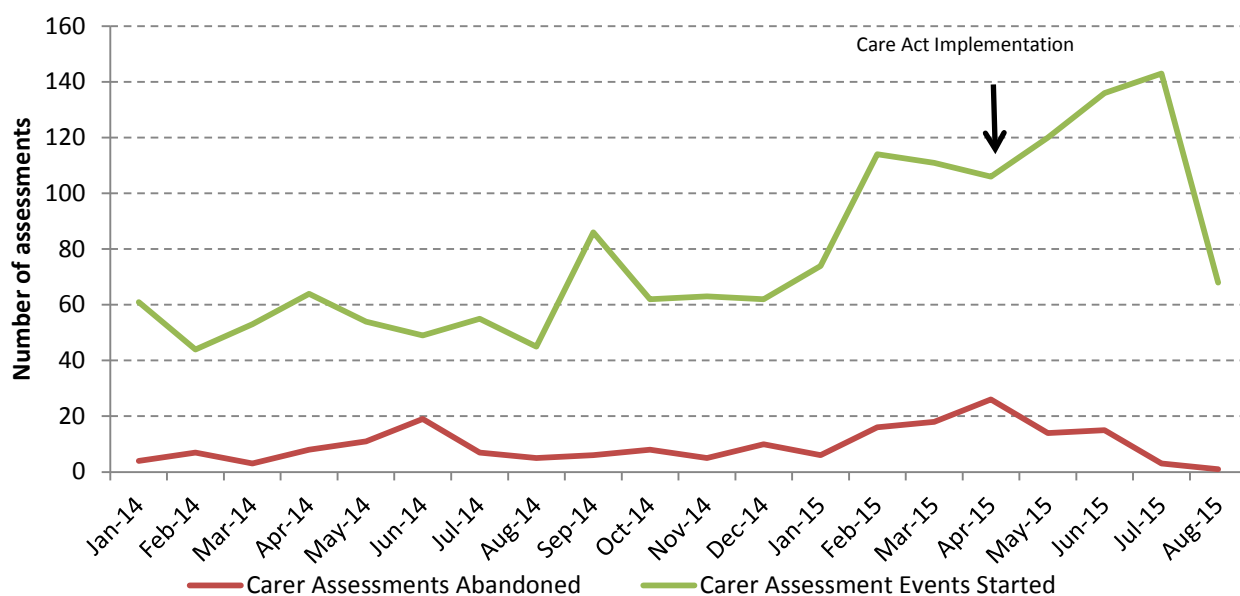
Figure 41: Carers Assessments Open



Source: CareFirst

The number of carer assessments started has doubled from an average of 70 per month in 2014/15 to 115 per month so far in 2015/16, however, the number of assessments started dropped significantly in August 2015, explained, at least in part, by the school holiday period.

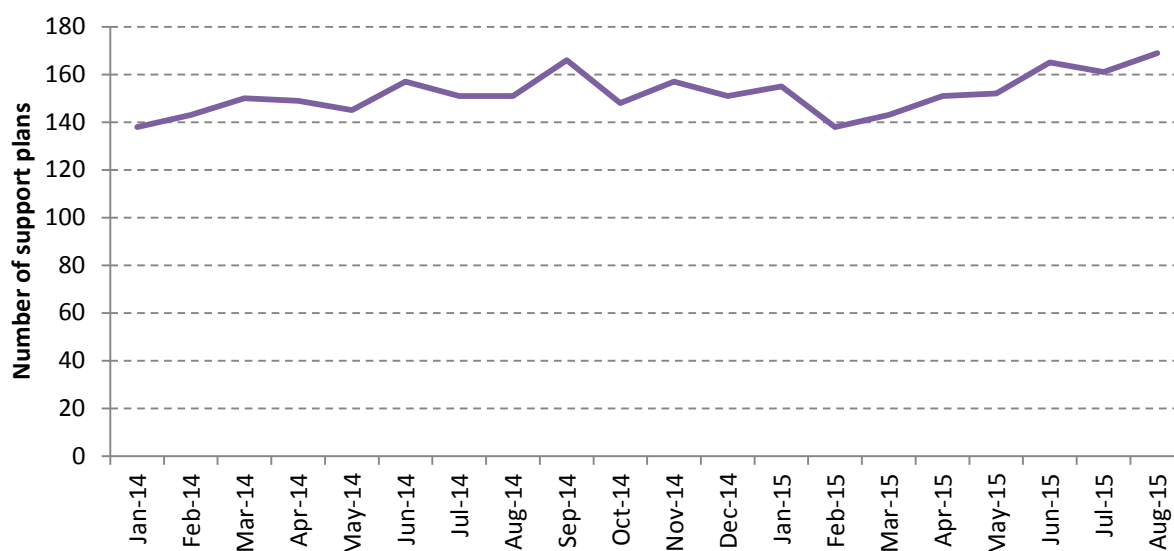
Figure 42: Carers Assessment Events started and Carers Assessments abandoned



Source: CareFirst

In terms of carer support plans, the number of open support plans has slowly risen over time, with no obvious impact from the implementation of the Care Act in April 2015. The average number of carer support plans open in 2014/15 was 151 per month compared with 160 per month so far in 2015/16.

Figure 43: Number of Carers Support Plans

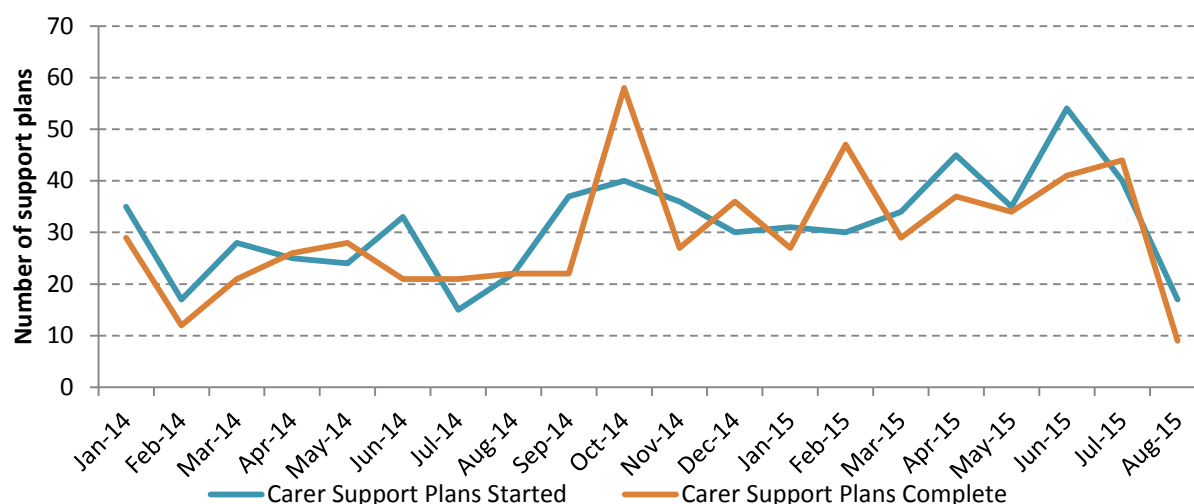


Source: CareFirst

In terms of the number of carer support plans started, on average the number has risen over time, although far less steadily than the number of carer assessments shown above, with a series of

monthly peaks and troughs. The number of carer support plans completed seems to follow this trend. Once again, a sharp drop in the number of carer support plans started and completed in August 2015 can be seen. A similar drop was seen in August 2014 although this was far less pronounced.

Figure 44: Number of Carers Support Plans started and complete



Source: CareFirst

Satisfaction with services

The main headline measure from the Warwickshire 2014/15 carers survey relates to the overall satisfaction with services provided for the carer and the person they care for. Of the 368 Warwickshire carers that responded to the 2014/15 survey, seven in 20 (35%) respondents were satisfied. Overall satisfaction levels for carers has fallen in 2014/15, from 51.4% in 2012/13 to 35% in the most recent survey; a fall of over 30%.

The results of the carers survey informs the Adult Social Care Outcomes Framework (ASCOF) measures. Four out of the five indicators have reduced compared to when the survey was last undertaken, the most significant of which is the overall satisfaction of carers measure.

A further breakdown of the carers satisfaction question is shown in Figure X. A total of 286 carers responded and 65 answered 'we haven't received any support or services from Social Services in the last 12 months.' Only 100 (35%) said they were extremely or very satisfied while 105 carers (37%) were quite satisfied. One in ten (33 carers) said they were dissatisfied.

Figure 45: Summary of Carers measures

Indicator	2012/13	2014/15	Direction of Travel
ASCOF 1D – Carer reported quality of life (score)	8.1	7.7	➔
ASCOF 1I pt2 - Proportion of carers who reported that they had as much social contact as they would like	40.3%	40.8%	➔
ASCOF 3B - Overall satisfaction of carers with social services	51.4%	35.0%	⬇
ASCOF 3C - The proportion of carers who report that they have been included or consulted in discussions about the person they care for	74.0%	71.2%	➔
ASCOF 3D pt2 - The proportion of carers who find it easy to find information about services	64.2%	60.2%	➔

Source: Warwickshire Carers Survey 2014/15

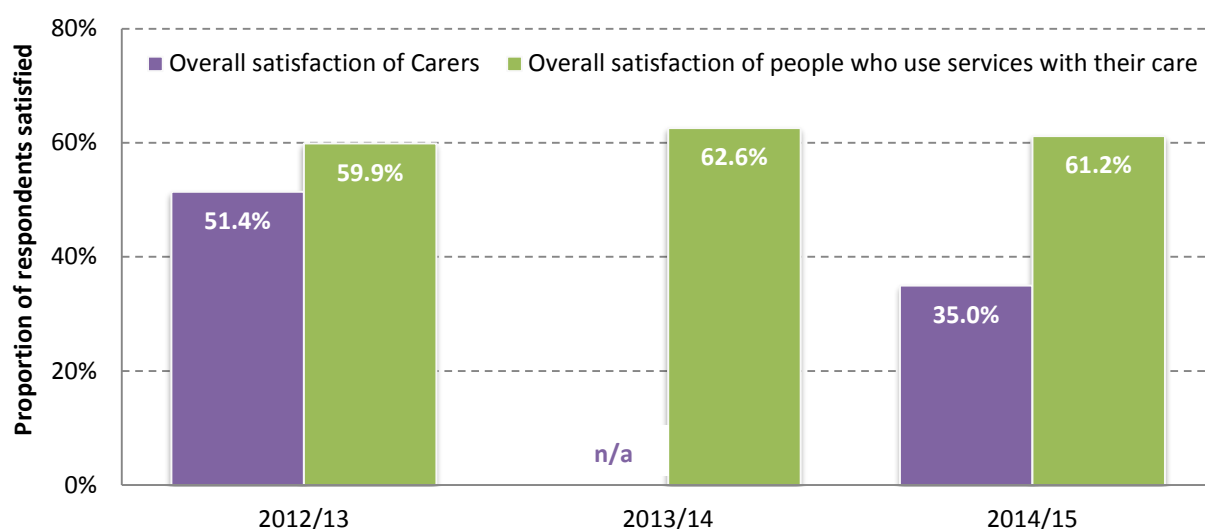
The main headline measures from both the Carers survey and the Adult Social Care Survey, which is primarily focused on those who are 'cared for' and supported by Warwickshire County Council, are useful to consider together. Figure X presents the two main satisfaction indicators for the two surveys; the overall satisfaction of carers from the Carers Survey and the overall satisfaction of people (who use a service) with their care and support from the Adult Social Care Survey. The indicators demonstrate while overall satisfaction of service users has remained relatively static over the last three years, the satisfaction of carers has decreased significantly (as previously identified).

Figure 46: Detailed answers to carers' satisfaction question

Answer	Number	Percentage
I am extremely satisfied	40	14%
I am very satisfied	60	21%
I am quite satisfied	105	37%
I am neither satisfied nor dissatisfied	48	17%
I am quite dissatisfied	20	7%
I am very dissatisfied	6	2%
I am extremely dissatisfied	7	2%

Source: Warwickshire Carers Survey 2014/15

Figure 47: Satisfaction levels for carers and the 'cared for' over time, 2012/13 – 2014/15



Source: Warwickshire Carers Survey 2014/15. Note: there is no figure in 2013/14 for carers as the survey is biennial

The 'cared for' person appears to be nearly twice as likely to be satisfied with the care and support they receive as the carers who responded to the survey. This may be because carers have a higher expectation of the services they expect for the person they care for, or that they are less satisfied with their own experience of dealing with social care professionals.

According to the results of Warwickshire Carers Survey, carers caring for people over the age of 85+ were the most satisfied with the care and support services they and the person they care for receive, whilst people caring for someone aged 31-64 years were the least satisfied. Unfortunately it was not possible to see whether there was any difference in levels of satisfaction by ethnicity due to only a few non-white British carers completing the survey.

In terms of the information and advice that carers received, just under a third of carers reported that they had not received any information or advice in the last 12 months. The majority (58%) of carers who had received information or advice replied that this was 'quite helpful', with only 16% replying that the information or advice received had been 'quite unhelpful' or 'very unhelpful'.

Response	Number	Percentage
I have not received any information or advice in the last 12 months	110	32.2%
Very helpful	61	17.8%
Quite helpful	135	39.5%
Quite unhelpful	27	7.9%
Very unhelpful	9	2.6%
Total Responses	342	100%

Carers Receiving Carer's Allowance

The main welfare benefit for carers is called Carer's Allowance. To be eligible for the benefit, the carer must be over the age of 16 years, spend at least 35 hours a week caring for someone who receives a qualifying disability benefit and not be in full time education or earning more than £110 a week.

Carer's Allowance is applied for directly by the individual and is therefore independent of any NHS or Warwickshire social care services. It is currently paid at a rate of £62.10 per week. However, it is not paid to people with a State Pension of more than £62.10 a week as the State Pension and Carer's Allowance are classed as 'overlapping' benefits.

The number of carers receiving Carer's Allowance is unlikely to represent the true number of carers in Warwickshire due to the restrictions for qualification; however, it is important that carers who are eligible for Carer's Allowance are receiving the benefit.

The number of claimants of Carer's Allowance in Warwickshire has increased year-on-year, from 3,750 claimants as at February 2010 to 4,930 claimants as at February 2015; an increase of 31%. Nuneaton & Bedworth has the highest number of claimants, accounting for around a third of all claimants each year. North Warwickshire has the lowest number of claimants each year, accounting for approximately 14% of total claimants.

Figure 48: Warwickshire Carers in Receipt of Carer's Allowance, by District/Borough by year

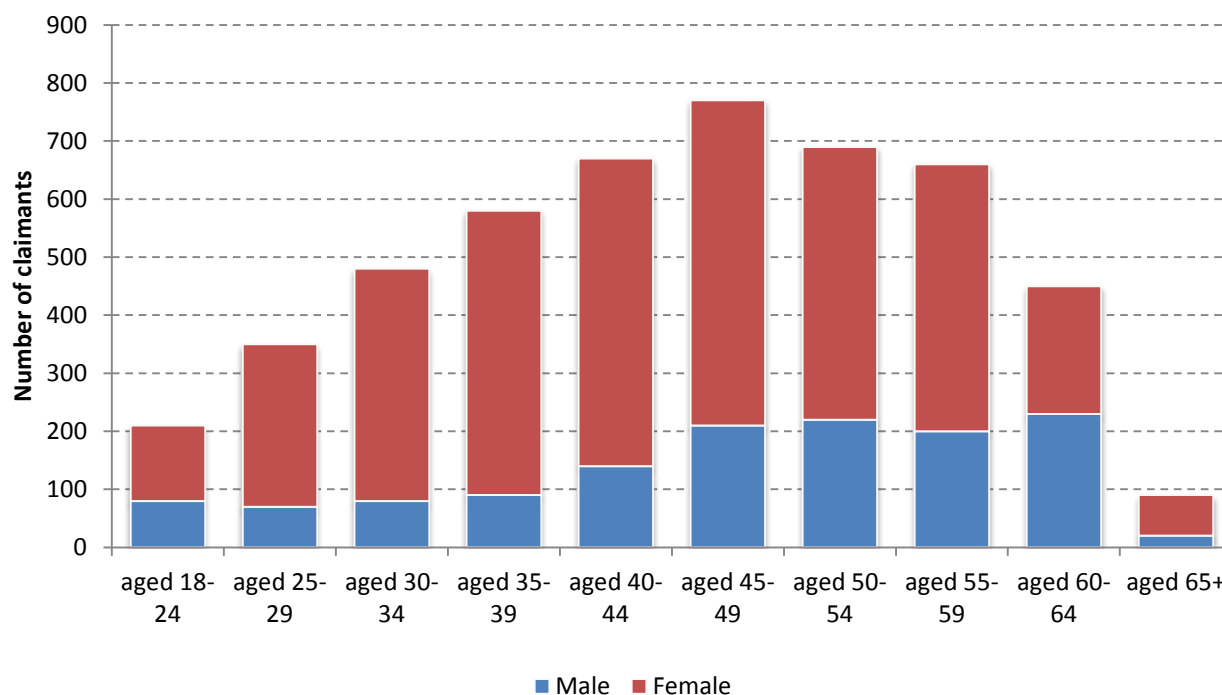
Date	Warwickshire	North Warwickshire	Nuneaton & Bedworth	Rugby	Stratford-on-Avon	Warwick
February 2010	3,750	580	1,250	610	650	660
February 2011	3,910	570	1,320	640	680	700
February 2012	4,150	590	1,370	670	720	780
February 2013	4,390	630	1,460	730	770	800
February 2014	4,610	640	1,550	770	800	850
February 2015	4,930	660	1,710	830	840	890

Source: NOMIS, Office for National Statistics

As at February 2015 there were 4,930 individuals in Warwickshire in receipt of Carer's Allowance, of whom 3,600 (73%) were female and 1,330 (27%) were male. Nearly all of these individuals (94%) were aged between 25 and 64 years of age, with just 4% below the age of 25 years and 2% aged 65+.

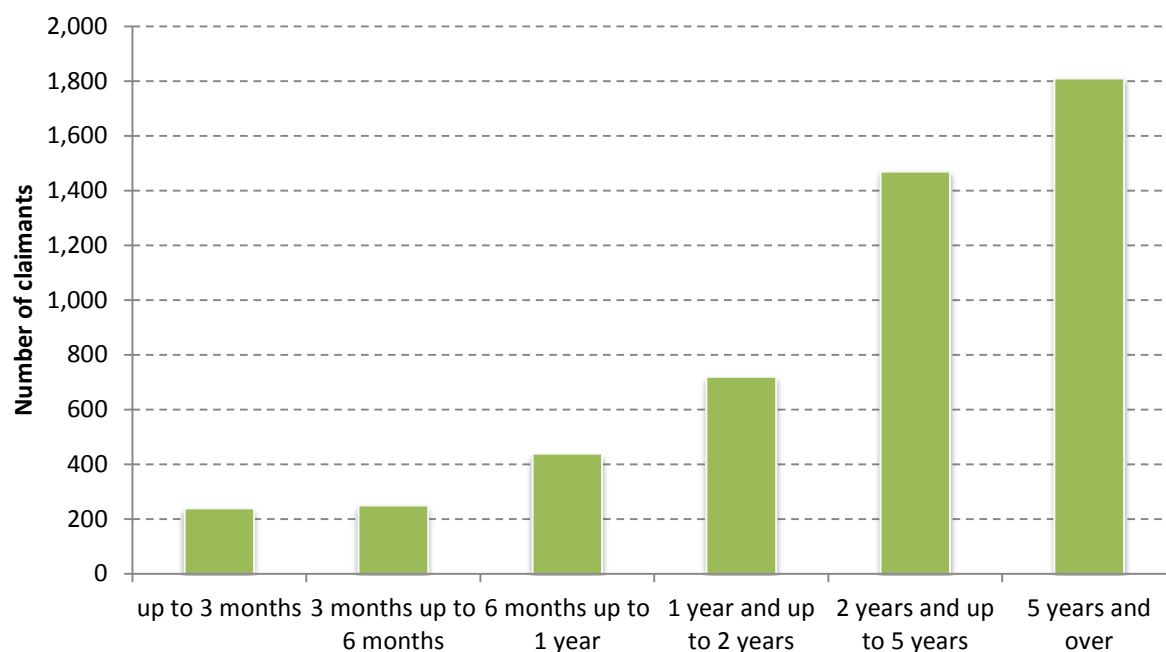
The figure below shows the length of time that individuals currently (February 2015) claiming Carer's Allowance have been claiming for. 67% of all claimants in Warwickshire have been claiming for two years or more, of whom 37% have been claiming Carer's Allowance for 5 years and over.

Figure 49: Warwickshire Carers in Receipt of Carer's Allowance, by age & sex as at February 2015



Source: NOMIS, Office for National Statistics

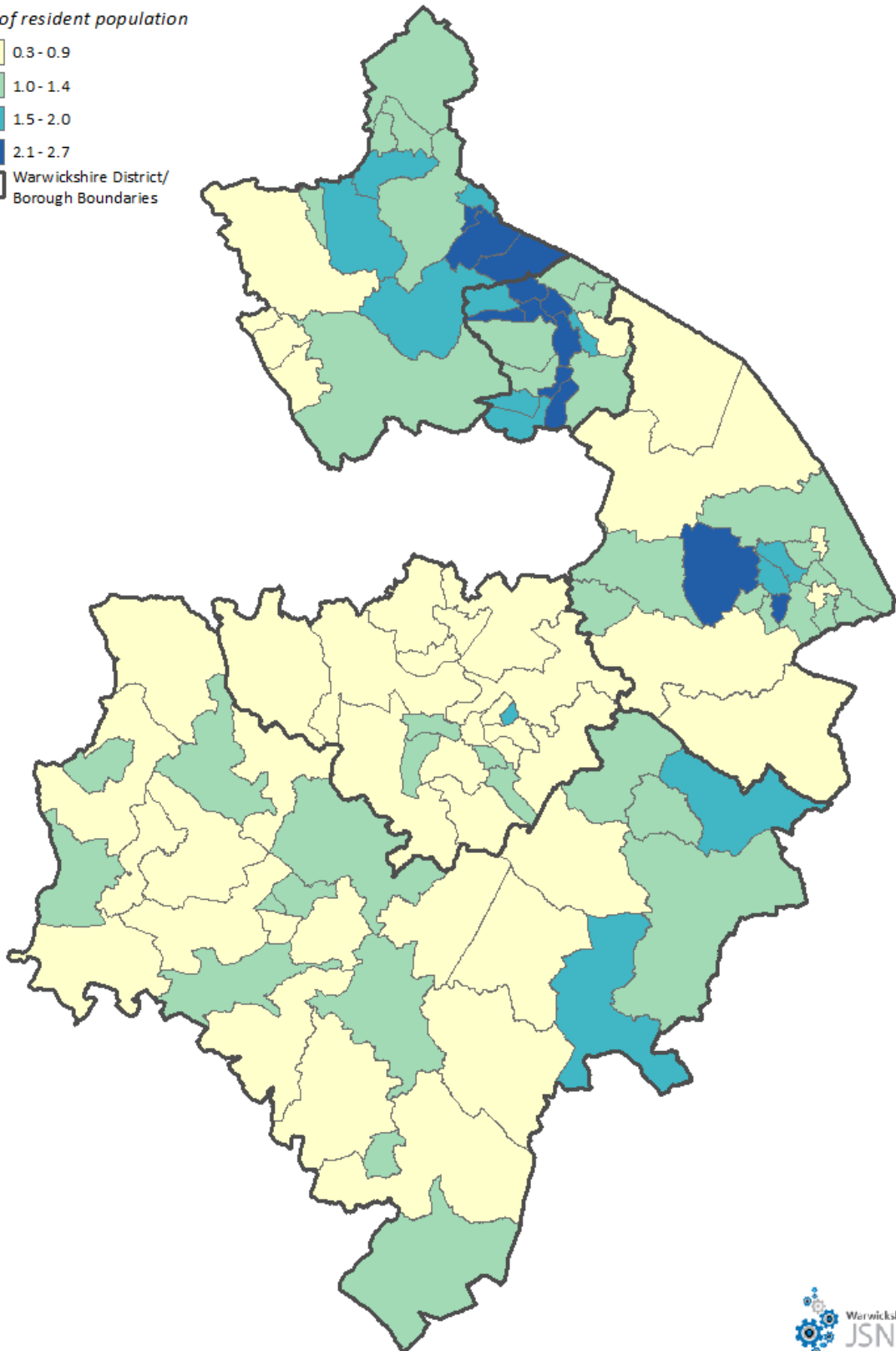
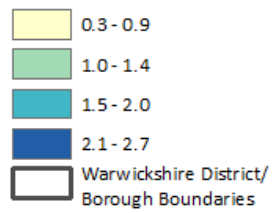
Figure 50: Warwickshire Carers in Receipt of Carer's Allowance by duration, as at February 2015



Source: NOMIS, Office for National Statistics

Working Age Carers claiming Carers Allowance, by ward (February 2015)

Rate of resident population



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In 2013, Carers UK analysed DWP data and calculated the number of carers who are likely to be missing out on Carer's Allowance nationally and locally using existing claimant count figures and take-up rates. Carers UK estimated that of the 6,862 Warwickshire residents eligible for Carers Allowance (as at May 2013), 2,402 were not claiming, meaning that around a third (35%) of all those eligible were missing out. The total value of this unclaimed benefit was estimated to be worth nearly £7.5 million per year⁷⁵.

Figure 51: Estimates on the number of carers in Warwickshire missing out on Carer's Allowance, as at May 2013, Carers UK

LA Name	Carers in receipt of Carer's Allowance	Total value of CA received (p/a)	Total estimated number eligible	Total estimated value of benefit eligibility (p/a)	Total estimated number of carers missing out	Total estimated value of unclaimed benefit (p/a)
North Warks	620	£1,926,340	954	£2,963,600	334	£1,037,260
Nun & Bed	1,500	£4,660,500	2,308	£7,170,000	808	£2,509,500
Rugby	740	£2,299,180	1,138	£3,537,200	398	£1,238,020
Stratford-on-Avon	780	£2,423,460	1,200	£3,728,400	420	£1,304,940
Warwick	820	£2,547,740	1,262	£3,919,600	442	£1,371,860
Warwickshire	4,460	£13,857,220	6,862	£21,318,800	2,402	£7,461,580

Source: NOMIS, Office for National Statistics

⁷⁵ <http://www.carersuk.org/for-professionals/policy/policy-library/carers-allowance-takeup>

ENGAGEMENT WITH CARERS AND GAPS IN PROVISION

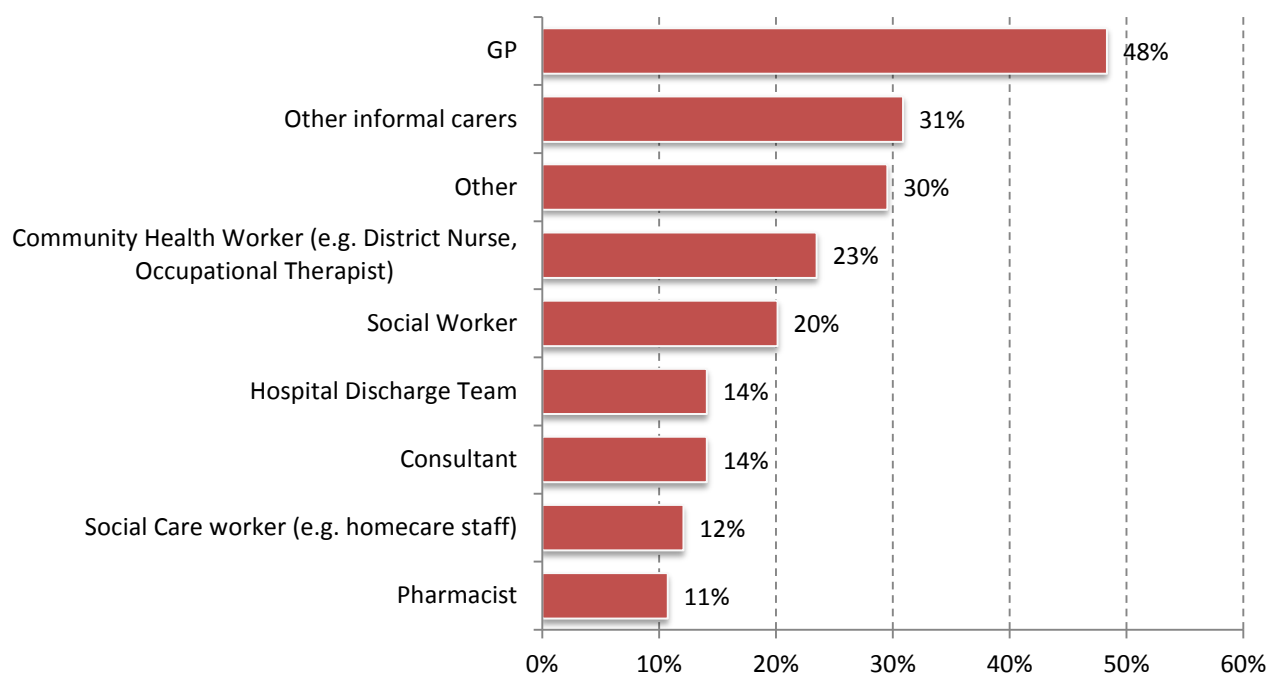
A range of methods of engagement were used to obtain views from hidden carers (carers that are not currently known to carers support services), and also from health and social care practitioners, including a dedicated engagement week including:

- Online survey
- Paper versions of surveys and response boxes left in 17 GP surgeries and three community hubs across the county
- Eight visits to three Warwickshire hospitals to engage with potential carers face-to-face through a 'market research' style approach
- Two focus groups with carers
- A workshop with health and social care practitioners
- Round table workshop with both carers and health and social care practitioners.

A number of potential gaps were identified as part of the engagement activity. The data below is taken from the customer engagement report produced by Osiris MR Limited, a external market research company. We identify direct feedback from carers in this section as much as possible; however, more carers views are also included within the redesign of carers support services paper.

Forms of support

Is there anyone with whom you have come into contact with, who you feel are well placed to advise about what services and support you are entitled to?



Category	Number	% respondents
GP	72	48.3%
Other informal carers	46	30.9%
Other	44	29.5%
Community Health Worker (e.g. District Nurse, Occupational Therapist)	35	23.5%
Social Worker	30	20.1%
Consultant	21	14.1%
Hospital Discharge Team	21	14.1%
Social Care worker (e.g. homecare staff)	18	12.1%
Pharmacist	16	10.7%
Total Number of Respondents	149	

Source: Warwickshire Carers Engagement survey, 2015

Nearly half of all respondents believe that their GP is well placed to advise about relevant services for carers. Three in ten carers identified other informal carers as the next most appropriate group, highlighting the importance of informal networks in supporting carers. Interestingly, the proportion of respondents that considered social workers to be well placed to advise what services and support are available was low at 20%.

The specific details of people responding with 'Other' were not always captured however, where respondents have provided answers it covers a range of people including friends and family, the Citizens Advice Bureau, or a specific group such as the Alzheimer's Society.

Many carers are spending a great deal of time trying to navigate complex systems in order to co-ordinate care and support services for the cared for person.

Carers tell us that they feel frustrated with the amount of time they have to spend and difficulties they face trying to navigate and negotiate a complex health and social care system with multiple points of contact, a lack of communication between different parts of the system, barriers to access and often long waiting times.

Carers told us that they need support to ensure that they are able to effectively navigate systems in order to co-ordinate care and support of the cared for person.

'If you get their care right I am OK'.

'Support to negotiate the system'.

'Single point contact for all care and NHS, I spent hours co-ordinating!'

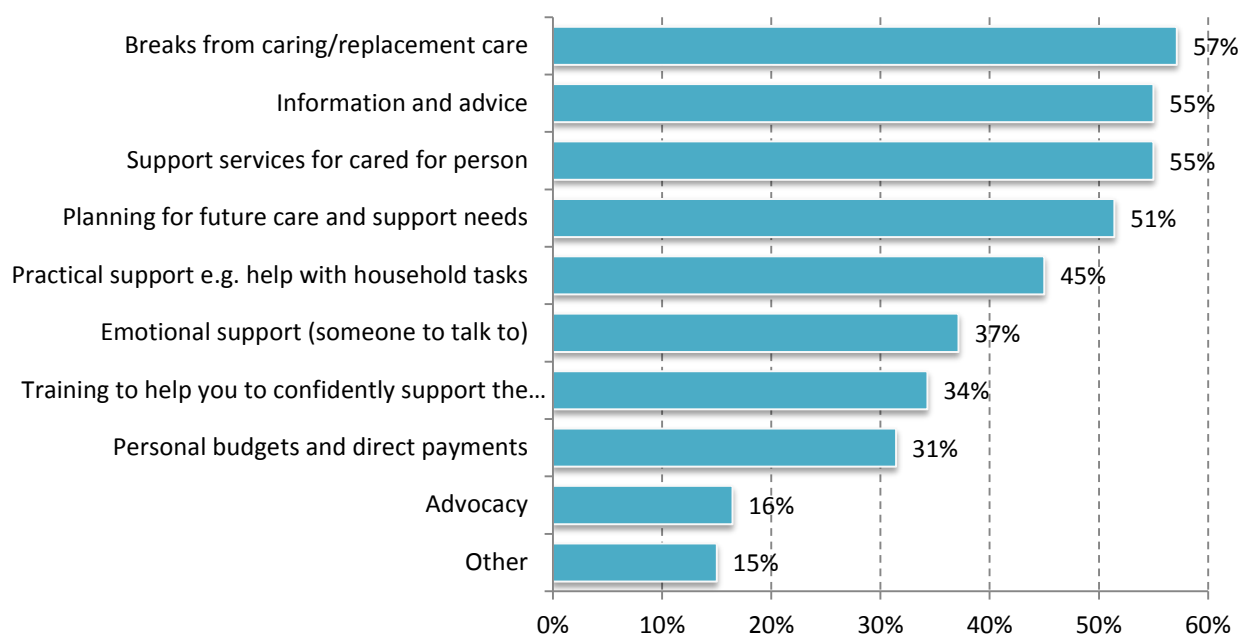
'A point of contact to help navigate through the system'.

'More co-ordinated care when dealing with multiple suppliers (e.g. equipment, spare oxygen, medication) need suppliers to co-ordinate'.

'When a diagnosis is included (e.g. Parkinsons/Dementia), there needs to be clear lines of communication between the Consultant, GP, Nurses and Social Care. Also need clarity regarding different roles and responsibilities'.

Respondents felt that *breaks from caring* or *replacement care* was most important to them (57%). Over half (55%) or carers identified that support services for the cared for person would help them in their caring role, with an equivalent percentage identifying information and advice. 51% of respondents felt that planning for future care and support needs would be helpful to them.

Which form of support would help you in your caring role & could give you a better quality of life?



Category	Number	% respondents
Breaks from caring/replacement care	80	57.1%
Support services for cared for person	77	55.0%
Information and advice	77	55.0%
Planning for future care and support needs	72	51.4%
Practical support e.g. help with household tasks	63	45.0%
Emotional support (someone to talk to)	52	37.1%
Training to help you to confidently support the person you care for	48	34.3%
Personal budgets and direct payments	44	31.4%
Advocacy	23	16.4%
Other	21	15.0%
Total Number of Respondents	140	

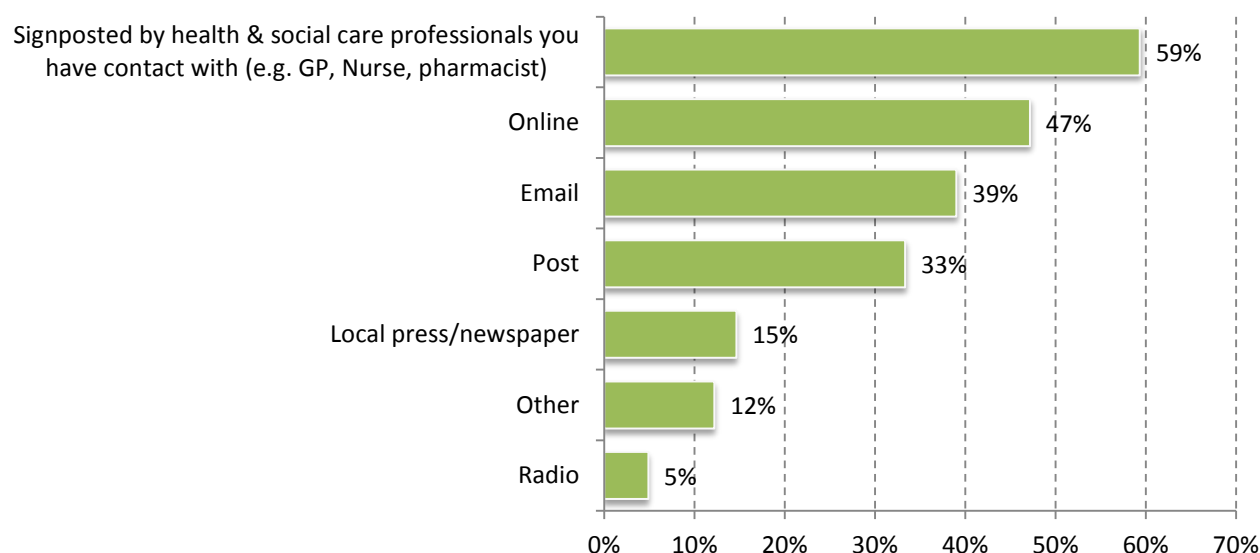
Source: Warwickshire Carers Engagement survey, 2015

‘Those who cannot leave the person that they care for are unable to get a ‘break from caring’. Particularly those who have been unable to get an assessment for the cared for, that might provide access to day care or home care; they simply cannot afford the cost of replacement care’.

‘Respite care at a centre or preferably in own home would enable carers who cannot easily go out on their own to do so. A known specialist agency who could provide such care either privately or via the system of financial support would be a bonus’.

These results suggest there is opportunity to improve interaction with carers directly. The challenge will be identifying further ways of communicating directly with carers to improve the information available to them in terms of the availability of services and support for them in their caring role.

If you would like more information about services and support, how would you prefer to find out about what is available to you?



Category	Number	% respondents
Signposted by health & social care professionals you have contact with (for example, GP, Nurse, pharmacist)	73	59.3%
Online	58	47.2%
Email	48	39.0%
Post	41	33.3%
Local press/newspaper	18	14.6%
Other	15	12.2%
Radio	6	4.9%
Total Respondents	123	

Source: Warwickshire Carers Engagement survey, 2015

When looking for more information about services, respondents felt that signposting was important to them with nearly 60% of carers identifying this as their preference to receive information and advice. Nearly half (47%) of respondents would prefer information to be accessible online and two in five (39%) carers would prefer information in an email solution and a third would prefer relevant information and advice by post.

The research from Osiris MR suggests that whilst there may be some demographic considerations with the digital route in terms of providing information; this may be a good way of creating and maintaining a database of connected carers and a cost effective route for disseminating the latest developments for carers to consider although the impact of this would need to be closely monitored.

Feedback from carers indicates that many carers are not aware of what support is available to them, especially early on in their caring journey.

‘Carers need to know what they don’t know. Carers tend not to know who or how to contact and what support is available and when’.

‘There is good help out there but how to know how to access it is the problem’.

‘More information regarding what support is available and where to go for help’.

‘More publicity is needed in a variety of ways to reach carers of different ages and at different stages of their caring journey’.

Carers told us that they felt that the same people that they indicated were well placed to support them to recognise themselves as carers (as detailed above), should also be able to signpost them to key sources of information, advice and support. Carers reported that they should be informed of and signposted to available information, advice and support services as early on as possible in their caring journey and this should be repeated at key points throughout their caring journey.

Carers reported that there were a number of key ‘touch points’ throughout the caring journey at which they should be supported to both recognise themselves as a carer, and be signposted to available sources of information, advice and support. The key touch points carers told us about are:

- GP visits
- Immediately after diagnosis of the cared for person
- Visits from Community Health Workers (e.g. District Nurses, OTs)
- At point of assessment (social care and/or health) for the cared for
 - Continued at subsequent reviews
- Hospital appointments / elective admissions
- Visits to A & E and non-elective admissions
- Hospital discharge
- Approaching end of life (at palliative care stage)

‘Information should be available whenever possible at point of diagnosis so liaison with NHS essential’.

‘Over 45’s MOT / Health check, they could ask the question during this session, ‘are you a carer or a cared for?’ Record contact details and share data’.

‘Dedicated staff needed in hospitals and surgeries, (for example Cheltenham Hospital, Gloucestershire Carers Support). It is very easy to identify carer whilst cared for is in hospital and at point of discharge. There should be a mechanism for someone to follow up with carers a couple of weeks or a month later’.

‘When a diagnosis is included (e.g. Dementia/Parkinson’s) it should trigger a referral for main caregiver (partner/family/friend) for discussion around what to expect, the possible impacts upon them and where they can go for help and support’.

‘Carer Support Services need liaison with specialists and any workers, and GPs who could give out support information as appropriate’.

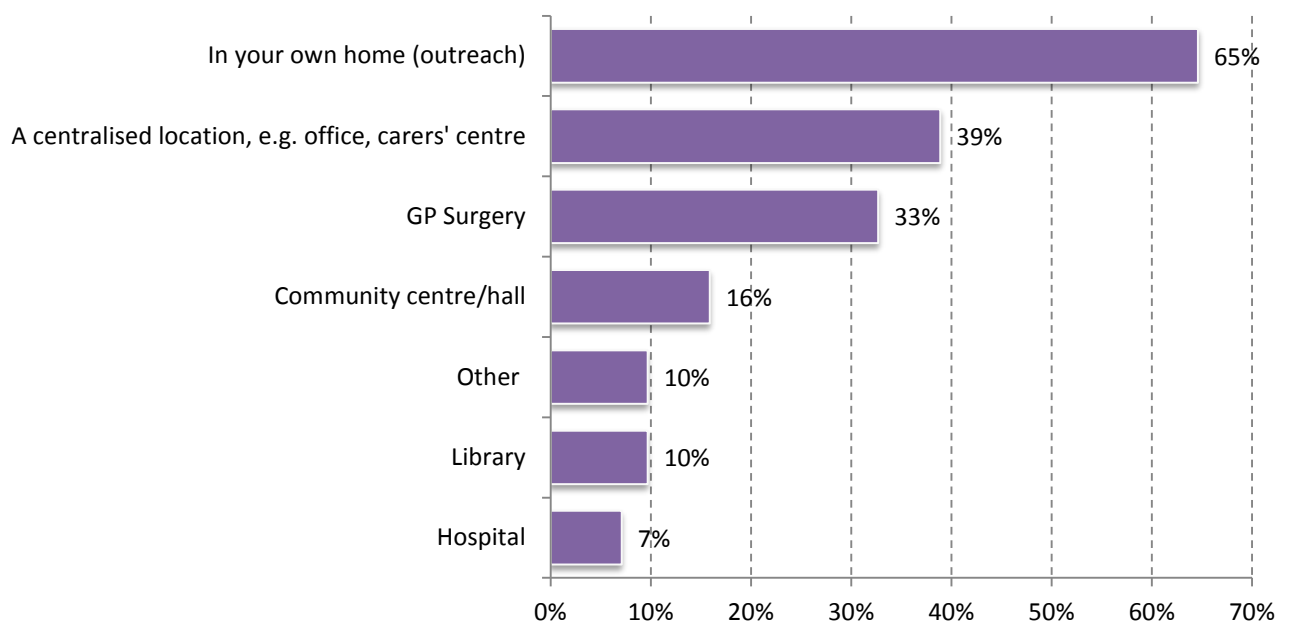
In addition to carers told us that access to written information (both online and hard copy) would be helpful, and it would be useful to be given some written information when they are signposted to available information, advice and support services.

‘A pack of information as to what support is available and how to contact those responsible for it would be helpful’.

‘Our age profile is such that not all use computers so whatever publicity there is should include all other means such as phone numbers as well as web pages and email addresses with publicity in non-computer media as well as on-line’.

Working in partnership across GP practices, hospitals, social care and commissioned carers support services to identify carers, support them to recognise themselves as carers and signpost and/or refer to available sources of information, advice and support is crucial.

Where would you prefer to access a face-to-face these support service?



Category	Number	% respondents
In your own home (outreach)	73	64.6%
A centralised location, e.g. office, carers' centre	44	38.9%
GP Surgery	37	32.7%
Community centre/hall	18	15.9%
Library	11	9.7%
Other	11	9.7%
Hospital	8	7.1%
Total	113	

Source: Warwickshire Carers Engagement survey, 2015

Nearly 65% of carers would prefer to access face-to-face support in their own home in comparison to 39% who would prefer a central location. A third of respondents would be happy accessing support via their GP surgery.

In summary, carers in Warwickshire were identifying that they would like further support and information. This could be in the form of a break from their caring responsibilities, or relevant information and advice, or support in planning the future care needs of the person they care for.

When the respondents were looking for support, three in five (59%) believe that it should be signposted by health and social care professionals and that support should be available online and by email.

A number of respondents identified that they would prefer to access face-to-face support during the daytime but they would prefer this support to be available in the home (65%).

When a Caring Role Ends

There will come a time when a person's caring role will come to an end, either because the person who was being cared for has recovered and no longer needs care, they can no longer be cared for at home, or because they have died. Whatever the reason, ceasing caring is likely to cause significant change to a carer's life. It is likely to be an emotional time, with the former carer experiencing mixed emotions likely to include guilt, grief, emptiness or loneliness and a sometime a sense of relief.

If a person's condition deteriorates and they require more support than their carer is able to give, the local authority should be asked to assess or reassess their care needs and offer a carer's assessment to the carer. Both the cared for and the carer may be entitled to extra support in these circumstances.

If it is no longer possible for the carer to give the person they care for the support that they need, it is sometimes appropriate for that person to be moved into a care home, supported accommodation or a hospice if it is end of life care. A carer is likely to feel a sense of guilt suggesting a move, but if the person's needs are overwhelming, it is only sensible to find an alternative, more sustainable way for them to get the care they need. Caring can be both physically and mentally exhausting and there are often limits to the level of care that can be provided in the home. If the person being looked

after is no longer able to look after themselves and their carer is unable to provide the care they need, for whatever reason, alternative accommodation is an option. It is better to arrange the best care possible than struggle on until the person reaches crisis point. The local authority and GP practices need to do more to signpost carers to local support groups and services when a person's caring role is likely to come to an end.

In Warwickshire, 4,871 people died in 2014, of which 70% were over the age of 75 years. This is in line with previous years. A substantial proportion of these people will have been cared for, especially towards end of their life.

Figure 52: Warwickshire Mortality Data by age of death, 2012-2014

Age group	2012	2013	2014
0-17 years	12	15	15
18-64 years	670	662	630
65-74 years	782	809	833
75-84 years	1,430	1,380	1,386
85+ years	1,959	2,043	2,007
Total	4,853	4,909	4,871

The end of a caring role may take time to adjust to. If someone is always used to the duties associated with caring, it can be hard for them to stop and think about what they would like to do and be able to make choices for themselves. Some people find that once they are no longer caring, they feel physically and emotionally exhausted, and may feel quite unwell for a time afterwards.

Over time, the end of a caring role can bring opportunity. Some people decide to volunteer, offering help to local people or organisations whilst in turn meeting new people. Others may feel that they would like to refresh skills which they have not used in a while, or learn a new skill at their local college or online. For some people, their caring role will have meant that they have had to give up work or reduce their hours. The end of their caring role may mean that they are able to return to work.