Suffolk Carers Needs Assessment

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SECTION 1: INTRODUCTION

1.1. Who are carers and how do they contribute?

The scope of this needs assessment covers carers across all ages, including young carers, young adult carers and adult carers.

There is currently no single agreed definition of what is meant by the term ‘carer’. For the purposes of this Needs Assessment, we have used the definition contained within ‘Commissioning for Carers’ (ADASS et al, 2009) which was developed jointly by a number of carers and commissioners’ organisations including the Association of Directors of Adult Social Services (ADASS) and the Improvement and Development Agency (IDeA):

‘A Carer spends a significant proportion of their time providing unpaid support to a family member, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems’.

For young carers, the following definition, developed by ADASS, the Association of Directors of Children’s Services and the Children’s Society (2012) is applied:

‘The term young carer should be taken to include children and young people under 18 who provide regular or ongoing care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances. A young carer becomes vulnerable when the level of care-giving and responsibility to the person in need of care becomes excessive or inappropriate for that child, risking impacting on his or her emotional or physical well-being or educational achievement and life chances’

Young adult carers fall between these two cohorts and include those with a caring responsibility as an adolescent who are transitioning into adulthood. Young adult carers are categorised in Suffolk as being aged 16-24.

Caring for our relatives and friends when they are in need is a challenge that the vast majority of us will need to rise to at some point in our lives. When a family member or friend becomes sick or experiences ill-health, it has the potential to change lives forever and can have a profound and lasting effect on the health and wellbeing of family members who look after them. The support offered by carers is critical to these people and is one of the most valuable assets within our communities. Without the work of carers, the formal care system would be likely to collapse (Royal College of General Practitioners, 2013).

Carers are as diverse as society itself. They may be any age and come from any cultural background. Many carers are invisible to the health and care system. This is partly because they do not define themselves as ‘carers’ and dislike the label, believing it detracts from their identity as parents, sons, daughters, partners or friends (RCGPs, 2013).

When considering a Clinical Commissioning Group (CCG) or Local Authority (LA) population of approximately 200,000 people, the diagram on page 6, taken from the
RCGP’s ‘Commissioning for Carers’ guidance, offers an overview of a typical caring community and the contribution carers make.

Fig 1: Your Caring Community (taken from RCGPs, 2013)

The most important thing that carers do is help the person or people they care for to remain independent and live the life they choose. They do this in a number of ways, such as undertaking practical things for the person they care for, knowing about the person and his or her health needs, and providing love, friendship, connection and reassurance for the person they care for (RCGPs, 2013).

Fig 2. What carers contribute (taken from RCGPs, 2013)
Although carers do not generally choose to care, most prefer to look after their family members or friends rather than have someone else care for them. The tasks that carers perform depend on a number of factors, including:

**The needs of the person:** a person with mental health problems will have very different needs to a person with paralysis;

**The carer’s circumstances:** if the carer works or has other caring responsibilities, he or she might not have time to perform some caring tasks. Similarly, if the carer has previous health or care experience, he or she might take on tasks that other carers would find too demanding.

**The environment:** the range of locally commissioned support services; whether the person lives close by or in the same home as the person; personal finances – whether the person is eligible for state funded care; the carers’ own financial situation.

### 1.2. Why is it important for Suffolk?

The reported prevalence of carers in England and Wales is around 6 million and 1.4 million people provide unpaid care for more than 50 hours per week (Health and Care Information Centre, 2012; Office for National Statistics, 2013a). The 2011 census identified that 77,745 people (of all ages) in Suffolk provide at least one hour of unpaid care a week. This represents 10.7% of Suffolk’s total population. This is in line with the regional and national averages (East of England: 10.2%; England: 10.2%) (ONS, 2013a).

To contextualise these figures at a micro level, for every 100 patients on a GP’s practice register, the RCGPs suggests the practice would expect to find 2 people to be caring for at least 50 hours a week, 3 or 4 to be caring for more than 20 hours each week, and 10 to be caring for under 20 hours (RCGPs, 2011).

At the macro level, the 2011 Census estimates there is a total 77,745 unpaid carers providing 1 or more hours of unpaid care. When stratified by the number of reported unpaid care hours per week, there are 17,194 carers providing 50+ hours, 9,044 providing 20-49 hours and 51,507 providing 1-19 hours (ONS, 2013a).

**Fig 3:** Suffolk’s Carer Population Stratified by Hours of Unpaid Care per Week
The ongoing support from carers will be a particular issue for the health and care system in the future, as changing demographic patterns, shifts in family composition, labour force participation and increased geographical mobility affect the availability of the unpaid care workforce (Pickard, 2013).

A growing family care gap means that 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, 1.1 million older people in England will need care from their families – an increase of 60 per cent – but the number of people able to care for older parents will have increased by only 20 per cent, creating a shortfall in our collective capacity to care for older generations (Pickard, 2013).

This is a particular concern for Suffolk given its current and projected population age profile. Figure 4 below highlights Suffolk has greater numbers of older people aged 65+ when compared to the England average.

By 2037, Suffolk will have a further 94,900 people overall. There will be 103,900 more over 65s and 37,400 more over 85s. About 31% of the population of Suffolk will be over 65 compared with 24.0% in England as a whole:

**Fig 4: Distribution of Population by Broad Age Band Residents of Suffolk County Council and England 2012 and 2037.**
There will also be more carers of working age in the future, requiring them to juggle responsibilities such as employment, raising young children and the coordination of health and care services.

Often these pressures can manifest in carer stress and, ultimately, if unaddressed, carer breakdown (Carers UK, 2014). This is a concern, as carer stress and having no carer are major precipitants of admission to long-term residential and nursing care. Bebbington et al (1996) estimate carer stress as the reason for admission to residential and nursing care in 38% of cases and family breakdown (including loss of the carer) the reason in a further 8%. Moreover, a study by Banerjee et al (2003) ‘Predictors of Institutionalisation in People with Dementia’ provided a longitudinal study of 100 people aimed at identifying what patients and carer characteristics influence transition into residential care for people with dementia. The most striking finding of this research is the 20-fold protective effect of having a co-resident carer.

As can be seen in Fig 5 below, Suffolk already has relatively high numbers of permanent admissions to residential and nursing care homes in people 65+ (797 per 100,000) when compared to national averages, so offering support and respite to enable people to continue caring clearly has the potential to impact upon and improve this outcome by delaying or preventing permanent admission to long-term care.

Figure 5: Permanent Admissions to Residential and Nursing Care Homes for People 65+
When considering young carers and young adult carers, the evidence-base associated with their socio-economic characteristics, educational attainment and chances of being in training or paid work is strengthening. There is no doubt that caring has a significant impact on many young carers and young adult carers. So much so that they face disadvantages that not only affect their childhood and education in the here and now, but also cast a shadow forward and affect their futures and prospects in later life (Children’s Society, 2013). Therefore, offering young carers and young adult carers in Suffolk the support they need to equalise these disadvantages and help them succeed at school, in employment and into adulthood is integral to Suffolk County Council’s (SCCs) strategic priorities such as Raising the Bar.

2014 is also a time of significant policy and legislative change for both adult and young carers with the introduction of the Care Act 2014 and the Children and Families Act 2014. More detail is offered on these Acts in the National Policy Context section of the needs Assessment on page 12. It is safe to say, however, these legislative changes will have significant implications for SCC and the way services in which carers services are commissioned and need to be delivered, potentially requiring significant re-design of current delivery and changes in professional practice.

Therefore, now is the time for those who commission and deliver carer support services in Suffolk to come together and work together to re-shape the commissioning and delivery of carer support services in ways that strengthen the rights of carers and achieve better outcomes for this vital cohort of people.

1.3. Outcomes Frameworks for Adult Social Care, Public Health and the NHS

The Department of Health (DoH) has committed to improving alignment between the Adult Social Care, Public Health and NHS Outcomes Frameworks, in recognition of the joint contribution of health and social care to improving outcomes. The three frameworks continue to contain a number of shared and complementary measures that relate to carers, and for 2014/15, a new complementary measure of people’s experience of integrated care is included in the Adult Social Care and the NHS Outcomes Framework.

The DoH has also pledged it’s commitment to pursuing the development of a population-based measure of loneliness for both the Adult Social Care and the Public Health Outcomes Framework, in recognition of the key role both adult social care services and public health services have to play in reducing loneliness.

Outlined below are the key outcome measures related to carers contained within the frameworks for Adult Social Care, Public Health and the NHS. Where measures relating to carers are shared or where a similar complimentary measure exists, these have been highlighted for the benefit of the reader. A measure is shared when the same measure appears in more than one framework. A measure is complementary when a similar
measure, addressing the same issue, features in more than one of the frameworks.

**Adult Social Care Outcomes Framework 14-15**

**Domain One: Ensuring quality of life for people with care and support needs**

- 1D. Carers can balance their caring roles and maintain their desired quality of life (NHSOF 2.4)
- 1I. Proportion of people who use services and their carers, who reported that they had as much social contact as they would like. (PHOF 1.18)

**Domain Three: Ensuring that people have a positive experience of care and support**

People who use social care and their carers are satisfied with their experience of care and support services:

- 3B. Overall satisfaction of carers with social services.
- New measure for 2014/15: 3E Improving people’s experience of integrated care (NHS OF 4.9).

Carers feel that they are respected as equal partners throughout the care process

- 3C. The proportion of carers who report that they have been included or consulted in discussions about the person they care for.

**NHS Outcomes Framework 14-15**

**Domain 2: Enhancing quality of life for people with long-term conditions**

- 2.4. Health related quality of life for carers

**Domain 4: Ensuring that people have a positive experience of care**

- 4.9. Improving peoples experience of Integrated Care.

**Public Health Outcomes Framework 13-16**

**Domain 2: Wider determinant of health**

- 1.8ii Social Isolation – percentage of adult carers who have as much social contact as they would like.

**1.4. National Policy Context**

1.4.1. Recognised Valued and Supported: Next Steps of the Carers Strategy (HM Government, 2010)

In 2010, the coalition government refreshed the National Carers’ Strategy, stating that by 2018 every carer should achieve the following five outcomes:
Outcome One: Recognised and supported as an expert care partner;
Outcome Two: Enjoying a life outside caring;
Outcome Three: Not financially disadvantaged;
Outcome Four: Mentally and physically well; treated with dignity; and
Outcome Five: Children will be thriving, protected from inappropriate caring roles.

In this refresh of the Carers' Strategy ‘Recognised, Valued and Supported: Next Steps for the Carers’ Strategy’ four priority areas were identified for action over the next four years. These priorities relate back to the outcomes above that the Government is seeking to achieve:

Priority 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 - relates most closely to outcome one.

Priority 2: Enabling those with caring responsibilities to fulfil their educational and employment potential’ - relates most closely to outcomes three and five.

Priority 3: Personalised support both for carers and those they support, enabling them to have a family and community life’ - relates most closely to outcome two.

Priority 4: Supporting carers to remain mentally and physically well’ - relates directly to outcome four.

Acting on these priorities to achieve the five outcomes is the overall goal of the refreshed National Carers’ Strategy and the basis for successful commissioning of services. More information about how these outcomes and priorities originated and the long-term plans to achieve them can be found in ‘Recognised, Valued and Supported: Next Steps for the Carers’ Strategy’ (HM Government, 2010) and the original strategy document ‘Carers at the Heart of 21st Century Families and Communities’ (HM Government, 2008).

1.4.2. The Care Act 2014 (DoH, 2008)

The legislative landscape related to carers is undergoing significant change. The Care Act 2014 gives LAs responsibility to assess a carer’s own needs for support. 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, and offer carers parity with the legal rights of the people they care for (GOV.UK, 2014a).

Appendix B of the Needs Assessment contains a short analysis, adapted from the Local Government Association (2014), of the Care Act 2014 clauses that the authors feel are most relevant to carers and carer services. The analysis describes whether these are new
provisions, or whether they are a consolidation or modernisation of law. The idea behind the analysis is that it may help the readers to consider the relative scale of challenge associated with each part of the reforms and what that mean for them and the local system. Naturally, local impact will depend on current local practice but the hope is that this will provide a starting point for anyone who wants to look at the provisions in Part 1 of the Care Act and how they relate to carers

1.4.3. The Children and Families Act 2014

In conjunction with the adults-focused Care Act 2014, the Children and Families Act 2014 seeks to make sure young carers get the support they need and are protected by law for the first time. Under the Children and Families Act 2014, local authorities are expected to try and identify young carers so they can be offered support and both adult and children’s social services should work together when helping young carers. When a child is identified as a young carer, the needs of everyone in the family should be considered. This should trigger both children’s and adults support services into action – assessing why a child is caring, what needs to change and what would help the family to prevent children from taking on this responsibility in the first place (Carers Trust, 2014).

1.4.4. NHS England’s Commitment to Carers

On 7th April 2014, NHS England launched the health services flagship policy for carers, titled: ‘A Commitment to Carers’ (NHS England, 2014). The policy recognises the valuable contribution carers make to their cared for and, moreover, to the health economy as a whole. Following extensive consultation involving carers and stakeholders from across the health and care system, eight key priority areas have been identified:

1. Raising the profile of carers;
2. Education, training and information;
3. Service development;
4. Person-centred, well-coordinated care;
5. Primary care;
6. Commissioning support;
7. Partnership links; and
8. NHS England as an employer.

Underneath these eight priorities sit 37 commitments to carers which are in the gift of NHS England, working with CCGs, to deliver on. More information on these 37 commitments can be found in ‘A Commitment to Carers’ (NHS England, 2014: 11-18).

1.4.4. The Better Care Fund

The other significant national policy driver is the Better Care Fund (formerly the Integration Transformation Fund). The £3.8bn fund was announced by the Coalition Government in the June 2013 spending round to support a transformation to more integrated health and social care. The Better Care Fund (BCF) is a single pooled budget to support health and social care services to work more closely together in local areas. The fund is created from
1.9bn of existing NHS funding and a further 1.9bn of funding that is currently allocated across the wider health and social care system (Local Government Association, 2013). This will comprise:

- £130m Carers’ Break funding
- £300m CCG reablement funding
- £354m capital funding (including £220m Disabled Facilities Grant)
- £1.1bn existing transfer from health to adult social care.

1.5. Local Policy Context

Suffolk’s local health and social care system is working hard on the implementation of these national policy and legislative drivers, against the backdrop of budgetary and demand pressures. In order to meet these challenges, Suffolk’s health and social care system has set out an ambitious transformation programme that has relevance to this needs assessment.

It is beyond the scope of the Needs Assessment to cover these areas in detail, therefore, this section aims to highlight to the reader where salient relationships exist between this work and existing local strategies and transformation programmes:

- **Suffolk Young Carers and Young Adult Carers Strategy:** In April 2010, SCC launched the Young Carers and Young Adult Carers Strategy which was designed to improve the outcomes for this cohort of children and young people aged 5 to 25 years, and for their families. The three year strategy was developed by a multi-agency steering group comprising representatives of the key statutory and voluntary agencies.

- **The Family Carers in Suffolk Strategy:** was a response to The Department of Health’s 2006 White Paper ‘Our Health, Our Care, Our Say’ from which the National Carers Strategy ‘Carers at the heart of 21st-Century Families and Communities’ emerged. In 2008 the Family Carers in Suffolk Strategy was endorsed by the Suffolk Primary Care Trust. Since 2008 Suffolk County Council and Voluntary Sector Organisations have been working towards the strategic priorities, such as a strengthening Family Carer communities and shifting to a more preventative focus of services.

- **Raising the Bar:** Is Suffolk’s response to raising levels of education attainment in Suffolk. The objectives of Raising the Bar are that:
  - Every child reaches their potential
  - Every child is taught by a good or outstanding teacher
  - Every child attends a good or outstanding school
  - Every child is given the best preparation for life before and beyond school

- **Supporting Lives, Connecting Communities:** Adult and Community Service’s (ACS) 3 tier offer to communities to keep people remaining in their communities and as independent as possible.
- **Making Every Contact Count**: SCC’s programme focusing on re-shaping Children and Young People’s Services (CYPS) so they ensure every intervention counts and that waste and inefficiency are driven out of service and operational processes.

- **Health and Social Care Integration (HASIC)**: Local CCGs, ACS and provider partners are working together to review, re-design and jointly commission fundamental areas of the health and social care system with the aim of placing them on a more sustainable footing to meet the challenges of an aging population and increasing numbers of people living with multiple co-morbidities.

Another important facet of the local policy context is the fact that ACS and local CCGs have key contracts for carer support services expiring in 2014-15, representing a unique opportunity to work together to respond to the challenges the health and care system faces by aligning resources and commissioning in more integrated ways.

1.5. Which Population is this Needs Assessment About?

This needs assessment will examine the needs of carers of all ages living in Suffolk County. This includes the areas covered by West Suffolk CCG (WSCCG), Ipswich and East Suffolk CCG (I&ESCCG) and Waveney, which is served by Great Yarmouth and Waveney CCG (GY&WCCG).

1.6. Aims and Objectives of This Needs Assessment

The overall aim of the carers needs assessment is to assess whether services for people who are carers are meeting current and future need. The objectives of the needs assessment are to:

1. Ascertain the size of the need for carers services in Suffolk, using descriptive and comparative epidemiological techniques.

2. Map the current services for Carers in Suffolk and identify any gaps.


4. Engage stakeholders, including both professionals and the public, in identifying need and finding solutions.

5. Make recommendations for actions that will address unmet need in order to improve the quality of life of people who are carers.

A population’s ‘need’ for a service can be defined as the capacity to benefit from that service; this may differ from the demand for services and the services supplied. This needs assessment aims to outline the needs of the population and consider any mismatches between need and supply.
The graphs used in this needs assessment to present epidemiological data are displayed at local authority level. Where possible, corresponding graphs and tables presenting the same information at CCG level have been included and can be found in Appendix A. Graphs where corresponding information can be found in Appendix A the graphs are marked with an asterix (*) for the benefit of the reader.
SECTION 2: DESCRIPTIVE EPIDEMIOLOGY

Descriptive Epidemiology - Summary

This section of the report presents the expected numbers, distribution and pattern of people who are carers in Suffolk. This information helps to paint a picture of the local need which can then be compared with the current services on offer. This information is broken down by person, place and time.

Who are carers?

- The 2011 Census estimates that there are more than 77,000 people providing unpaid care in Suffolk.
- More than 12,000 people claim Carers Allowance in Suffolk.
- More than half of all carers provide between 0-19 hours of care per week, however more than a quarter of carers provide 50 hours or more of care per week.
- The largest proportion of carers are in the 50-64 and 65+ age groups.
- There are more women who are carers than men.
- There is some evidence to suggest that carers are more likely to have poorer health compared to non-carers.
- The largest proportions of carers identified through the 2011 Census are white. This is in-line with the East of England average but higher than the England average (93.9%).
- Ipswich has the highest proportions of non-white ethnic groups providing unpaid care.

What are the patterns over time?

- In absolute terms, the total number of people providing 1 hour or more of unpaid care in Suffolk has increased from 66,486 in 2001 to 77,000 in 2011, representing a 15.8% increase. As a proportion of the Suffolk’s total population, this represents an increase from 10.1% in 2001 to 10.7% in 2011, a 0.6% increase.
- The total hours of unpaid care in the East of England has increased by 5.9% between 2001 and 2011 according to 2011 Census data.
- The number of people claiming Carers Allowance in Suffolk rose by between 2.6% (Suffolk Coastal) - 11.5% (Waveney) across all of Suffolk’s district and boroughs between 2009 and 2013.
- It is predicted that the demand for carers will increase due to the proportional increase in the elderly population whilst the potential supply of carers will decrease.

- Based on 2011 Census figures, it is predicted that the number of people aged 65 and over providing unpaid care in Suffolk will rise from 23,051 in 2014 to 31,296 in 2030.

**Where do carers live?**

- The number of carers varies between CCG and local authority areas. Of the three CCGs, Great Yarmouth and Waveney have the greatest number of carers and West Suffolk has the least.

- The greatest percentage increase in the number of people claiming Carer’s Allowance is in Waveney local authority district.

- The self-reported health of carers in Waveney is worse than the national and regional average whereas other districts are comparable to regional and national averages.
2.1. Person

2.1.1. Prevalence

Prevalence is a measure of the proportion of a population that has a condition at a specific point in time.

We do not know the true number of people who are carers in Suffolk due to people not necessarily identifying themselves as a carer. This means that we have to use ways to estimate the number of people who are carers in Suffolk. In this report we use two different ways to estimate the number of people who are carers in Suffolk:

The first estimate of prevalence is taken from the 2011 Census reported by the Office of National statistics. This states that there are 77,745 people of all ages providing unpaid care in Suffolk. This may be subject to under-reporting however, if respondents do not consider themselves a carer. This represents 10.7% of the total population of Suffolk and is marginally higher than the East of England (10.2%) and England (10.2) average.

Graph 1: Estimated number of people providing unpaid care in Suffolk by local authority* (adapted from, ONS 2013a)
The second estimate of prevalence is taken from the number of people claiming Carers Allowance in Suffolk reported by the Department of Work and Pensions (DWP). This method is likely to significantly underestimate the number of carers in the county as we know that substantial numbers of carers do not claim Carers Allowance and, moreover, people under the age of 16 are not eligible to claim for the benefit. It may, however, help indicate the number of carers known to local authorities. In Suffolk, there are 12,150 people claiming carers allowance as of November 2013.
Graph 3: Number of people claiming carers allowance by local authority (adapted from Department for Work and Pensions, 2013)

Graph three shows that the number of claimants of Carers Allowance is highest in Waveney with almost 3000 people claiming the benefit. This is followed by Ipswich with 2550. Both of these local authority districts were estimated by the 2011 census to have over 13,000 unpaid carers. In Suffolk Coastal, where the 2011 census indicated there was the highest number of unpaid carers (just under 15,000 unpaid carers), there are 1950 claimants of the carers allowance. The eligibility criteria applied by government for claiming carers allowance is as follows (Gov.uk, 2014b):

- Claimants’ are 16 or over
- Claimants’ spend at least 35 hours a week caring for someone
- Claimants’ normally live in England, Scotland or Wales, or you live abroad as a member of the armed forces
- Claimants’ are not in full time education or studying for more than 21 hours a week
- Claimants’ earn less than £102 a week (after taxes, care costs while you’re at work and 50% of what you pay into your pension)
2.1.2. Incidence

Incidence is a measure of new occurrences of a state or condition within a specific time period.

It is difficult to ascertain exactly how many people become a carer for the first time across a time period as all data available refers to prevalence.

Published literature from the RCGPs (2013) suggests for a typical population of 200,000 people there will be ~ 6,000 people transitioning in or out of a caring role every year. By extrapolating these figures and modelling them to the current Suffolk population figure of 730,100, we might crudely estimate there are around 21,900 people transitioning in and out of a caring role each year in Suffolk.

2.1.3. Reasons for Caring

Adults

The 2011 Census and DWP Carers Allowance reports provide useful data in helping understand more about the prevalence of carers across the county, however, it offers little in terms of understanding the reasons people become carers or the health and social care needs of the people they care for.

Although limited to unpaid carers aged 18 and over, the Personal Social Services Survey of Adult Carers in England does provide data that commissioners might look to. The survey is a biennial survey undertaken by councils across England, which took place in its current format for the first time in 2012-13.

Nationally, 57,810 people out of a total sample of 125,950 carers using adult social care services responded to the survey, giving a response rate of 46%. For Suffolk, a total of 703 questionnaires were returned with the main respondents being in the 75-84 (28.4%) and 85+ (28.1%) age ranges. The majority of these respondents cared for people who were living at home with them (79.1%), with the remainder reported as living somewhere else (20.9%). Physical disabilities (57.1%), long-standing illness (42.2%) and problems connected with aging (40.5%) were the top three conditions experienced by the people being cared for:
Young People

There is a dearth of local data to help commissioners understand who young people are caring for. The Longitudinal Survey of Young People in England (LYSPE) does, however, provide a worthwhile source of information on young people’s lives and their journeys through compulsory education and into adulthood.

The LYSPE was commissioned by the then Department for Children, Schools and Families (DCSF, 2004) as a major innovative panel study of young people. It began in 2004, with over 15,000 young people aged 13 and 14 completing questionnaires, and finished in 2010 with over 9000 young people in the original cohort still completing questionnaires.

The LYSPE study offers rich data around the lives of young carer’s circumstances, lives and outcomes.

Previous research has shown that the person receiving care is often a parent, but can be a sibling, grandparent or relative (Becker, 2000). A survey of young carers undertaken by Dearden and Becker (2004) found that 66% cared for their parents, 31% cared for their siblings, 3% cared for their grandparents and 1% cared for wider family or community members. In addition, 10% of young carers cared for more than one person.

The LYPSE data points toward a greater proportion of young carers caring for their siblings, just under one in three were caring for their parents, one in eight were caring for their grandparents, and around one in ten were caring for relatives or non-relatives.
Whilst the LYPSE survey does not provide additional information about the reasons why young people are caring, existing research has found that when asked about the needs of the people they cared for, 50% said they were caring for someone with a physical health problem, 29% for a person with a mental health problem, 17% for someone with a learning difficulty and 3% for someone with a sensory impairment (Dearden & Becker, 2004).

2.1.4. Type of Care Provided

According to the Personal Social Services Survey of Adult Carers in England, the top three types of care that carers (18 and over) in Suffolk were providing were: ‘other practical help’ (94.1%), ‘keeping an eye on him/her to see he/she is all right’ (91.6%) and ‘help with dealing with care services and benefits’ (91.6%).
Table 1: Types of help being offered by unpaid carers in Suffolk (adapted from HSCIC, 2013)

<table>
<thead>
<tr>
<th></th>
<th>Personal care</th>
<th>Physical help</th>
<th>Helping with dealing with care services and benefits</th>
<th>Helping with paperwork or financial matters</th>
<th>Other practical help</th>
<th>Keeping him/her company</th>
<th>Taking him/her out</th>
<th>Giving medicines</th>
<th>Keeping an eye on him/her</th>
<th>Giving emotional support</th>
<th>Other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffolk</td>
<td>72.2%</td>
<td>64.4%</td>
<td>90.3%</td>
<td>88.7%</td>
<td>94.1%</td>
<td>83.9%</td>
<td>79.3%</td>
<td>80.2%</td>
<td>91.6%</td>
<td>87.7%</td>
<td>20.3%</td>
<td>690</td>
</tr>
<tr>
<td>England</td>
<td>66.1%</td>
<td>57.1%</td>
<td>85.8%</td>
<td>85.6%</td>
<td>92.9%</td>
<td>82.8%</td>
<td>76.1%</td>
<td>75.1%</td>
<td>90.6%</td>
<td>84.3%</td>
<td>21.2%</td>
<td>65,495</td>
</tr>
<tr>
<td>Eastern</td>
<td>68.5%</td>
<td>58.7%</td>
<td>86.8%</td>
<td>86.8%</td>
<td>94.5%</td>
<td>82.5%</td>
<td>76.0%</td>
<td>75.4%</td>
<td>91.8%</td>
<td>84.2%</td>
<td>18.9%</td>
<td>5,015</td>
</tr>
</tbody>
</table>

2.1.5. Amount of Care Provided

The amount of care provided varies widely. Graph one, below, shows the percentage of people of all ages providing unpaid care by number of hours per week by local authority.

Graph 5: Provision of unpaid care by number of hours per week and local authority *(adapted from ONS, 2013a)
It can be seen from graph five that in all district and borough council areas, more than half of carers provide between 0-19 hours of care each week, with the smallest proportion of carers providing 20-49 hours per week.

Between areas, district and borough councils have broadly similar proportions in each category; however Waveney have a smaller proportion of caregivers providing 0-19 hours per week than other areas, whilst the proportion of caregivers providing 50+ hours per week in Waveney is higher than the other council areas, East of England and England average.

The ONS analysis of unpaid care in England and Wales suggest a strong relationship between the percentage of an authority’s usual residents who are limited in daily activities and in the amount of unpaid care their residents provide (ONS, 2013b). This relationship can be seen in areas of Suffolk, with Waveney and Ipswich ranked highest in the county for the proportion of people reporting their day-to-day activities are ‘limited a lot’ and the percentage of unpaid care provision in the 20-49 and 50+ hours per week categories also featuring amongst the highest in the county.

Table 2: People reporting their day-to-day activities are ‘limited a lot’ (adapted from ONS, 2013b)

<table>
<thead>
<tr>
<th>Total Population</th>
<th>People reporting their day-to-day activities are ‘limited a lot’</th>
<th>Rank in Suffolk</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Persons Number</td>
<td>Persons Percentage</td>
</tr>
<tr>
<td>Suffolk</td>
<td>728,163</td>
<td>7.9</td>
</tr>
<tr>
<td>Waveney</td>
<td>115,254</td>
<td>10.5</td>
</tr>
<tr>
<td>Ipswich</td>
<td>133,384</td>
<td>8.0</td>
</tr>
<tr>
<td>Suffolk Coastal</td>
<td>124,298</td>
<td>7.9</td>
</tr>
<tr>
<td>Babergh</td>
<td>87,740</td>
<td>7.2</td>
</tr>
<tr>
<td>St Edmundsbury</td>
<td>111,008</td>
<td>7.1</td>
</tr>
<tr>
<td>Forest Heath</td>
<td>59,748</td>
<td>6.7</td>
</tr>
<tr>
<td>Mid Suffolk</td>
<td>96,731</td>
<td>6.7</td>
</tr>
</tbody>
</table>

2.1.6. Mortality

There is no local evidence to indicate whether mortality rates are higher in carers than the average population within Suffolk.

2.1.7. Morbidity

Data from the 2011 census indicates that the majority of carers in each local authority district self-report their health to be ‘very good’ or ‘good’. This proportion ranges from 69.2% in the Waveney area to 76.6% in Mid Suffolk. The proportion rating their health as ‘very good’ or ‘good’ in Waveney is slightly lower than the East of England and England average (74.0% and 72.7% respectively) (ONS, 2013a).
Regarding the percentage of unpaid carers rating their health as ‘bad or very bad’, Waveney have a higher proportion of these carers (7.5%) compared to the East of England and England average (5.7% and 6.6% respectively). Forrest Heath and Ipswich also have a slightly higher percentage of unpaid carers rating their health as ‘bad or very bad’ when compared to the East of England average (5.7%) (ONS, 2013a)

Graph 6: General health of people providing unpaid care in Suffolk* (adapted from ONS, 2013a)

There is evidence in the published literature to suggest that people providing unpaid care are at increased risk of psychological stress depending on their age and place in the labour market, which has a negative effect on their health and emotional wellbeing. The general health question asked in the 2011 Census encompasses mental as well as physical aspects of health. Therefore, the general health status of the local authority populations is likely to be influenced by the level of unpaid care its population provides (ONS, 2013a).

For example, Waveney has a high proportion of people providing unpaid care for 50 hours or more per week - ranked 37 out of 348 local authorities in England and Wales - and the percentage of people in its population reporting their health as ‘very good’ was ranked 333 out of 348 local authorities in England and Wales.
Table 3: Self-assessed general health rankings by Suffolk local authority (adapted from ONS, 2013b)

<table>
<thead>
<tr>
<th>Local Authority</th>
<th>Very good health</th>
<th>Good health</th>
<th>Fair health</th>
<th>Bad health</th>
<th>Very bad health</th>
<th>Provides no unpaid care</th>
<th>Provides 1 to 19 hours unpaid care a week</th>
<th>Provides 20 to 49 hours unpaid care a week</th>
<th>Provides 50 or more hours unpaid care a week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Babergh</td>
<td>180</td>
<td>46</td>
<td>187</td>
<td>249</td>
<td>275</td>
<td>215</td>
<td>45</td>
<td>249</td>
<td>217</td>
</tr>
<tr>
<td>Forest Heath</td>
<td>120</td>
<td>78</td>
<td>246</td>
<td>254</td>
<td>268</td>
<td>21</td>
<td>327</td>
<td>295</td>
<td>248</td>
</tr>
<tr>
<td>Ipswich</td>
<td>222</td>
<td>44</td>
<td>161</td>
<td>188</td>
<td>185</td>
<td>89</td>
<td>274</td>
<td>192</td>
<td>179</td>
</tr>
<tr>
<td>Mid Suffolk</td>
<td>129</td>
<td>90</td>
<td>205</td>
<td>285</td>
<td>302</td>
<td>193</td>
<td>58</td>
<td>279</td>
<td>236</td>
</tr>
<tr>
<td>St Eds</td>
<td>156</td>
<td>57</td>
<td>218</td>
<td>263</td>
<td>262</td>
<td>100</td>
<td>178</td>
<td>293</td>
<td>225</td>
</tr>
<tr>
<td>Suffolk Coastal</td>
<td>197</td>
<td>79</td>
<td>141</td>
<td>236</td>
<td>267</td>
<td>298</td>
<td>15</td>
<td>178</td>
<td>182</td>
</tr>
<tr>
<td>Waveney</td>
<td>333</td>
<td>20</td>
<td>21</td>
<td>72</td>
<td>72</td>
<td>290</td>
<td>144</td>
<td>87</td>
<td>37</td>
</tr>
</tbody>
</table>

Whether this suggests care is affecting health or whether care is higher because levels of ‘very good’ general health are lower and, therefore, there is greater need for care, is uncertain (ONS, 2013a).

When looking to the published literature, the University of York (2000) present evidence from the British Household Panel Survey reported that carers’ health was adversely impacted upon by their status as a carer in the following ways:

- Health of carers is more likely to deteriorate over time compared to the health of non-carers
- Many detrimental changes in unpaid carers health are over and above that which could be attributed to taking on a caring role
- No conclusive evidence that the health of unpaid carers improves once caring duties cease
- Greatest impact is upon emotional health and particularly amongst those providing more than 20 hours per week of care.
- Spouse-carers and mothers of disabled children are at greatest risk of psychological ill health
- There is a potential relationship between unpaid carers health and length of time as a carer with a carers health deteriorating as the caring role continues.
- Unpaid carers are likely to make additional contact with GPs both during and after the care episode

A study undertaken in Ireland undertaken in 2001 suggested that carers reported a higher level of longstanding illness than non-carers (42% compared to 38%), and carers were almost twice as likely to suffer from stress as non-carers (17% compared to 9%). The report also found that a higher percentage of carers smoke than non-carers (36% to 31%) although this was only significant in women. The relationship also only existed where the
carer lived with the dependent (Department for Health, Social Services and Public Safety, 2001)

The Princess Trust (2011) undertook a survey of older carers (over 60 years of age) and found that two thirds of older carers reported having long term health problems or disabilities themselves and one third reported having to cancel a planned treatment or operation due to their caring responsibilities. Seven-tenths of respondents felt that caring had a negative impact on their physical health and three quarters felt that caring had a negative impact on their mental health.

A recent survey by Sempik and Becker (2013a) looking at the impact of caring on 101 young adults in further or higher education found that 39% rated their physical health as either ‘just ok’ or ‘poor’ and 45% reported having mental health problems.

2.1.8. Characteristics of population affected

2.1.8a. Age

Graph seven below shows the percentage of people of all ages providing unpaid care by age group and local authority.

The graph shows that in all district and boroughs, the proportion of carers in each age group is broadly similar. When compared to the other local authority populations in Suffolk, Ipswich and Forrest Heath have higher proportions of young adult carers in the 16-24 & 25-34 age groups and lower proportions of cares in the 50-64 and 65 and over age group. Waveney has the highest proportion of carers in the 65 and over age group.

In absolute numbers, table four shows that the highest numbers of unpaid carers in Suffolk fall into the 50-64 and 65+ age brackets:
Graph 7: Provision of unpaid care by age group and local authority as a percentage of the population* (adapted from ONS, 2013a)

Table 4: Provision of unpaid care by age group and local authority in absolute numbers* (adapted from ONS, 2013a)

In the East of England, figures show that there is a smaller difference in the proportion of carers between the 50-64 and 25-49 age groups as there is in Suffolk. However, these proportions are smaller in the England figures. This may be due to the difference in age structure of the respective populations as it is known that Suffolk has a higher proportion of older people than the England average. It may, therefore, be expected that there are less young carers available in Suffolk.

2.1.8b. Age of Unpaid Carers and Hours Spent Caring

Graphs 8 & 9 depict the number of people providing between 0-19 and 50+ hours of unpaid care per week. Looking at graph 8, we can see the majority of people providing 0-19 hours...
of unpaid care fall into the 50-64 year age group, whereas the largest proportion of people providing 50+ hours pushes into the 65+ age group:

Graph 8: People providing 1-19 hours of unpaid care a week by age group and local authority* (adapted from ONS, 2013a)

Graph 9: People providing 50 hours or more hours of unpaid care a week by age group and local authority* (adapted from ONS, 2013a)
This graph shows that the largest proportions of carers who claim carers allowance are in the 65+ age group. This is true across all local authority districts, but is largest in Mid Suffolk.

2.1.8c. Gender of Unpaid Carers in Suffolk

The data available shows that the greater proportions of unpaid carers in Suffolk are female in all local authorities. Graph 11 below shows that there are around 15% more female carers than male and that this pattern is consistent across each local authority district area and nationally.
When analysis of the claimants of carers allowance is broken down by gender it can be seen from graph 12 that there is almost double the proportion of female carers receiving carers allowance compared to males.

**Graph 12: Proportion of claimants of carer’s allowance by gender (adapted from DWP, 2013)**

### 2.1.8d. Ethnicity

Table 5 below shows the ethnic groups of carers by local authority district, county, region and country as a proportion of the total carers identified through the 2011 Census. Table 6 offers the same date but in absolute numbers.
Table 5: Ethnic Group of Carers by Local Authority District, County, Region and Country (personal of all ages – Census 2011)

<table>
<thead>
<tr>
<th>Area</th>
<th>White</th>
<th>Mixed/multiple ethnic group</th>
<th>Asian/Asian British</th>
<th>Black/African/Caribbean/Black British</th>
<th>Other ethnic group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Babergh</td>
<td>98.6%</td>
<td>0.5%</td>
<td>0.5%</td>
<td>0.2%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Forest Heath</td>
<td>97.4%</td>
<td>0.6%</td>
<td>1.2%</td>
<td>0.5%</td>
<td>0.3%</td>
</tr>
<tr>
<td>Ipswich</td>
<td>92.7%</td>
<td>1.7%</td>
<td>3.0%</td>
<td>2.3%</td>
<td>0.4%</td>
</tr>
<tr>
<td>Mid Suffolk</td>
<td>98.7%</td>
<td>0.4%</td>
<td>0.6%</td>
<td>0.2%</td>
<td>0.1%</td>
</tr>
<tr>
<td>St Eds</td>
<td>98.0%</td>
<td>0.6%</td>
<td>0.8%</td>
<td>0.5%</td>
<td>0.2%</td>
</tr>
<tr>
<td>Suffolk Coastal</td>
<td>98.3%</td>
<td>0.6%</td>
<td>0.8%</td>
<td>0.2%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Waveney</td>
<td>98.7%</td>
<td>0.5%</td>
<td>0.5%</td>
<td>0.2%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Suffolk</td>
<td>97.4%</td>
<td>0.7%</td>
<td>1.1%</td>
<td>0.6%</td>
<td>0.2%</td>
</tr>
<tr>
<td>East of England</td>
<td>97.4%</td>
<td>0.7%</td>
<td>1.1%</td>
<td>0.6%</td>
<td>0.2%</td>
</tr>
<tr>
<td>England</td>
<td>93.9%</td>
<td>0.9%</td>
<td>3.6%</td>
<td>1.2%</td>
<td>0.3%</td>
</tr>
</tbody>
</table>

The proportional breakdown of ethnic groups of carers in Suffolk mirrors the East of England averages, with the largest ethnic group of carers identifying themselves as White (97.4%), followed by Asian/Asian British (1.1%). The lowest proportion of carers in an identifiable ethnic group is Black/African/Caribbean/Black British (0.6%). When compared with the England averages, Suffolk has a higher proportion of White carers (Suffolk 97.4% - England 93.9%) and smaller proportions of carers in Asian/Asian British and Black/African/Caribbean/Black British ethnic groups.

Table 6: Ethnic Group of Carers by Local Authority District, County, Region and Country (personal of all ages – Census 2011)

<table>
<thead>
<tr>
<th>Area</th>
<th>White</th>
<th>Mixed/multiple ethnic group</th>
<th>Asian/Asian British</th>
<th>Black/African/Caribbean/Black British</th>
<th>Other ethnic group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Babergh</td>
<td>9,716</td>
<td>9,582</td>
<td>48</td>
<td>50</td>
<td>22</td>
</tr>
<tr>
<td>Forest Heath</td>
<td>4,952</td>
<td>4,821</td>
<td>29</td>
<td>58</td>
<td>27</td>
</tr>
<tr>
<td>Ipswich</td>
<td>13,062</td>
<td>12,106</td>
<td>226</td>
<td>387</td>
<td>296</td>
</tr>
<tr>
<td>Mid Suffolk</td>
<td>10,468</td>
<td>10,330</td>
<td>45</td>
<td>60</td>
<td>22</td>
</tr>
<tr>
<td>St Eds</td>
<td>11,059</td>
<td>10,833</td>
<td>66</td>
<td>84</td>
<td>51</td>
</tr>
<tr>
<td>Suffolk Coastal</td>
<td>14,837</td>
<td>14,580</td>
<td>86</td>
<td>123</td>
<td>37</td>
</tr>
<tr>
<td>Waveney</td>
<td>13,651</td>
<td>13,477</td>
<td>68</td>
<td>66</td>
<td>27</td>
</tr>
<tr>
<td>Suffolk</td>
<td>77,745</td>
<td>75,729</td>
<td>568</td>
<td>828</td>
<td>482</td>
</tr>
<tr>
<td>East</td>
<td>597,591</td>
<td>561,388</td>
<td>5,659</td>
<td>21,660</td>
<td>7,118</td>
</tr>
<tr>
<td>England</td>
<td>5,430,016</td>
<td>4,839,604</td>
<td>67,192</td>
<td>353,301</td>
<td>131,356</td>
</tr>
</tbody>
</table>
In absolute terms, Suffolk Coastal has the highest number of people identifying themselves as white carers and Ipswich has the highest numbers identifying themselves as mixed/multiple ethnic group carers, Asian/Asian British carers and Black/African/Caribbean/Black British carers.

2.2. Place

2.2.1 Unpaid Care by Local Authority District and Borough

Both the 2011 Census and carers allowance data give an indication of the location of carers in Suffolk. Graph 13 shows that the highest numbers of unpaid carers are in Suffolk Coastal District, Waveney and Ipswich. The lowest number of unpaid carers is in Forest Heath.

Graph 13: Number of people providing unpaid care in Suffolk by local authority district*(adapted from ONS, 2013a)

Graph 14, below, shows that Suffolk Coastal and Waveney also have the highest proportion of carers in their resident population and that this proportion is above both the England and regional average. Forest Heath, Ipswich and St Edmundsbury have a smaller proportion of unpaid carers than the England and regional average. These figures do not however take into account any differences in age structures of the relative populations.
2.2.2. Claimants of Carers Allowance by Local Authority District and Borough

Graph 15 shows that the number of claimants of carers allowance is highest in Waveney with almost 3000 people claiming. This is followed by Ipswich with 2550. Both of these local authority districts were estimated by the 2011 census to have over 13,000 unpaid carers. In Suffolk Coastal, where the 2011 census indicated there was the highest number of unpaid carers (just under 15,000 unpaid carers), there are 1950 claimants of the carers allowance.
Graph 15: Number of claimants of Carer’s Allowance by local authority (adapted from DWP, 2013)

2.2.3. Unpaid Care by Age and Lower Layer Super Output Area

The next three graphics map the proportion of unpaid care provision with the population at Lower Layer Super Output Area (LSOA). The first map depicts the percentage of people of all ages providing unpaid care. The two thereafter show the percentage of people aged under and over 25 years of age, as reported in the 2011 Census.
2.3. Time

2.3.1 Changes in Estimated Unpaid Care Hours by Local Authority 2001-2011

The tables below, adapted from ONS (2013c) offer a comparison of the 2001-2011 census data by local authority, showing the total proportion of the population providing no unpaid care and, additionally, a breakdown of the number of hours of unpaid care provided within the respective populations. Looking across the individual local authority populations, the proportion of people providing unpaid care has remained almost unchanged over the ten year period. However, the hours of unpaid care being provided has marginally increased in the 20-49 and 50+ hour cohorts:

Tables 7 – 13: 2001 – 2011 Comparison of Proportion of Unpaid Care Hours by Local Authority (adapted from ONS, 2013c)

<table>
<thead>
<tr>
<th>Table 7: Suffolk Coastal 2001-2011 Census Data Comparison</th>
<th>2001</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provides no unpaid care %</td>
<td>89.3</td>
<td>88.1</td>
</tr>
<tr>
<td>Provides 1-19 hours unpaid care%</td>
<td>8</td>
<td>8.3</td>
</tr>
<tr>
<td>Provides 20-49 hours unpaid care %</td>
<td>0.9</td>
<td>1.3</td>
</tr>
<tr>
<td>Provides 50+ hours unpaid care%</td>
<td>1.9</td>
<td>2.4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 8: Waveney 2001-2011 Census Data Comparison</th>
<th>2001</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provides no unpaid care %</td>
<td>89.3</td>
<td>88.2</td>
</tr>
<tr>
<td>Provides 1-19 hours unpaid care%</td>
<td>7.2</td>
<td>7.1</td>
</tr>
<tr>
<td>Provides 20-49 hours unpaid care %</td>
<td>1.1</td>
<td>1.5</td>
</tr>
<tr>
<td>Provides 50+ hours unpaid care%</td>
<td>2.4</td>
<td>3.2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 9: Ipswich: 2001-2011 Census Data Comparison</th>
<th>2001</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provides no unpaid care %</td>
<td>90.4</td>
<td>90.2</td>
</tr>
<tr>
<td>Provides 1-19 hours unpaid care%</td>
<td>6.5</td>
<td>6.1</td>
</tr>
<tr>
<td>Provides 20-49 hours unpaid care %</td>
<td>1.1</td>
<td>1.3</td>
</tr>
<tr>
<td>Provides 50+ hours unpaid care%</td>
<td>2.1</td>
<td>2.4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 10: Babergh 2001-2011 Census Data Comparison</th>
<th>2001</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provides no unpaid care %</td>
<td>89.6</td>
<td>88.9</td>
</tr>
<tr>
<td>Provides 1-19 hours unpaid care%</td>
<td>7.7</td>
<td>7.8</td>
</tr>
<tr>
<td>Provides 20-49 hours unpaid care %</td>
<td>0.9</td>
<td>1.2</td>
</tr>
<tr>
<td>Provides 50+ hours unpaid care%</td>
<td>1.7</td>
<td>2.1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 11: Mid Suffolk: 2001-2011 Census Data Comparison</th>
<th>2001</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provides no unpaid care %</td>
<td>90.1</td>
<td>89.2</td>
</tr>
<tr>
<td>Provides 1-19 hours unpaid care%</td>
<td>7.5</td>
<td>7.7</td>
</tr>
<tr>
<td>Provides 20-49 hours unpaid care %</td>
<td>0.9</td>
<td>1.1</td>
</tr>
<tr>
<td>Provides 50+ hours unpaid care%</td>
<td>1.6</td>
<td>2.1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 12: St Edmundsbury: 2001-2011 Census Data Comparison</th>
<th>2001</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provides no unpaid care %</td>
<td>90.7</td>
<td>90</td>
</tr>
<tr>
<td>Provides 1-19 hours unpaid care%</td>
<td>6.8</td>
<td>6.8</td>
</tr>
<tr>
<td>Provides 20-49 hours unpaid care %</td>
<td>0.9</td>
<td>1.1</td>
</tr>
<tr>
<td>Provides 50+ hours unpaid care%</td>
<td>1.6</td>
<td>2.1</td>
</tr>
</tbody>
</table>
### Table 13: Forrest Heath: 2001-2011 Census Data Comparison

<table>
<thead>
<tr>
<th>Provides no unpaid care %</th>
<th>2001</th>
<th>2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provides 1-19 hours unpaid care%</td>
<td>92.2</td>
<td>91.7</td>
</tr>
<tr>
<td>Provides 20-49 hours unpaid care%</td>
<td>5.5</td>
<td>5.2</td>
</tr>
<tr>
<td>Provides 50+ hours unpaid care%</td>
<td>0.7</td>
<td>1.1</td>
</tr>
<tr>
<td>Provides 50+ hours unpaid care%</td>
<td>1.6</td>
<td>2</td>
</tr>
</tbody>
</table>

### 2.3.2 Changes in Numbers of Claimants of Carers Allowance by Local Authority 2009 - 2013

It can be seen from graph 16 below that the number of claimants of carers allowance in Suffolk has increased from between 2.6% (Suffolk Coastal) to 11.5% (Waveney) between 2009 and 2013. It is not possible to ascertain the exact reasons for this increase but it may be due to changes in need due to increasing age and comorbidities over time.

Graph 16: Percentage change in number of claimants of Carer’s Allowance (adapted from DWP, 2013)

#### 3.3 Changes in Estimated Number of Carers Over 65 Years of Age 2014 – 2030

The tables below are adapted from POPPI (Projecting Older Population Information) and show the changes in estimated numbers of carers over 65 years of age between 2014 and 2030. The projections that follow are segmented further by age and the number of unpaid care hours provided.

Total population figures for Suffolk will see the numbers of people providing unpaid care over 65 rising from 23,051 in 2014 to 31,296 in 2030, representing a percentage increase of 36%.
Table 14: Projections of Carers 65 and Over Providing 1 or More Hours of Unpaid per Week, Suffolk, 2014 - 2030 (adapted from Projecting Older People Population Information, 2014)

<table>
<thead>
<tr>
<th></th>
<th>2014</th>
<th>2015</th>
<th>2020</th>
<th>2025</th>
<th>2030</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffolk: Total population aged 65 and over providing unpaid care</td>
<td>23,051</td>
<td>23,631</td>
<td>25,743</td>
<td>28,202</td>
<td>31,296</td>
</tr>
</tbody>
</table>

Table 15: Projections of Carers 65 and Over Providing 1 - 19 Hours of Unpaid per Week, Suffolk, 2014 – 2030 (adapted from POPPI, 2014)

<table>
<thead>
<tr>
<th></th>
<th>2014</th>
<th>2015</th>
<th>2020</th>
<th>2025</th>
<th>2030</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffolk: People aged 65-69 providing 1-19 hours of unpaid care</td>
<td>5,592</td>
<td>5,669</td>
<td>5,030</td>
<td>5,382</td>
<td>6,188</td>
</tr>
<tr>
<td>Suffolk: People aged 70-74 providing 1-19 hours of unpaid care</td>
<td>2,923</td>
<td>3,075</td>
<td>3,951</td>
<td>3,529</td>
<td>3,800</td>
</tr>
<tr>
<td>Suffolk: People aged 75-79 providing 1-19 hours of unpaid care</td>
<td>1,894</td>
<td>1,913</td>
<td>2,234</td>
<td>2,901</td>
<td>2,611</td>
</tr>
<tr>
<td>Suffolk: People aged 80-84 providing 1-19 hours of unpaid care</td>
<td>1,086</td>
<td>1,111</td>
<td>1,267</td>
<td>1,507</td>
<td>1,972</td>
</tr>
<tr>
<td>Suffolk: People aged 85 and over providing 1-19 hours of unpaid care</td>
<td>658</td>
<td>684</td>
<td>808</td>
<td>988</td>
<td>1,236</td>
</tr>
</tbody>
</table>

Table 14: Projections of Carers 65 and over providing 20-49 Hours of Unpaid per Week, Suffolk, 2014 – 2030 (adapted from POPPI, 2014)

<table>
<thead>
<tr>
<th></th>
<th>2014</th>
<th>2015</th>
<th>2020</th>
<th>2025</th>
<th>2030</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffolk: People aged 65-69 providing 20-49 hours of unpaid care</td>
<td>934</td>
<td>947</td>
<td>840</td>
<td>899</td>
<td>1,034</td>
</tr>
<tr>
<td>Suffolk: People aged 70-74 providing 20-49 hours of unpaid care</td>
<td>629</td>
<td>661</td>
<td>850</td>
<td>759</td>
<td>817</td>
</tr>
<tr>
<td>Suffolk: People aged 75-79 providing 20-49 hours of unpaid care</td>
<td>586</td>
<td>592</td>
<td>691</td>
<td>898</td>
<td>808</td>
</tr>
<tr>
<td>Suffolk: People aged 80-84 providing 20-49 hours of unpaid care</td>
<td>416</td>
<td>426</td>
<td>486</td>
<td>577</td>
<td>756</td>
</tr>
<tr>
<td>Suffolk: People aged 85 and over providing 20-49 hours of unpaid care</td>
<td>259</td>
<td>269</td>
<td>318</td>
<td>388</td>
<td>486</td>
</tr>
</tbody>
</table>

Table 15: Projections of Carers 65 and Over Providing 50 or More Hours of Unpaid per Week, Suffolk, 2014 – 2030 (adapted from POPPI)

<table>
<thead>
<tr>
<th></th>
<th>2014</th>
<th>2015</th>
<th>2020</th>
<th>2025</th>
<th>2030</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffolk: People aged 65-69 providing 50+ hours of unpaid care</td>
<td>2,098</td>
<td>2,127</td>
<td>1,887</td>
<td>2,020</td>
<td>2,322</td>
</tr>
<tr>
<td>Suffolk: People aged 70-74 providing 50+ hours of unpaid care</td>
<td>1,727</td>
<td>1,816</td>
<td>2,334</td>
<td>2,084</td>
<td>2,244</td>
</tr>
<tr>
<td>Suffolk: People aged 75-79 providing 50+ hours of unpaid care</td>
<td>1,737</td>
<td>1,755</td>
<td>2,049</td>
<td>2,661</td>
<td>2,395</td>
</tr>
<tr>
<td>Suffolk: People aged 80-84 providing 50+ hours of unpaid care</td>
<td>1,394</td>
<td>1,425</td>
<td>1,626</td>
<td>1,934</td>
<td>2,530</td>
</tr>
<tr>
<td>Suffolk: People aged 85 and over providing 50+ hours of unpaid care</td>
<td>1,117</td>
<td>1,162</td>
<td>1,372</td>
<td>1,676</td>
<td>2,098</td>
</tr>
</tbody>
</table>
Section 3: Existing Services

Existing Services – Summary

This section describes the current services provided to carers in Suffolk. It aims to summarise what services are delivered, how they are accessed and where they are delivered. Where available, it includes a summary of service activity data and details of which commissioning body funds the service.

The service mapping reveals a wide range of carer support services across Suffolk that broadly reflects the full range of needs carers may experience as a result of their caring responsibilities. However, there are a number of issues that should be explored further by commissioners:

1. The mapping suggests a rather emergent approach to commissioning adult carers services. It is hard to identify a clear operating model or care pathway under which the current service offer for carers in Suffolk is being framed, communicated and delivered. There is no clear service taxonomy detailing how services are categorised and then appropriately matched to the needs of the carer or, moreover, how a carer might move through or between different service offers as their level of need fluctuates up or down.

Overcoming this issue will be important for ACS and compliance with the Care Act 2014, which places new requirements on the Directorate relating to carers and carers services including principles around Integration, Prevention, Information and Advice, and Assessment.

The Integrated Carers Commissioning Officers Group (ICCOG) are cognisant of this issue and posit ACS’s new operating model ‘Supporting Lives, Connecting Communities’ as a solution to help frame discussions about future re-design and commissioning of carer support services, applying a three tier stepped care model: Help to Help Yourself, Help When You Need It, Ongoing Support for those Who Need It (see p42).

This is a sound approach and would offer greater coherence to current service delivery and a more communicable care pathway for carers.
Consideration does, however, need to be given the size of the population requiring services in each tier of the operating model, as this will help determine how much resource needs to be targeted at the different service offers. Applying Suffolk’s unpaid care hours as a proxy indicator for a carers level of need and then overlaying this on the three tier operating model might provide a useful estimate of where resources should be focussed:

As with any stepped care model, commissioners also need to give consideration to how customers will move up and down the tiers (i.e. whether threshold criteria should apply)
and, moreover, how someone with acute and high levels needs might bypass or fast-track through steps in the model (i.e. moving straight through universal services to more specialised provision)

2. The mapping reveals there are seven different commissioning organisations involved in funding carer support services in Suffolk: ACS; CYP; Suffolk Fire and Rescue Service; Public Health Suffolk; I&ESCCG; WSCCG; and GY&WCCG.

Arguably this allows for a more localised approach to commissioning focused around the specific population needs of those commissioning organisations. However, it also has the risk of service inequality to emerge and there are clear indications of this starting to happen. For example, Respite on Prescription & Carer Support Workers in General Practice are services currently only available to certain populations in Suffolk.

The Integrated Carers Commissioning Officers Group (ICCOG) has been established to promote integrated commissioning and mitigation of this type of risks. A move toward a pooled budget arrangement, managed by members of ICCOG, may go even further in helping to bring greater coherence to commissioning, reduce service inequality and ensure resources are targeted in an intelligence led way.

3. It is unclear from the service mapping whether commissioners are trying to pursue a strategy that is focussed around disease/client specific groups, age related groups or a more global offer to all carers, irrespective of disease/client group or age. Current carer provision reflects a matrix approach to commissioning across these domains. A matrix commissioning may well be valid in certain areas but it carries risks of over commissioning to meet the same or similar needs.

4. The information about the volume and characteristics of the users of many carers services is variable, with some services able to provide more comprehensive information than others. The available activity lifeline alarms for carers data suggests that only a small proportion of the estimated number of people reporting themselves as an unpaid carer are receiving services. For example, there are 17,194 unpaid carers in Suffolk providing 50+ hours of unpaid care per week, yet only 922 customers in Suffolk received an Enhanced Carers Budget in 2013-14.

This may be due to a number of reasons, such as:

- There is a lack of capacity or resource going into current services;
- There is a lack of identification of carers and onward signposting to support services;
- There is a lack of awareness about the available services amongst the public and referring provider services and professional groups; and,
- Carers do not feel they require services and are managing their care and support themselves.

5. Data from the Annual Carers Survey for England 2012-13 (HSCIC, 2013) suggest some service areas of carer support may be lacking or poorly targeted at this cohort (e.g. table
below - lifeline alarms for carers). Commissioners need to investigate this issue further and the authors recommend using the Carers’ Hub ‘Toolkit for Commissioners’ (Fig 7 below) to help undertake a more thorough gap analysis of current service provision to ensure it is linked to meeting all five outcomes contained in ‘Recognised Valued and Supported: Next Steps of the Carers Strategy’:

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don’t Know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffolk</td>
<td>23.4%</td>
<td>76.1%</td>
<td>0.5%</td>
<td>580</td>
</tr>
<tr>
<td>England</td>
<td>36.0%</td>
<td>62.9%</td>
<td>1.1%</td>
<td>48,455</td>
</tr>
<tr>
<td>East of England</td>
<td>35.1%</td>
<td>64.3%</td>
<td>0.6%</td>
<td>4,295</td>
</tr>
</tbody>
</table>

6. There appears to be a lack of activity and performance data available for some service areas. The Carers Commissioners Group should consider how best to approach the issue of trying to better understand the value of its commissioned services in the next commissioning round.

**Figure 7: Carers’ Hub Toolkit for Commissioners (Carers Trust, 2013):**
3.1. Commissioned Carer Services

The below offers a summary of carer support services and includes those services directly commissioned by members of the ICCOG (ACS, CYP, PHS, WSCCG, I&ESCCG, GYW&WCCG). It is beyond the scope of the main report of this needs assessment to include all of the externally funded family carer support services in Suffolk.

The summary of services is separated into two parts:

- Young Carers & Young Adult Carers Provision
- Adult Carers Provision

3.1.1. Young Carers and Young Adult Carers Commissioned Services

Young Carers and Young Adult Carers Project:
Specialist support for young carers and young adult carers is commissioned by CYPS, Suffolk County Council and provided by Suffolk Family Carers (SFC). This involves a range of services and interventions that fall under the umbrella of the Young Carers and Young Adult Carers Project, namely:

- Information, advice and guidance
- Group activities and residential programmes;
- One to one intervention work;
- Supporting schools to provide a young carer friendly ethos;
- Core support for Young Adult Carers.

A detailed breakdown of the interventions carried out within the scope of the Young Carers Project includes:

- Information, Advice and Guidance – dedicated phone line in the Young Carers Team to answer questions from carers, their families and professionals. Open Monday to Friday, 9am to 4.30pm.
- The management of social media – regular consultation with young carers via Tumblr and for over 13s via Facebook. Production of a termly newsletter with young carer input;
- Meetings with young carers – yearly assessment/review meetings with all referred young carers who receive a service. Additional 1:1s with young carers who require extra support;
- Working with families within the CAF (Common Assessment Process). Attendance at TAC (Team Around the Child) and CIN (Child in Need) meetings advocating for young carers;
- Monthly clubs – 6 monthly clubs run in term-time, based in Lowestoft, Felixstowe, Woodbridge, Bury St Edmunds and Ipswich x 2;
- Short breaks – day events and activities and residential breaks to enable Young Carers to have a break from their caring role;
- Transport – help with transport for those who otherwise could not access short breaks;
- Condition specific work – tailored work with young carers on their ‘cared fors’ condition. These would usually be in 1:1 setting but ad hoc group work where there is need;
- School engagement – working with schools to engage them in carer sensitive practices. Awareness raising, supporting them to adopt good practice within the school, teacher training and encouraging them to work towards the Schools Award;
- Work within school – delivering assemblies, liaising with staff on specific young carer issues, running drop-ins for young carers;
- 5 – 8s pilot work – one off funding to ascertain the feasibility of extending the service to younger carers;
- University Campus Suffolk (UCS) research project – one off funding to work with UCS and 3 schools to identify what support works best in schools.

A detailed breakdown of the interventions carried within the scope of the Young Adult Carers Project work includes:

- Information, Advice and Guidance – dedicated phone line in the Young Adult Carers Team to answer questions from carers and professionals. Open Monday to Friday, 9am to 4.30pm.
- The establishment and running of social media, including a Facebook group for young adult carers to obtain information about events and services;
- Meetings with young adult carers – yearly assessment/review meetings with all referred young adult carers who receive a service. Additional 1:1s with young adult carers who require extra support;
- Short breaks – day events and activities and residential breaks to enable Young Adult Carers to have a break from their caring role;
- Empowerment and enabling – life skills and other life enhancing experiences (such as support to master independent travel) aimed at empowering young adult carer to lead fuller, independent lives and to engage in their local communities;
- Employment support – support for NEETs and other young adult carer in danger of becoming NEET with CV writing and interview skills etc.;
- Colleges – drop ins to provide information, advice to young adult carers;
- Colleges – working with professionals and support for staff to improve young adult carer good practice;
- Condition specific work – working with young adult carers on their ‘cared for’s condition;
- Wellbeing Work – Confidence and Self-Esteem courses; healthy eating and first aid courses;
- Mental health pilot work – one off additional funding to support young adult carers who are looking after someone with a mental health condition.
**Activities Unlimited:** this service is provides early help to children and young people and their families 0-18 years and 18-25 years, where young adults are in full time education. Interventions include short-breaks to meet the diversity of needs; specialist and inclusive activity provision; direct family help and self-support tools; access to overnight short break resources; targeted and themed breaks; and, contract beds. This service is funded by Suffolk County Council, CYPS.

**Suffolk Wellbeing Service:** Suffolk Wellbeing Service enables people in Suffolk to experience improved emotional wellbeing and promote early recovery from emotional health problems (e.g. low mood, stress and anxiety). This is a composite service which includes Norfolk and Suffolk NHS Foundation Trust Link Workers, Improving Access to Psychological Therapies (IAPT) and is joined by partner organisations from the 3rd sector. These services are primarily commissioned by I&ESCCG and WSCCG, with a contribution from the mental health pooled fund (which includes funding from Adult and Community Services). These services are not available in Waveney.

- **Boosting R Wellbeing:** SFC deliver this element of the composite service. The service offers locality based workshops over a 3 day period, totaling 12 workshops in total. The sessions are all aimed at boosting confidence and emotional resilience and wellbeing for young carers and young adult carers. This service is open to young carers and young adult carers aged 13-25 years.

### 3.1.2 Commissioned services for Adult Carers

Adult carers services have been organised using ACS’s Supporting Lives, Connecting Communities operating model as a framework to help organise and structure the list of adult services offered.

**Help to Help Yourself**

These services have been categorised as part of the universal service offer available to all carers. These services apply no criteria for access and people can self-refer or be signposted to them by health and social care professionals, VCS organisation or a member of the carer’s community.

**Information Line:** this service is provided by SFC and offers information, advice and guidance to adult carers over the telephone. Additionally, they provide 1-2-1 clinics with carers out in the community. Access into this service is open to self-refers, professionals and members of the wider public seeking information, advice and guidance. In 2013-14, there were 2,961 enquiries received by the service. Operating hours for this service are 0900 – 1630 hours Monday to Friday. This service is commissioned by ACS.

**Carers Centre:** Suffolk Family Carers provide the Carers Centre. Based in Claydon, the centre acts as a central gateway for telephone enquiries into SFC and provides a meet and greet service for any visitors to the site. Access to the Carers Centre is open to young
Carers, young adult carers and adults seeking information, advice and guidance. In 2013-14, there were 2,000 visitors to the centre and ~15,000 telephone enquiries. Operating hours for this service are 0900 – 1630 hours, Monday – Friday. This service is commissioned by ACS.

Community Development Work: The service is provided by SFC in partnership with other voluntary sector groups. It offers 1-2-1 support from an experienced adviser in a community setting as well as networking events offering information, advice and guidance in isolated communities and hard to reach groups. This provides opportunities for carers to network, meet other carers and learn from each other’s experiences. These events are open to carers of all ages and referral into the events is open to self and professional referrers. In 2013-14, there were 1500 referrals into these events. Operating hours are typically between 0900-1630hrs, Monday to Friday. This service is commissioned by ACS.

Carer Advisors in Primary Care: SFC provide advisory support to GP surgeries and community pharmacies to help in the identification of carers and the provision of information, advice and guidance. It offers 1-2-1 support work meetings, group work with carers and provides education to the practice staff. Although the service predominantly tends to support more adult carers, there are no exclusion criteria to this service and it accepts referrals from carers of all ages. The service is available to GP surgeries in West Suffolk only and has been running for 7 months. It has received 517 referrals. Operating hours for this service are 0900 – 1630 hours, Monday to Friday and occasional Saturdays. This service is commissioned by WS CCCG.

Hospital Based Carer Support & Carers Cabin: this service is provided by SFC at Ipswich Hospital and Papworth Trust at West Suffolk Hospital. The service aims to help identify carers, assist them in navigating the hospital processes and provide support to them during their cared fors stay in hospital. The service is available to adult carers only. Referral into the service can come from self-refers, health and social care professionals or wider members of the hospital staff. In 2013-14, there were 457 users of the service. There are no fixed operating hours for this service and it is delivered flexibly for 30 hours per week. This service is commissioned by ACS.

Louise Hamilton Centre: this service is provided by SFC and is situated at the James Paget University Hospital. It offers 1-2-1 support to carers, group workshops, information and advice. Access to the service is available to carers of all age groups and people can either walk in or be referred by a health and social care professional. The services operating hours are Monday to Friday, 0930-1930hrs and weekends from 1030 – 1730hrs. This service is commissioned by the GY&W CCG.

Parent Partnership Service: this service is provided by Access Unlimited and offers information, advice and guidance to parents about Suffolk’s SEND offer, in relation to their choices and concerns about Suffolk’s education provision. The service is delivered via a dedicated confidential helpline and trains parents to help them engage productively with education providers. This service is commissioned by CYPS.
**Dementia Advisors Service:** this service is provided by Age UK and delivers information and advice for people affected by dementia and their carers. This service is available county-wide and anyone is able to refer. This service is commissioned by ACS. Funding for this service runs out in March 2015, although a business case has been submitted to extend the contract.

**Dementia Helpline:** this service is provided by Sue Ryder and offers telephone information, advice and guidance for carers and their cared for. This service is available county-wide and is open to anyone seeking support. The services operating hours are 0900-1700hrs, Monday to Friday. In addition, the service operates 'listening ear' which offers emotional support to carers 24 hours a day. This is commissioned by I&ESCCG and WSCCGs. Funding for this service runs out in March 2015.

**Dementia Talking Support:** this service is delivered by volunteer telephone befrienders and coordinated by SFC. It offers structured telephone support to carers. The service is available county-wide and access is open universally to anyone affected by dementia seeking support. This is commissioned by I&ESCCG and WSCCGs. Funding for this service runs out in March 2015.

**Dementia Cafés:** these services are provided by Sue Ryder, Orbit Housing, and BUPA, offering a network of dementia friendly environments for carers and their cared for. Peer support and talks are delivered to carers. Access to the service is open universally to anyone affected by dementia seeking support. ACS has provided grant support for the development of these services.

**Dementia Peer Support:** provided by the Alzheimers Society, this service provider ~8 peer support groups that are facilitated by a support worker who also offers information advice and guidance. This is commissioned by I&ESCCG and WSCCGs, with additional grant support from Suffolk County Council. CCG funding for this service runs out in March 2015.

**ADHD (Attention Deficit Hyperactivity Disorder) Carer Wellbeing Service:** The primary contractor for this service is Norfolk and Suffolk NHS Foundation Trust but operational delivery of the service is sub-contracted to SFC. This service offers 2 wellbeing based support programmes for carers looking after someone with ADHD or ASD (Autism Spectrum Disorder). Each condition has its own carer-led programme and is structured over 3 weeks, lasting 3 hours per week. The service is provided throughout East and West Suffolk and forms the basis for ongoing peer support with other carers who are caring for someone diagnosed with the same condition. This service is primarily commissioned by I&ESCCG & WSCCG, with a contribution from the Mental Health Pooled Fund (which includes funding from ACS). This service is not available in Waveney.

**Suffolk Wellbeing Service:** Suffolk Wellbeing Service enables people in Suffolk to experience improved emotional wellbeing and promote early recovery from emotional health problems (e.g. low mood, stress and anxiety). This is a composite service which includes Norfolk and Suffolk NHS Foundation Trust Link Workers, Improving Access to Psychological Therapies (IAPT) and is joined by partner organisations from the 3rd sector.
These services are primarily commissioned by I&ESCCG and WSCCGs, with a contribution from the Mental Health Pooled Fund (which includes funding from ACS). These services are not available in Waveney.

- **Wellbeing for Me**: SFC deliver 18 courses per annum, each of 5 sessions, using SFC’s wellbeing toolkit. This service is open to adult carers 25+ years.

**Stroke Association**: This service is commissioned by GY&WCCG.

**Feed Back**: This service is commissioned by GY&WCCG.

**GY&W Mind**: This service is commissioned by GY&WCCG.

**Innovations Panel Funded Services**: the innovations panel is a carer led panel that evaluates bids for small sums of grant funding from a variety of voluntary sector groups. A range of small-scale initiatives are currently funded, including: Open Door Carer Support Group; Better Lives; CSV Media; Sensing Change; Halesworth Carers Group; Inspire; Sue Ryder; Lofty Heights; Bangladeshi Support Centre; Relate Norfolk and Suffolk; Kernos Centre; Carers Arts and Crafts Groups.

**Help When You Need It**

Commissioned services grouped under this category have been defined as those offering structured time-limited, goal orientated interventions that help people return to or maintain independence:

**Suffolk Careline Emergency Care Plan Service**: this service is provided by Suffolk Careline and offers carers an emergency support plan to give them peace of mind in the event of an unforeseen emergency. The aim of the service is to allow the cared for person to be looked after in the comfort and safety of their own home should an emergency situation occur. A plan is completed, including who to contact to attend to the cared for person in the event of an emergency. This service is commissioned by ACS.

**Respite on Prescription**: this service is provided by SFC and offers replacement care to allow carers to access hospital services to prevent deterioration of their own health. This service is available to adult carers in I&ESCCG and WSCCG populations. Referral must come via the carers GP. Between 2013-14, the Ipswich and East Suffolk service received 79 referrals. The West Suffolk Service commenced in 2014 and has received 10 referrals to date. This service is commissioned by I&ESCCG & WSCCG.

**Moving and Handling Tuition**: This service is provided by SFC and offers tuition to people whose cared for require the use of equipment (i.e. hoists, slide sheets, transfer boards etc.) to support their activities of daily life. The service is available in Ipswich and East Suffolk and open to carers of all age groups. In 2013-14, there were approximately 200 referrals into the service. This service is commissioned by I&ESCCG.

**Admission Prevention Service - Carer Support**: this service is delivered by Crossroads East Anglia and provides emergency respite support in the carers own home. The service
is available to carers of all ages and access to the service is via professional referral. The service is commissioned by WSCCG and available to carers in the WSCCG population only.

**iCARE Budget**: access to this budget is administered by SFC and provides small grants to carers of either £150 or £250 (one award per year). The iCARE budget is available to adult carers and can be accessed via self-referral or professional signposting. This budget is funded by ACS.

**Break Charity**: this service is commissioned by GY&WCCG and provides family respite for carers of children aged 5-18 years.

**Better Lives Programme**: SFC provide support worker input to the Better Lives Programme, offering support and advice to carers on issues relating to personalisation and transition from CYPS to ACS. This service is commissioned by ACS.

**James Paget Paediatric Service**: commissioned by GY&WCCG, this service provides respite service for families caring for young people aged 0-18 years.

**Caring for Dementia with Confidence**: provided by SFC, this service offers a structured programme of information and advice about how to care for people with dementia, covering the practical and legal issues associated with caring for people with dementia.

**Flexible Dementia Service**: this service is delivered by a range of different providers that includes: Allied Health, Care UK and Orwell. They provide a flexible re-ablement support service enabling people with dementia in crisis or potential crisis situation to remain in their own homes, including support for carers. The service also includes giving carers advice guidance and support to continue in their caring role. This service is commissioned by ACS on a spot purchase basis.

**Ongoing Support for Those Who Need It**

Service and interventions grouped within this category are more likely to be aimed at carers with substantial and sustained needs. These interventions may often have more specific eligibility criteria and be micro-commissioned by the carer themselves through a social care personal budget or direct payment:

**Carers Breaks Scheme for Carers of People with Neurological Conditions**: This service is provided by SFC and offers short-breaks and replacement care for carers of people with a neurological condition up to a value of £700. The service is available to I&ESCCG and WSCCG populations only. Carers of all ages can access the service and referral must be via a healthcare professional. In 2013-14, there were 50 referrals to the Carers Breaks scheme.

**Enhanced Carers Budget**: this budget is available to social work teams and can be used to prevent the escalation of crisis situation and carer breakdown. Family carers can receive
up to £1000 as a direct payment or managed personal budget. This budget is funded by ACS.

**Respite for People with LD and their Families:** two respite options are available to people with LD and their families. One is 28 respite nights or, alternatively, the other option is a personal budget to purchase respite of choice (maximum of £3,000). This budget is funded by ACS.

**Adjunctive Services**

These services have been identified as being directly commissioned but not sitting directly within the SLCC Operating Model. They have been described as adjunctive as they’re commissioned to supplement and improve the overall efficacy of the three tier operating model:

**Substance Misuse Involvement Officer:** this is a part-time post commissioned by PHS (Public Health Suffolk) and delivered through SFC. This post sits independent of the Drug and Alcohol Team (DAAT) commissioned service provider and supports the facilitation of service user and carer involvement in the evaluation improvement of DAAT’s commissioned services.

**Community Inclusion and Diversity:** provided by SFC, this facet of their service provides community development and service advice and equality standards for carers. This service is commissioned by ACS as part of the Strategic Partnership Agreement with SFC.

**Professional Training:** SFC provide professional training and education to health and social care professionals to help raise awareness of carers’ issues and identification of carers support needs in daily practice. This service is commissioned by ACS as part of the Strategic Partnership Agreement with SFC.

**Dementia Care Coaching Programme:** this is a programme to teach 76 people how to coach others in dementia care, with the intended outcome of creating an army of experts in dementia care.
Section 4: Service User Experience

Service User Experience - Summary

This section of the needs assessment has been informed by a variety of national and local engagement activities where data was gathered from carers and wider stakeholders involved in the delivery of carer support. The engagement activities include:

- NHS England’s Commitment to Carers;
- The Personal Social Services Survey of Adult Carers in England;
- Adult and Community Services Evaluation of the iCAREbudget 2011;
- Suffolk Family Carers and Papworth Trust’s 2013-14 end of year report on the iCAREbudget;
- A National Survey by Semper and Becker (2013) broken down into three analyses:
  1. Young Adult Carers at School: Experiences and Perceptions of Caring and Education
  2. Young Adult Carers at College and University
  3. Young Adult Carers and Employment
- 60 semi-structured interviews with carers undertaken by commissioners in Adult and Community Services as part of the co-production with carers to gather views about current service provision and changes they would like to see in future services.
- A local questionnaire sent out to health and social care professional in Suffolk to gather their views about carer support and care support services.

From these engagement activities, a number of common themes have been raised by carers & relevant stakeholders:

- More work is needed to enable identification of carers and onward signposting to appropriate support services, particularly amongst health and social care professionals.

- Information, advice and guidance needs to be made available at critical touch points in a carers journey (i.e. at point of diagnosis) and delivered from key settings such as primary care practices and hospitals.

- Health and social care professionals have asked that information about carers services needs to be concise, available all in one place, and in different media options i.e. in print and online. Health and social professionals also report benefit from receiving team presentations and visits from voluntary sector support services to explain the services they offer.
• Carers would like clinicians to provide them with good information about their cared for’s diagnosis/medical conditions and how this may impact upon their lives and caring role. They would like to be offered training and education to help them manage or facilitate self-management of their cared for’s condition(s).

• The Personal Social Services Survey of Adult Carers in England 2012-13 suggests Suffolk performs worse than the regional and national averages at delivering carers with lifeline alarms, structured training, employment support, and the offer of personal assistants.

• The introduction of personal budget has been positively received by the majority carers who received an iCAREbudget. When micro-commissioning for themselves, carers procure a diverse range of services and goods. Pursuing hobbies and interests or short breaks away were among the most popular ways to use the money in 2013-14.

• Further work is needed to improve the identification and support offered to young carers and young adult carers in Suffolk’s schools and colleges. Many of the recommendations made by Sempik and Becker (2013) are already been implemented in Suffolk’s schools by SFC projects but further gravitas could be given to this area of work if it were adopted as a strand of Suffolk County Council’s Raising the Bar programme.

• In depth customer interviews revealed the following emergent themes:
  
  o Carers would like better information about the wide range of different support service available. This needs to be delivered in appropriate settings, including primary and secondary care;
  
  o Carers report frustration with the need to constantly repeat their story to the different professionals and agencies involved in their lives;
  
  o Accessing planned respite has become an increasingly difficult issue for carers in Suffolk;
  
  o A range of different emotional and practical support interventions are needed i.e. support groups, benefits advice, short breaks;
  
  o Carers want to be seen as active participants in the care of their cared for. They require clinicians to offer them detailed advice about the medical condition, how this may impact upon their cared for’s lives and that of the wider family and, practical advice about how they can help with the ongoing management or self-management of their cared for.
The returned questionnaires from health and social care professionals revealed the following findings and themes:

- Professionals ranked access and referral to information, advice and guidance, carers breaks services and emotional support/counselling services as the most valuable services to them in their daily practice.
- On the subject of information about commissioned carer support services, professionals wanted information about these services to be presented in different media forms (print, online) and, where possible, delivered face-to-face at team meetings. The strongest theme to emerge in the feedback was that this information should be concise, consolidated all in one place, and shared with existing online platforms (i.e. trust & CCG website) which professionals are familiar navigating and use frequently.
- When asked if there were ‘any services we should be commissioning more of’ GP respondents wanted more access to emergency respite. There were also emergent themes about a lack of respite and general carer support services in the North of the county.
4.1. NHS England’s A Commitment to Carers: findings and outcomes from the participation exercise

On Wednesday 7th May NHS England (2014) published its commitment to carers to give them the recognition and support they deserve for the invaluable care they provide. There are 37 commitments spread across eight key priorities which include raising the profile of carers, education and training, person-centred coordinated care and primary care.

Methodology

The first step in reaching these priorities and commitments was to engage in a four week participation exercise, which was supported by stakeholders including carer and disease-specific charitable organisations. As part of the participation exercise, an online questionnaire was undertaken which a total of 301 people responded to.

The participation exercise culminated in an event which took place in December 2013. Almost 90 stakeholders were involved, including carers, carer groups, 3rd sector organisations, NHS England professionals, and health and social care professionals from a range of different sectors.

Key Findings and Emergent Themes for Carers

- According to the questionnaire results, 66% of respondents reported that health staff didn’t help to signpost them to relevant information or support (see Fig 4 below).
- When information and signposting was given, most people reported charities and support groups (Fig 5 below).

The key emergent themes from the event and carer’s feedback were categorised as:

1. Recognising me as a carer
2. Information is shared with me and other professionals
3. Care is flexible and is available when it suits me and the person I care for
4. Recognise that I may need help
5. Treat me as an expert in care, involve me.
6. Signpost me to information and link professional together
7. Treat me with compassion

4.2. Personal Social Services Survey of Adult Carers in England 2012-13

The Personal Social Services Survey of Adult Carers in England is a biennial survey, undertaken by councils, which took place in its current format for the first time in 2012-13. Carers’ thoughts and opinions are sought on a number of topics that are considered to be indicative of a balanced life alongside their caring role. Nationally, 57,810 people out of a sample of 125,950 carers of social care users responded to the survey, which is a response rate of 46%. The survey covered carers who are aged 18 or over when the questionnaires are distributed, and who are helping or looking after someone aged 18 or over.

Methodology

For Suffolk, a total of 703 questionnaires where returned with the main respondents being in the 75-84 (28.4%) and the 85+ (28.1%) age ranges. The main groups respondents where caring for were defined as people with physical disabilities (57.1%) and people with long-standing illness (42.2%). The majority of respondents cared for were living at home with their carer (79.1%) with the remainder living somewhere else (20.9%):

Age of people being cared for

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Percentage</th>
<th>Suffolk County</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>3.5%</td>
<td>Carer's Survey 2012/13</td>
</tr>
<tr>
<td>25-34</td>
<td>5.6%</td>
<td>28.4%</td>
</tr>
<tr>
<td>35-44</td>
<td>5.2%</td>
<td>28.1%</td>
</tr>
<tr>
<td>45-54</td>
<td>6.8%</td>
<td></td>
</tr>
<tr>
<td>55-64</td>
<td>6.9%</td>
<td></td>
</tr>
<tr>
<td>65-74</td>
<td>15.4%</td>
<td></td>
</tr>
<tr>
<td>75-84</td>
<td>28.4%</td>
<td></td>
</tr>
<tr>
<td>85+</td>
<td>28.1%</td>
<td></td>
</tr>
</tbody>
</table>

Conditions experienced by people being cared for

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
<th>Suffolk County</th>
</tr>
</thead>
<tbody>
<tr>
<td>A physical disability</td>
<td>67.1%</td>
<td>Carer's Survey 2012/13</td>
</tr>
<tr>
<td>Long-standing illness</td>
<td>42.2%</td>
<td>28.4%</td>
</tr>
<tr>
<td>Problems with eating</td>
<td>40.5%</td>
<td>28.1%</td>
</tr>
<tr>
<td>Depression</td>
<td>37.3%</td>
<td></td>
</tr>
<tr>
<td>Slight or missing teeth</td>
<td>33.3%</td>
<td></td>
</tr>
<tr>
<td>A mental health problem</td>
<td>21.6%</td>
<td></td>
</tr>
<tr>
<td>A learning disability</td>
<td>18.9%</td>
<td></td>
</tr>
<tr>
<td>Terminal illness</td>
<td>6.3%</td>
<td></td>
</tr>
<tr>
<td>Alcohol or drug dependency</td>
<td>1.1%</td>
<td></td>
</tr>
</tbody>
</table>
Key Findings

To arrive at these findings, Suffolk’s responses to the questionnaires were compared against both regional (East of England) and national (England) averages to identify questions and areas of service delivery where there was variation in carer’s feedback, both positive and negative. Definitive conclusions about individual service quality should not be drawn from these findings. Instead, commissioners might use this data to explore in greater depth some of the service areas where Suffolk appears to be underperforming in.

- Fewer carers in Suffolk reported having been offered a lifeline alarm compared to the East of England and National averages.

<table>
<thead>
<tr>
<th>Question: Has the person you care for used any of the support or services listed, in the last 12 months? - Lifeline Alarm</th>
<th>Yes</th>
<th>No</th>
<th>Don’t Know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffolk</td>
<td>23.4%</td>
<td>76.1%</td>
<td>0.5%</td>
<td>580</td>
</tr>
<tr>
<td>England</td>
<td>36.0%</td>
<td>62.9%</td>
<td>1.1%</td>
<td>48,455</td>
</tr>
<tr>
<td>East of England</td>
<td>35.1%</td>
<td>64.3%</td>
<td>0.6%</td>
<td>4,295</td>
</tr>
</tbody>
</table>

- Fewer carers in Suffolk reported having been offered training to help them fulfil their caring role compared to the East of England and National averages.

<table>
<thead>
<tr>
<th>Question: Have you used any of the support or services listed, to help you as a carer over the last 12 months? - Training for carers</th>
<th>Yes</th>
<th>No</th>
<th>Don’t Know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffolk</td>
<td>2.8%</td>
<td>95.5%</td>
<td>1.7%</td>
<td>470</td>
</tr>
<tr>
<td>England</td>
<td>5.3%</td>
<td>93.0%</td>
<td>1.7%</td>
<td>48,910</td>
</tr>
<tr>
<td>East of England</td>
<td>3.8%</td>
<td>94.9%</td>
<td>1.2%</td>
<td>4,255</td>
</tr>
</tbody>
</table>

- Fewer carers in Suffolk reported having been offered support to help them remain in employment compared to the East of England and National averages.

<table>
<thead>
<tr>
<th>Question: Have you used any of the support or services listed, to help you as a carer over the last 12 months? - Support to keep you in employment</th>
<th>Yes</th>
<th>No</th>
<th>Don’t Know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffolk</td>
<td>2.2%</td>
<td>96.4%</td>
<td>1.3%</td>
<td>450</td>
</tr>
<tr>
<td>England</td>
<td>3.4%</td>
<td>94.5%</td>
<td>2.1%</td>
<td>46,895</td>
</tr>
<tr>
<td>East of England</td>
<td>3.0%</td>
<td>95.3%</td>
<td>1.7%</td>
<td>4,025</td>
</tr>
</tbody>
</table>

- Fewer carers in Suffolk reported having used a Personal Assistant compared to the East of England and National Averages.

<table>
<thead>
<tr>
<th>Question: Has the person you care for used any of the support or services listed, in the last 12 months? - Personal assistant assistant</th>
<th>Yes</th>
<th>No</th>
<th>Don’t Know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffolk</td>
<td>11.7%</td>
<td>87.6%</td>
<td>0.7%</td>
<td>540</td>
</tr>
<tr>
<td>England</td>
<td>14.4%</td>
<td>83.4%</td>
<td>2.2%</td>
<td>45,735</td>
</tr>
<tr>
<td>East of England</td>
<td>12.6%</td>
<td>85.8%</td>
<td>1.5%</td>
<td>4,065</td>
</tr>
</tbody>
</table>

- More carers in Suffolk reported receiving information and advice compared to the East of England and National Averages.

<table>
<thead>
<tr>
<th>Question: Have you used any of the support or services listed, to help you as a carer over the last 12 months? - Information and advice</th>
<th>Yes</th>
<th>No</th>
<th>Don’t Know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffolk</td>
<td>65.8%</td>
<td>32.3%</td>
<td>1.9%</td>
<td>645</td>
</tr>
<tr>
<td>England</td>
<td>55.6%</td>
<td>42.0%</td>
<td>2.5%</td>
<td>52,965</td>
</tr>
<tr>
<td>East of England</td>
<td>54.0%</td>
<td>44.2%</td>
<td>1.95%</td>
<td>4,695</td>
</tr>
</tbody>
</table>
- More carers in Suffolk reported receiving support from carers groups or someone to talk to in confidence compared to East of England and National Averages:

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don't Know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffolk</td>
<td>44.1%</td>
<td>54.9%</td>
<td>1.0%</td>
<td>575</td>
</tr>
<tr>
<td>England</td>
<td>31.3%</td>
<td>67.1%</td>
<td>1.6%</td>
<td>51,885</td>
</tr>
<tr>
<td>East of England</td>
<td>27.4%</td>
<td>71.4%</td>
<td>1.3%</td>
<td>4,560</td>
</tr>
</tbody>
</table>

- More carers in Suffolk reported using day care services compared to East of England and National Averages:

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don't Know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffolk</td>
<td>37.1%</td>
<td>62.4%</td>
<td>0.5%</td>
<td>605</td>
</tr>
<tr>
<td>England</td>
<td>30.7%</td>
<td>68.2%</td>
<td>1.1%</td>
<td>48,845</td>
</tr>
<tr>
<td>East of England</td>
<td>31.3%</td>
<td>67.8%</td>
<td>0.9%</td>
<td>4,335</td>
</tr>
</tbody>
</table>

- More carers in Suffolk reported receiving support or services allowing them to take a break from caring for more than 24 hours when compared to the East of England and National Averages:

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Don't Know</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffolk</td>
<td>26.7%</td>
<td>72.0%</td>
<td>1.3%</td>
<td>605</td>
</tr>
<tr>
<td>England</td>
<td>22.9%</td>
<td>74.9%</td>
<td>2.2%</td>
<td>49,715</td>
</tr>
<tr>
<td>East of England</td>
<td>22.2%</td>
<td>76.0%</td>
<td>1.8%</td>
<td>4,375</td>
</tr>
</tbody>
</table>

- More carers in Suffolk report difficulties in looking after themselves compared to the England and East of England Average

<table>
<thead>
<tr>
<th></th>
<th>I look after myself</th>
<th>Sometimes I can't look after myself well enough</th>
<th>I feel I am neglecting myself</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffolk</td>
<td>55.1%</td>
<td>28.9%</td>
<td>16.0%</td>
<td>690</td>
</tr>
<tr>
<td>England</td>
<td>59.6%</td>
<td>26.4%</td>
<td>14.0%</td>
<td>55,950</td>
</tr>
<tr>
<td>East of England</td>
<td>61.4%</td>
<td>25.6%</td>
<td>12.9%</td>
<td>4,990</td>
</tr>
</tbody>
</table>

- More carers in Suffolk report feeling socially isolated and lacking in the social contact they would like when compared to the England and East of England average.

<table>
<thead>
<tr>
<th></th>
<th>I have as much social contact as I want with people I like</th>
<th>I have some social contact with people but not enough</th>
<th>I have little social contact with people and feel socially isolated</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suffolk</td>
<td>28.9%</td>
<td>53.8%</td>
<td>17.3%</td>
<td>690</td>
</tr>
<tr>
<td>England</td>
<td>41.5%</td>
<td>44.8%</td>
<td>13.7%</td>
<td>56,120</td>
</tr>
<tr>
<td>East of England</td>
<td>41.6%</td>
<td>44.8%</td>
<td>13.6%</td>
<td>4,985</td>
</tr>
</tbody>
</table>
Carers in Suffolk report they are receiving less encouragement and support than they would like when compared to the England and East of England average.

<table>
<thead>
<tr>
<th>Question: Thinking about encouragement and support in your caring role, which of the following statements best describes your present situation?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>I feel I have encouragement and support</strong></td>
</tr>
<tr>
<td>Suffolk</td>
</tr>
<tr>
<td>England</td>
</tr>
<tr>
<td>East of England</td>
</tr>
</tbody>
</table>

Some carers in Suffolk report finding information and advice fairly easy to find compared to the England and East of England average. However, a proportion of carers in Suffolk are still finding it difficult to find the information and advice they need when compared to the England and East of England Average.

<table>
<thead>
<tr>
<th>Question: In the last 12 months, have you found it easy or difficult to find information and advice about support, services or benefits?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>I have not tried to find information or advice in the last 12 months</strong></td>
</tr>
<tr>
<td>Suffolk</td>
</tr>
<tr>
<td>England</td>
</tr>
<tr>
<td>East of England</td>
</tr>
</tbody>
</table>

More carers in Suffolk reported the information they receive as being ‘quite helpful’ or ‘quite unhelpful’ when compared to the England and East of England average.

<table>
<thead>
<tr>
<th>Question: In the last 12 months, how helpful has the information and advice you have received been?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>I have not received any information or advice in the last 12 months</strong></td>
</tr>
<tr>
<td>Suffolk</td>
</tr>
<tr>
<td>England</td>
</tr>
<tr>
<td>East of England</td>
</tr>
</tbody>
</table>

4.3. iCAREbudget Evaluation 2011

The iCAREbudget was introduced by Adult and Community Services in 2010. It is offered to carers who meet certain needs criteria and is offered to them as a personal budget which they can use to purchase services or items that would assist them in their caring role.

**Methodology**

A questionnaire was designed and circulated via SurveyMonkey to customers in receipt of an iCarebudget in 2011. 84 people responded to the questionnaire.
Key Findings

- Carers used their personal budget to purchase a diverse range of services and items. For example: a contribution towards a new car to take their cared for to and from the hospital; having a garden landscaped to make it more manageable; gym membership; holidays and breaks; and, a new washing machine.
- When asked whether the iCARE budget provided them with a meaningful break from their caring role, 70.5% of respondents said ‘yes, very much so’; 21.8% said ‘yes, to a small degree’; 3.8% of said ‘no, not really’; and a further 3.8% said ‘no, not at all’.
- When asked whether the iCARE budget helped to support carers in their caring role, 70.9% of respondents said ‘yes, very much so’; 20.3% said ‘yes, to a small degree’; 7.6% said ‘no, not really; and, 1.3% said ‘no, not at all’.
- When asked whether the iCARE budget had a positive impact on their role as a carer, 77.8% of respondents said ‘yes, very much so’; 21.0% said ‘yes, to a small degree’; and, 1.2% said ‘no, not really’. No respondents felt the iCARE budget had no positive impact on their role as a carer.

4.4. iCARE budget: 2013-14 End of Year Report

In 2012, responsibility for the management of the iCARE budget was given to Suffolk Family Carers and Papworth Trust. The findings below are taken from an end-of-year report on the progress of the iCARE budget, including feedback from recipients of the budget.

Methodology

Evaluation questionnaires were sent out to 515 carers across Suffolk. 196 questionnaires were returned, representing a 38% response rate.

Key Findings

- 47% of respondents said they feel more confident in their caring role as a result of receiving the budget;
- 81% of carers said that having an iCARE budget made them feel recognised as a carer;
- Over 70% of carers who have received an iCARE budget had not had an iCARE budget before;
- A breakdown of the types of services carers commissioned for themselves included: Alternative Therapies (8.7%), Equipment (10.33%), Hobbies and Interests (22.48%), Holidays/Short Breaks (25.44%), Other (25.99%), Replacement Care (3.26%), Training (0.49%), Blank/Non Answer Provided (3.31%)
- Qualitative feedback from carers included statements such as:

  ‘This budget makes a massive difference to me. I can enjoy time for myself without feeling guilty or considering that I should have spent the money in another way. I always feel so much better after time at the spa. It gives me the energy to keep going. I can enjoy the time with my husband when I come home from a break so we both benefit in this way’
‘I care for 2 people. While it is difficult to find time to myself, with the cinema ticket I can turn off my phone and escape the roundabout of my life for a couple of hours and be myself. I can lose myself in a film, just relax and even snooze if I want to’

4.5. Young Adult Carers Survey

In 2013, The Carers Trust commissioned Dr Joe Sempik and Professor Saul Becker from the University of Nottingham to undertake research to find out the experiences and aspirations of young adult carers in relation to school, further and higher education and work.

Three reports were produced:

- Young Adult Carers at School: Experiences and Perceptions of Caring and Education (Sempik and Becker, 2013a)
- Young Adult Carers at College and University (Sempik and Becker, 2013b)
- Young Adult Carers and Employment (Sempke and Becker, 2013c)

The first in this series of reports explores the experiences and perceptions of school by young adult carers who are still at school (n=61).

4.5.1. Young Adult Carers at School: Experiences and Perceptions of Caring and Education

Methodology

An online survey was created in spring 2013 to collect the experiences of school of young adult carers (aged 14–24) and their views of higher and further education and employment. A total of 295 respondents provided data that was valid for inclusion in the analysis. Of all respondents, 61 were still at school and the results from this group are presented below.

Summary of Findings

- A survey of young adult carers (average age 15.5 years) who were still at school shows that two thirds were providing a high or very high level of care.
- Almost a third (29%) reported that their own physical health was ‘just OK’, and 38% reported having a mental health problem.
- Only half had received additional support from a member of staff at school. 42% said there was not a particular person at school who recognised them as a carer and helped them.
- Less than half (46%) thought they had received good careers advice and only 19% of the total sample thought that it took their caring role into account.
The majority of young adult carers (78%) considered they were doing well at school but less than half (48%) actually said they enjoyed school.

The majority (84%) said they intended to go to university or college. However, 24% thought they could not afford to go, and 41% were 'unsure' whether they could afford it. Young Adult Carers at School: Experiences and Perceptions of Caring and Education.

Most (67%) young people informed school staff that they were a carer but the majority of those who did not felt that 'there was no point' in telling anyone.

A quarter (26%) were bullied at school because of their caring role.

Few (15%) had received a formal review or assessment of their needs, and only half felt that their family received good support and services.

The majority of respondents who attended a young carers project or a young adult carers project (65%) felt that it had improved their confidence, and 54% thought that they had more friends as a result. 39% felt they had performed better at school because of the project.

4.5.2. Young Adult Carers at College and University

Methodology

The data were collected as part of an online survey of young adult carers conducted from April to August 2013. A total of 295 respondents provided information that was valid for inclusion in the analysis. Data were analysed using the statistical package SPSS, and parametric tests (ANOVA and t-test) and nonparametric tests (Chi Squared) were used as appropriate. These findings and recommendation only deal with those 101 respondents who were in further or higher education, including those at sixth form college.

Summary of Key Findings

- The 101 young adult carers who were in further or higher education showed that on average they provided a ‘Very high’ level of care.
- 39% rated their physical health as either ‘Just OK’ or ‘Poor’; and 45% reported having mental health problems.
- Despite most respondents (79%) enjoying college or university, over half of them (56%) were experiencing difficulties because of their caring role. 16% were concerned that they might have to drop out of college or university.
- Those who reported that they found college or university difficult had significantly higher caring responsibilities.
- 75% of respondents informed college or university staff of their caring role. Despite this, 45% said there was no one who recognised them as a carer and helped them. Of those who did not inform college or university staff, the main reason for not doing so was that there was "no point".
- The majority of respondents (62%) had not had a formal assessment by a social worker or other health/social care professional. Almost a third (30%) believed they had not received good services as a young carer or adequate support for their families (31%).
56% of respondents received a bursary to help with their studies, including 12 of the 17 at university. Only four respondents (4.6%, n=87) received Carer's Allowance, and 13 (21%, n=62) were in receipt of some other form of benefit.

60 of the respondents were currently attending a young carers or young adult carers service. Of these, almost all (95%) felt that their confidence had improved as a result and that they had more friends (87%).

4.5.3. Young Adult Carers and Employment

Methodology

The data were collected as part of an online survey of young adult carers conducted from April to August 2013. A total of 295 respondents provided information that was valid for inclusion in the analysis. These findings deal with those 77 respondents who have left school and are either in work or NEET.

Summary of Key Findings

- A survey of 77 young adult carers who had left school and were either in work, or NEET showed that, on average, they provided a ‘very high’ level of care. 27 of the young adult carers (39.1%) who responded did not think that their family were receiving good support and services.
- 45% reported that their own physical health was ‘Just OK’ or ‘Poor’, and over half (51%) reported having a mental health problem.
- Of the 77 respondents, almost half (49.6%) were unemployed. This represents 21% of the total young adult carers in the wider survey who were no longer at school (n=183).
- The most frequently reported highest qualification held by the respondents were GCSEs at grade D–G (28%). Of those no longer in education, only a small percentage (8%) of respondents had no qualifications. Qualifications of the rest ranged from GCSEs (49%) through to degrees (12%).
- Of the 37 respondents who answered the question, over half (54%) felt that they would have got better grades at school if it was not for their caring role.
- 87% (of 37 respondents) felt that they had not received good career advice at school; and that the advice did not take into account their caring role.
- Of the 38 respondents who had been to college or university, 11 (29%) had dropped out because of their caring role. This is four times greater than the national average for degree courses.
- Of the 39 respondents who were in work, 17 (44%) had chosen the job because it was not far to travel and they could continue to care; 38% of the young adult carers had also considered flexibility of working hours (so that they could care) when choosing their job.
- On average, young adult carers were absent from work for the equivalent of 17 days per year, and were late or had to leave early on approximately 79 days per year because of their caring responsibilities. This suggests that ongoing caring commitments can have a substantially disruptive effect on workplace attendance.
32 young adult carers in work (67%) informed their managers of their caring role, 41% of these reported that their managers were not supportive.

Only a small proportion of the sample (six of the 77 respondents) were in receipt of any benefits. Many more would have an entitlement to some form of financial support but for whatever reason had not claimed, or had not received, any assistance.

4.6. Adult and Community Services: Semi-Structure Interviews with Carers

As part of the co-production of future services Adult and Community Services Commissioners worked with carers to gather views about current service provision and to shape the changes and developments they would like to see in future services.

Methodology

60 semi-structured interviews were undertaken with carers, caring for people from a cross-section of 12 different client groups, including: mental health, dementia, black and minority ethnic groups (BME), lesbian, gay, bisexual and transgender (LGBT), acquired brain injury, palliative, parent carers, learning disabilities, sensory deprivation and older people. This helped to ascertain whether there were different needs within these client groups.

Key Emergent Themes

The key themes to emerge from the semi-structured interviews are summarised as:

1. The need for better information and signposting about available services:

   ‘I don’t know who to go to when in crisis and for sustained support’

   ‘We want one stop for info and really good signposting’

   ‘Need information about what’s around and what you might need to know – if an organisation says ‘we’re here, but doesn’t say what they do, it’s difficult’

2. Frustration with repetition of story and lack of information sharing across organisations:

   ‘Telling my story more than once – there is something about closing a service off, if I have had a service and then leave it, if I return to it later, if necessary, why do I have to tell my story all over again’

3. Difficulty with booking planned respite for their cared for:

   ‘It is virtually impossible to plan and book respite, it is far easier to book emergency respite’
‘Planned respites, the difficulty in getting respite is getting greater particularly planned respites, not emergency respite’

4. The need for a combination of both practical and emotional support services:

‘Carer needs emotional and practical support, benefits advice’

‘Really understanding the benefits system’

‘Need to learn something pertinent, having a cup of tea and a chat isn’t enough, parents are too busy. Having a professional who knows there is the key’

‘The intervention for the cared for’s condition is not always enough, what about training for the carer / family to help support the cared for’

5. Transport for carers

‘Some carers have no access to travel – and also no desire to travel’

‘With LD and autism travelling by bus is a real issue – bus company drivers need training in how to support these client bases’

6. More information at point of diagnosis

‘Good hard medical information is needed, what’s the condition, how will it manifest, what are the behavioural changes and how do we deal with them’

‘Good medical information – practical information, hard facts in terms of life expectancy, what behaviours to expect and when etc – thank goodness for Google!!’

4.7. Carers Needs Assessment Questionnaire for Health and Social Care Professionals

As part of this Needs Assessment, Public Health Suffolk undertook a local survey of health and social care professionals to ascertain their views on carer support services and some of the key issues surrounding carer support in Suffolk.

Methodology:

A total of 200 questionnaires were distributed, covering a range of settings including: West Suffolk GPs, West Suffolk Hospital NHS Trust, Ipswich Hospital NHS Trust and Adult and Community Services Social Workers. A total of 89 people responded, representing a 45% response rate.
A breakdown of the different professional group who responded is offered below:

![Bar chart showing distribution of professionals]

**Key Findings:**

- Professionals ranked information, advice and guidance; carers breaks and emotional support/counselling as the top three most valuable services accessed as part of their daily practice.
- The vast majority of frontline professionals (85.7%) stated they were aware of the family carer support services available to them.
- When asked how they would like to receive information about the family carer support service available, themes emerged suggesting all mediums - online/electronic, hard copy leaflets or packs, and face-to-face presentations to teams – all had their merits. More importantly, however, was the content rather medium, with strong themes emerging around a Directory of Services or information that was all in one place. Respondents also wanted information that succinct, accessible and included valid contact numbers. A sample of verbatim comments is offered below:

  ‘An available electronic directory or via CCG website. Information that could be linked to for carers via practice website would be helpful’.

  ‘One leaflet with all service names on or one telephone number who can direct me to the right service’

  ‘Easy to read, short and to the point info with clear contact numbers that can be put on a fridge, purse, wallet etc’.

  ‘Come and talk to us at team meeting. Send emails - we do get a lot of information via email and we do not get the time to read them. Leaflets we can give to carers.'
An up to date and regularly updated list that we can assess on web site for professionals. This might already be in place?’

- When asked if there were any types of service the CCGs and Local Authority should be commissioning more of, themes emerged around the different professional groups that responded and also themes linked to specific geographies:

  - For GP respondents, access to respite services at short notice and Carer Support Workers linked to the surgery were strong themes to emerge:

    ‘Respite Care, easily accessible by the GP at short-notice’

    ‘Respite access’

    ‘Liaison staff whose prime responsibility it is to form a link between the clinic and family obviously not for every a patient but those identified by either staff or possibly by family carers’.

    ‘Suffolk Family Carers have successfully worked with GP’s in the west so funding to mirror this work in the East. Commissioning a self-help guide for family carers that is available on-line and a booklet’.

  - From dementia advisors, there was a strong request for a voluntary or funded sitting service:

    ‘The most frequently unmet need, in our role of working as a Dementia Advisor, is that of a voluntary sitting service therefore giving full time carers the opportunity to fulfil some of their needs. Virtually every case we see would benefit greatly from this service. The emphasis is on voluntary as most carers feel unable to spend money they feel has to be used for care on themselves’

  - There were also strong themes relating to gaps in service provision in the north of the county:

    ‘Locally in the Waveney area other than Lowestoft and Halesworth I feel there is little out there for carers support wise. It is not always possible for people to travel and this needs to be taken into account. We are lacking in day services which gives carers a good break. Rayner Green in Halesworth is oversubscribed and has a massive waiting list’

    ‘We are in desperate need of bed based respite and day services for older people with mental health needs and dementia, in the north of the county, Waveney’

- When asked how health and social care staff could be more supportive of family carers, the strongest theme to emerge was around the issues of getting across good information in a timely way:
‘We are offering health checks annually to carers. Social Care – I have contact numbers – positive response to carers when they contact support services’

‘More information, more help. GPs and hospitals do not have time to inform people of all the services’.

‘More literature to hand out to carers, patients etc. Be more available’

‘Greater awareness and access to services. Would be good to have a central site from which information about all services could be found’
Section 5: Evidence of Effectiveness

Evidence of Effectiveness - Summary

This needs assessment has identified that there is a lack of a clear care pathway or service operating model for adult carers; national evidence suggesting issues around identification of carers needs amongst some health and social care professionals; a request from carers for better and more detailed information about their cared fors medical condition(s); and, a request for both practical and emotional support services to enable them to fulfil their caring role.

This section of the report therefore presents evidence of how these issues may effectively be addressed, through a combination of best practice recommendations from national charities and thinktanks, NICE Quality Standards (QSs); case study evidence of innovative practice; and, available academic research. The key findings can be summarised as:

- There is evidence that hosted and linked Carer Support Workers (CSWs) in GP surgeries has a positive impact on practices identification of carers.

- There is evidence to suggests telecare and telehealth have the potential to reduce carer stress, promote independence of the cared for and help people sustain their caring role for longer.

- Several studies report that access to breaks services leads to significant reductions in carer strain, psychological morbidity and have the potential to delay permanent admission into permanent residential care. This needs to be measured against conflicting evidence which suggest residential respite can expedite a permanent move to residential care.

- Five National Institute for Health and Care Excellence (NICE) Quality Standards with specific Quality Statements relevant to carers have been identified, including: QS2 Stroke, QS1 Dementia, QS13 End of Life, QS11 Alcohol Dependency & Harmful Alcohol Use, QS3 Venous Thromboembolism Prevention. More work is needed to determine whether current operational practice is consistently meeting these quality statements.

- The Triangle of Care offers six key quality standards for the treatment of carers of dementia patients receiving inpatient care. Although designed with dementia patients in mind, these six quality standards lend themselves well to, and can be applied in, other inpatient settings. More work is needed to establish whether these standards have been implemented across all of Suffolk’s acute trusts.
5.1. Pathways for Carer Support

‘Commissioning for Carers: an Action Guide for Decision-Makers’ (ADASS et al) offers a care pathway for carer support that considers the four key personalisation strands taken from ‘Putting People First’ (DoH, 2007) and suggests specific service categories that allow carers to be included, informed and supported according to their choices:

**Four Key Personalisation Strands from Putting People First:**

- Greater choice, control and independence for everyone who uses services and carers.
- Everyone able to make informed choices through a ‘universal offer’ of advice and information
- Development of ‘community capital’: people and families becoming expert care partners.
- Early intervention and prevention as well as support at the point of crisis.

Figure 8: Carers at the Heart of Communities and Services – A Care Pathway for Carer Support

The pathway covers both carers with entitlements to a high level of statutory support and those with few or as yet undefined entitlements. The categories of support offered are:

- The universal offer of advice and information for all carers set out in Putting People First
- Assessment, brokerage and advocacy to help people find their way through the system
- Preventative and emergency support, currently the subject of a major funding stream.

Overarching all these categories of support the action guide recommends the need for capacity building and local infrastructure work which put caring at the heart of the community. This could include:
- Training agencies to be more carer-friendly and raise local awareness
- Working with local employers to become more carer- and disability-friendly
- Advocating on behalf of carers and helping carers’ voices to be heard by decision-makers
- Working with overlooked groups and communities.

### 5.2. Carer Support Workers in GP Surgeries

Research suggests that ‘carers play a key role in both the initial decision to seek long-term care, and in selecting a home’ but, significantly, that ‘carers rarely experience a move to long-term care as desirable or a positive choice’ (Arksey & Glendinning, 2007). So identifying carers and supporting them to maintain their caring, working and family life is likely to result in fewer uptakes of residential care and outcomes more in line with the preferences of people.

The Carers’ Resource in Harrogate, Craven and Airedale produced compelling evidence showing how treating carers as partners in care uncovers and meets unmet need. They found that listening/emotional support, followed by personalised information, topped the list of priorities for the carers they supported. The chart below demonstrates the huge difference in numbers of carers identified each year by GP practices (y axis), according to the level of partnership between the GP practice and the Carers’ Centre:

![Chart showing the difference in carers identified each year](chart2.png)

Torbay Care Trust commissioned Manchester Personal Social Services Research Unit to evaluate the use of Carers Support Workers (CSWs) in GP surgeries in 2002. CSWs typically advise or train primary care staff in carer-awareness and/or provide direct advice, advocacy and emotional support to carers themselves. General Health Questionnaires were used with 68 randomly selected carers.
Whilst over half of the carers said that they were in good health, GHQ scores indicated almost all were suffering significant mental distress. After support from a Carers Support Worker, the proportion of carers who could be identified as symptomatic cases fell by 21%. In particular, the proportion of carers having problems with concentration and sleeplessness reduced substantially.

5.3. Emergency Support

Research into the effectiveness of approaches to emergency support planning is still relatively immature. Typically, whilst little respite care is actually drawn upon, large numbers of registered carers report significant increases in peace of mind from having emergency support available, meaning that the unit cost of such schemes can be very low and carer satisfaction high.

Failure to avoid an emergency admission for the person being cared for could have long term consequences and costs. Sometimes the built up pressures of caring may mean once someone has been admitted to hospital, a refusal of their carer to allow them to return home can be ‘a common point of admission’ to nursing care (Bebbington et al, 1996). Equally, several studies show that ‘medical practitioners and social workers can be particularly persuasive; expressing the view that admission to a care home is the only realistic solution’ (Arksey & Glendinning, 2007). Time frames for making these decisions can be limited and the longer term costs high.

5.4. Telecare & Telehealth

Telecare and telehealth have the potential to achieve better outcomes for carers as outlined in ‘The Gift of Peace of Mind in 2005’ (Bryne, 2005). A Scotland Government report has considered the impact upon carers of providing Telecare to people with dementia, learning disabilities and others (York Health Economics Consortium, 2009). It indicated that nearly three quarters of carer respondents felt that telecare equipment had reduced the pressure on them by reducing stress levels; with only 4.3% feeling that their stress levels had increased.

Families and carers had greater peace of mind as they worried less (e.g. about falls and risks). The report suggested that people with learning disabilities could enjoy greater independence whilst people with dementia could remain living in the community for longer. Where stress levels had fallen, several respondents highlighted that caring nevertheless was still very demanding and stressful (especially if the client would not use the new equipment). There are three valuable outcomes here for carers: caring is sustained; people continue to live independently and fears for well-being and safety reduced. Feedback from carers suggests these are important outcomes (Miller, 2007).

One randomised controlled trial (RCT) by Venebes (2006) looked at the effects on carer distress of an additional specialist clinical assessment for vulnerable older people at risk of
residential placement. The study found this could be effective in reducing carer distress by targeting services towards the distressing behaviours of the person for whom they cared. This was particularly so where the older person had symptoms of depression.

5.5. Carers Breaks

A dementia study found that breaks services can lead to significant reductions in carer strain and psychological morbidity (Pinquart & Sorensen, 2006). In a Research in Practice summary of the cost-effectiveness of various kinds of carer support, Pickard (2004) notes that ‘both day care and residential respite care have positive outcomes for carers’. The examples given include day care reducing stress for about 85% of carers (particularly for those caring for severely cognitively impaired older people and for carers in paid employment) and increases in home care reducing stress among carers of older people (Davies et al, 2000).

There is mixed evidence on the impact of the uptake of breaks upon nursing home use. This may be because carers tend to require more breaks as caring roles become less manageable. In some areas, carers can only access breaks at high levels of need. Some studies have shown both that use of respite delays nursing home placement (Kosloski & Montgomery, 1995). For some older people, however, residential respite care can increase the probability of permanent admission (Davies et al, 2000; Zarit & Leitsch, 2001).

An RCT that looked at a Dutch programme of day care based respite, coupled with carer support and advice, found that the programme achieved significant delays in transfer to residential care (Droes et al, 2006).

5.6. NICE Quality Standards Relevant to Carers

The National Institute for Health and Care Excellence (NICE) produce evidence-based QSs for those commissioning and providing health and social care services. NICE QSs offer explicit quality statements and associated quality measures that should be adopted by commissioners and implemented by providers as part of local policy and practice. Where possible, these quality statements should be incorporated by health and social care commissioners to formulate service specifications and contracts, ensuring delivery through contractual monitoring of key performance indicators.

NICE have now produced a number of QSs and associated quality statements that are relevant to carers, with the intention of driving up standards and the quality of service provision for this important group of people.

It is beyond the scope of this needs assessment to comprehensively cover full details of all the relevant NICE QSs to carers. Therefore, for the benefit of the reader the first QS on stroke (QS2 below) is outlined in full by way of example. The QSs that follow thereafter have been truncated. The summary below focuses on those QSs that included quality statements that are specific to carers.
5.6.1. QS2 Stroke (NICE, 2010a)

- **Quality Statement 11 - Carer Provisions:**

  Carers of patients with stroke have: a named contact for stroke information; written information about the patient’s diagnosis and management plan; and sufficient practical training to enable them to provide care.

- **Quality Measure:**

  **Structure**

  a) Evidence of local arrangement to ensure that carers of patients with stroke have: a named contact for stroke information; written information about patients diagnosis and management plan; and sufficient practical training to enable them to provide care.

  b) Evidence that a carer’s experience survey has been completed.

  **Process:**

  Proportion of patients with stroke whose carers have: a named contact for stroke information; written information about patient's diagnosis and management plan; and sufficient practical training to enable them to care.

  Numerator – the number of carers who have:

  (a) A named contact for stroke information

  (b) Written information about the patient's diagnosis and management plan

  (c) Sufficient practical training to provide care.

  Denominator – the number of carers of patients with stroke.

- **What the quality statement means for each audience:**

  **Service providers** ensure that local policies are in place to ensure that the carers of all patients with stroke have: a named contact for stroke information; written information about the patient's diagnosis and management plan; and sufficient practical training to enable them to provide care. They obtain the carer’s opinion through a carer's experience survey.

  **Health and social care professionals** ensure that carers of all patients with stroke have: a named contact for stroke information; written information about the patient's diagnosis and management plan; and sufficient practical training to enable them to provide care.

  **Commissioners** ensure that services are in place to enable carers of every patient with stroke to have: a named contact for stroke information; written information about the
patient's diagnosis and management plan; and sufficient practical training to enable them to provide care. Commissioners ensure that service providers obtain the carer's opinion through a carer's experience survey.

Carers have: a named contact for stroke information; written information about the patient's diagnosis and management plan; and sufficient practical training to enable them to provide care. The carer's opinion will be obtained through a carer's experience survey.

5.6.2. QS1 Dementia (NICE, 2010b)

- **Quality Statement 3 – Written and Verbal Information:**
  People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area.

- **Quality Statement 5 – Decision Making:**
  People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of:
  - Advance Statements
  - Advance Decisions to Refuse Treatment
  - Lasting Power of Attorney
  - Preferred Priorities of Care

- **Quality Statement 6 - Emotional, Psychological and Social Needs of Carers:**
  Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.

- **Quality Statement 10 – Respite Service for Carers:**
  Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia.

5.6.3. QS13 - End of Life Care for Adults (NICE, 2011a)

- **Quality Statement 2 – Communication and Information**
  People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.

- **Quality Statement 7 – Holistic Support for Families and Carers**
Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.

- **Quality Statement 14 – Care after Death: Bereavement Support**

People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.

5.6.4. **QS11 - Alcohol Dependence and Harmful Alcohol Use (NICE, 2011b)**

- **Quality Statement 7 - Families and Carers:**

Families and carers of people who misuse alcohol have their own needs identified, including those associated with risk of harm, and are offered information and support.

5.6.5. **QS3 - Venous Thromboembolism Prevention (NICE, 2010)**

- **Quality Statement 6 – Information for Families and Carers**

Patients/carers are offered verbal and written information on VTE prevention as part of the discharge process.

5.7. **The Triangle of Care. Carers Included: A Guide to Best Practice for Dementia Care (Carers Trust & Royal College of Nursing, 2013)**

**Summary**

The Triangle of Care describes a therapeutic relationship between the person with dementia (patient), staff member and carer that promotes safety, supports communication and sustains wellbeing. The Triangle of Care model of carer inclusion and support has proved to be very successful in mental health services with over three quarters of mental health providers in England involved in the project and the model being adapted for use in Scotland and Wales.

Although the Triangle of Care was originally developed for use in mental health services, the standards outlined below have been found applicable in other care settings.

**The Key Standards to Achieving a Triangle of Care**

Six key standards required to achieve better collaboration and partnership with carers.

The rationale for each of these standards is explained, and examples of best practice highlighted. Planning to achieve an effective Triangle of Care is based on the recognition
that the service needs to ensure each element is put in place to create and sustain the engagement required to achieve better outcomes.

The six key standards state that:

1) **Carers and the essential role they play are identified at first contact or as soon as possible thereafter.**
   - Carers are identified and have their needs assessed along with the person with dementia.
   - Carers' views and knowledge are sought, shared, used and regularly updated as overall care plans to support treatment and care are developed.

2) **Staff are ‘carer aware’ and trained in carer engagement strategies.**
   - Staff need to be aware of and welcome the valuable contribution carers can make and be mindful of carers’ own needs as well as the needs of people with dementia.
   - Staff need knowledge, training and support to become carer and dementia aware.

3) **Policy and practice protocols regarding confidentiality and sharing information are in place.**
To ensure proactive engagement carers need to be part of care planning and treatment and the service should have clear policies and mechanisms and ensure these are routinely used, including:

- Guidelines on confidentiality and for sharing information – a three-way process between the person with dementia, carer and professional – which includes assessment of capacity and best interests decisions.
- Protocols and approaches that facilitate information sharing.
- Use of lasting power of attorney advance directives or plans.

4) Defined post(s) responsible for carers are in place.

- Carers lead or champions for all wards and teams who are skilled and knowledgeable about dementia.

5) A carer introduction to the service and staff is available, with a relevant range of information across the care pathway.

- An introductory letter from the team or ward explaining the nature of the service provided and who to contact.
- An appointment with a named member of the team to discuss the carers’ views and involvement.
- Ward orientation/induction procedure and leaflet.
6) A range of carer support services is available.

- Carer support.
- Carer needs assessment.
- Mechanisms for gathering feedback which are used to inform service improvement.

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Good Practice Example: Somerset Partnership’s Initial Family Liaison Meeting Letter

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Good Practice Example: West Suffolk NHS Foundation Trust’s Carer Feedback Questionnaire
Section 6: Key Findings and Recommendations

This needs assessment has highlighted the invaluable contribution carers make to Suffolk’s communities and the health and social care system as a whole. It has also identified the key organisational strategies, policies and programmes across Suffolk County Council, Suffolk’s CCGs and external partners with which this work has relevance.

What follows is a set of evidence-informed findings and recommendations that the authors and steering group responsible for this work believe, if taken forward and implemented, can bring about benefits in service quality and efficiency, stronger relationships and more coherent commissioning, support for frontline doctors, clinicians and social work practitioners and, critically, better outcomes for carers themselves.

The key findings are presented alongside recommendations of how to address the issues. Where appropriate, we identify who should be responsible for taking forward the recommendation, ensuring clear lines of accountability are drawn for taking action.

The recommendations have been framed under the MoSCoW technique for prioritisation. MoSCoW is applied to help give readers a understanding of the importance the authors and steering group feel should be applied to each recommendation. The MoSCoW categories are as follows:

- **M - MUST**: Describes the recommendations that the authors and steering group believe must be satisfied.
- **S - SHOULD**: Represents a high-priority recommendation that the authors and steering group believe should be included if it is possible.
- **C - COULD**: Describes a recommendation which the authors and steering group consider desirable but not necessary. This will be included if time and resources permit.
- **W - WON'T**: Represents a recommendation that the authors and steering group have agreed will not be implemented in a given release, but may be considered for the future.

6.1. Must Do Recommendations

**Governance & Co-Commissioning:**

There are seven different commissioning bodies currently funding carers services in Suffolk and there is evidence that this is leading to fragmented unilateral decision making and inequality in service provision emerging across the County. Moreover, commissioning for adult carers services often takes place within disease specific pathways which comes with risks of further unilateral commissioning decisions being taken, further exacerbating service inequality.

The genesis of the Integrated Carers Commissioning Officer Group in 2014 offers great potential to overcome this problem, bringing together commissioners from across the health and care system and, with this, opportunities to develop a multilateral commissioning
strategy across Suffolk’s three CCGs and the co-design of a much needed system-wide specification for carers that includes the core services that make up a coherent care pathway in every locality.

Whilst there is always value in bringing together partners to discuss challenging issues, what currently limits this group’s effectiveness is its lack of recognition as a joint-commissioning group and the need for commissioners to defer back to their individual organisations before decisions can be considered and agreed. Therefore, it is a joint-commissioning function frustrated by its lack of influence, budget (whether virtual or real) and the empowerment to drive service re-design and change.

**Recommendation 1:**

a) For the Integrated Carers Commissioning Officers Group to be formally recognised as a joint commissioning group sponsored by the System Leaders Partnership Board and, moreover, for its recommendations to carry parity of influence with other established joint commissioning groups such as those for Mental Health and Learning Disabilities.

b) For the System Leaders Partnership Board to endorse a move toward the creation of a virtual pooled fund arrangement for this joint commissioning group by 2016/17, akin to the Mental Health Pooled Fund.

**Inequalities in Service Provision:**

The epidemiology from the Needs Assessment highlights that Waveney has the highest number of carers claiming Carers Allowance in the County, the highest proportion of carers delivering 50+ hours of unpaid per week in the county and the second highest number of carers delivering 1 or more hours of care per week. When this identified need is cross-referenced with the Service Mapping, the mapping suggests a number of services that are currently available in the East and West of the County are not available in Waveney. Comments received from frontline operational staff as part of the Stakeholder Engagement activities offer support to these findings and a street level perspective on some of deficits in provision:

‘Locally in the Waveney area other than Lowestoft and Halesworth I feel there is little out there for carers support wise. It is not always possible for people to travel and this needs to be taken into account. We are lacking in day services which gives carers a good break. Rayner Green in Halesworth is oversubscribed and has a massive waiting list’

‘We are in desperate need of bed based respite and day services for older people with mental health needs and dementia, in the north of the county, Waveney’

Below is a short summary highlighting for readers some of the inequalities and inconsistencies identified from the service mapping:
- Carer Advisors Linked to Primary Care – delivered in West and East Suffolk only.
- Hospital Based Carer Support Workers – delivered in Ipswich Hospital and West Suffolk Hospital only.
- Respite on Prescription – delivered in East and West Suffolk only.
- Moving and Handling Tuition for Carers – delivered in East Suffolk only.
- ADHD (Attention Deficit Hyperactivity Disorder) Carer Wellbeing Service – delivered in East and West Suffolk only.
- Suffolk Wellbeing Service: Boosting R Wellbeing and Wellbeing for Me – delivered in East and West Suffolk only.
- Admission Prevention Service (Carer Support) - delivered in East and West Suffolk only
- Carers Breaks for People with Neurological Conditions – delivered in East and West Suffolk only.

Recommendation 2:

- For the Integrated Carers Commissioning Officers Group to work together to reduce the inequalities in service provision identified by developing a system-wide service specification outlining the essential service components that should be commissioned to make up a comprehensive carers pathway, ensuring carers across Suffolk get a broadly similar level of service, irrespective of their place of residence.

Developing a Care Pathway / Operating Model for Carers:

The Service Mapping chapter of the Needs Assessment highlights the lack of a clear service model or care pathway around which adult carer support services are being commissioned and delivered. Moreover, within current commissioned services there is no clear service taxonomy detailing which services are universal and open to all and which are more specialised.

Whilst this process may be tacitly understood by those who commission or deliver these services, it is postulated that this less well understood or communicated to those who refer into or receive these services. Clarity of this process and categorisation of carer support services will be key to Care Act 2014 compliance.

Adult and Community Services three tier operating model Supporting Lives Connecting Communities offers a stepped care model that could be applied and ‘Commissioning for Carers: an action guide for decision makers’ offers a slight variation of a similar approach:
Alternatively, ‘Commissioning for Carers: an action guide for decision makers’ offers an alternative variation on this theme:

Recommendation 3:

a) The Integrated Carers Commissioning Officers Group develop a clear care pathway or operating model approach to the commissioning and delivery of carer support services in the future, including a coherent taxonomy of services based around the pathway/operating model design (e.g. identification and outreach services, universal services, specialised services).
b) This pathway/operating model should form an integral part of a system wide specification for carer support services, bringing a greater degree of consistency in the delivery of carer support services across the County.

Planned and Emergency Respite

An important theme that emerged from the questionnaires circulated to health and social care professionals and from the semi-structured interviews with carers, was on the theme of accessing both planned and emergency respite.

When asked ‘are there any carer services we should be commissioning more of?’ Greater access to emergency respite was an important theme for GP respondents:

‘Respite Care, easily accessible by the GP at short-notice’

For carers, challenges with accessing planned respite for their cared for was a re-occurring issue:

‘It is virtually impossible to plan and book respite, it is far easier to book emergency respite’

Recommendation 4:

- Whilst the themes emerging from questionnaires and interviews are indicative of an under-supply of respite access across Suffolk, further in-depth analysis is required on this matter to establish a firmer evidence-base from which to base commissioning decisions. It is therefore recommended that the Integrated Carers Commissioning Officers Group undertake a focused piece of work on respite provision with the support of Public Health Suffolk in order to gain better insight into the availability of emergency and planned respite access across the county.

Commissioning

The authors have already identified that there are inequalities in the range of carer support services available in some areas of the County and have made recommendations for commissioners to address these imbalances by producing a system-wide specification for carers services that can be replicated across the three commissioning splits in Suffolk (I&ESCCG, WSCCG, GY&WCCG).

Additionally, there are several specific service areas identified through the Personal Social Services Survey of Adult Carers in England 2013-14 where there is variation (albeit small in some cases) between the numbers of carers receiving these services in Suffolk compared to the regional and national averages. The authors still feel, however, this demands further investigation to ensure there aren’t gaps in commissioning and that services in the areas are being appropriately targeted at the adult carer cohort. The service areas include:
- Telecare & lifeline alarms
- Training for Carers
- Support to keep carers in employment
- Personal Assistants

**Recommendation 5: For the Integrated Carers Commissioning Officers Group to undertake further investigation and gap analysis in these service areas and use the findings to inform their commissioning decisions.**

**Young Carers + Young Adult Carers**

At its inception, the scope of this Needs Assessment was set to include young carers, young adult carers and adult carers. Whilst the authors and steering group have attempted to ensure sufficient focus is given to each of these cohorts within the context of this Needs Assessment, we recognise an inadvertent but strong older people’s bias to the work and need for further work to comprehensively capture the needs of young carers.

**Recommendation 6: Public Health Suffolk need to build on this work and undertake a further needs assessment for young carers and young adult carers.**

6.2. Should Do Recommendations

**Service Quality**

The Evidence of Effectiveness chapter of the Needs Assessment highlighted five NICE Quality Standards which included specific quality statements relevant to carers. Furthermore, this chapter also highlighted the Carers Trust’s Triangle of Care and the six quality standards outlined as best practice in acute mental health support for carers of dementia patients.

Whilst there is evidence of good progress around carer support in Suffolk’s provider services, it was unclear whether the quality standards recommended by NICE and those within the Triangle of Care are consistently being met.

**Recommendation 7:**

a) *For commissioners in Suffolk to establish dedicated task and finish groups to undertake rigorous self-assessment of their own performance against the quality statements for carers covering the following Quality Standards and care pathways:*

- QS2 Stroke,
- QS1 Dementia,
- QS13 End of Life,
- QS11 Alcohol Dependency & Harmful Alcohol Use,
- QS3 Venous Thromboembolism Prevention.
b) For the Norfolk and Suffolk Mental Health Foundation Trust, Ipswich Hospital NHS Trust, West Suffolk NHS Trust and James Paget University Hospital to undertake rigorous self-assessment of their services against the standards set out in the Triangle of Care. Furthermore, that those Trusts consider working toward the Triangle of Care membership as a sign of their commitment to carer inclusion in the delivery of their clinical services.

Information about Carer Services for Professionals and Carers

Access to good information that consolidates details about carers services commissioned across the health and social care divide was a strong theme to emerge out of the Stakeholder Feedback section of the Needs Assessment. Health and social care professionals requested information about carer support services that is offered in a variety of mediums but, crucially, information that is concise, all in one place, and available via I.T. platforms which they use regularly and are comfortable navigating. Comments included:

‘An available electronic directory or via CCG website. Information that could be linked for carers that could be linked via practice website would be helpful’.

‘Easy to read, short and to the point info with clear contact numbers that can be put on a fridge, purse, wallet etc’.

Carers echoed these views, sharing comments they do not always know where to go for information and also want information that is consolidated in one place and easy to find:

‘I don’t know who to go to when in crisis and for sustained support’

‘We want one stop for info and really good signposting’

Recommendation 8:

a) Consideration should be given to this issue by all commissioners in Suffolk. The authors understand this issue is not uncommon in other service areas where commissioning also falls between health and social care. Therefore we seek to build on rather than duplicate existing work, asking that this issue is given due consideration and built into any ongoing projects that are seeking to address this problem.

b) The Integrated Carers Commissioning Officers Group should, however, support ongoing project efforts by mapping a Directory of Services that includes all universal services for adult carers commissioned by health and social care. Different professional stakeholders should then be actively engaged in order to establish their preferences on how they wish to receive communication about carers services.
c) The Integrated Carers Commissioning Officers Group should give consideration to designing into the carers pathway a single information gateway, offering referrers and carers a single point of contact from which signposting to all other universal carer service offers can be managed. Suffolk Family Carers already provide such a service in the form of their telephone advice line. However, this service has not been explicitly commissioned for this purpose and this concept has not been communicated to wider stakeholders.

6.3. Could Do Recommendations

Employment

Juggling employment with caring is already an issue challenging many carers in Suffolk and from the epidemiology we know there will be a need for more carers of working age to support Suffolk’s increasing numbers of older people in the future.

The question of how we can best support carers to maintain their employment is a complex one that lacks a clear service solution. We recommend leveraging Local Government and CCGs position as community leaders to both model and influence good HR policy and practice in carer support, setting the standard for others to follow. Local Government and Suffolk’s CCGs also contract for millions of pounds worth of services from the private sector, offering practical opportunities to cascade these policies and practices through the contracts they let.

Recommendation 9:

Suffolk Family Carers should develop a model HR policy and good practice guidance for carers support in the workplace.

Corporate Management Teams at Suffolk County Council and Suffolk’s three CCGs should consider endorsing and adopting this model policy and good practice advice, making a commitment to carers by becoming exemplar employers.

Corporate Management Teams at Suffolk County Council and Suffolk’s three CCGs should give consideration to introducing this model HR policy and good practice guidance into new contracts with external providers, therefore, using their collective purchasing power to cascade good practice with external providers.
7. Reference List


NICE (2010b) ‘Dementia Quality Standard’ [Online] Available at: https://www.nice.org.uk/guidance/QS1


Sempik and Becker (2013a) ‘Young Adult Carers at School: Experiences and Perceptions of Caring and Education’. London: The Carers Trust

Sempik and Becker (2013b) ‘Young Adult Carers at College and University’. London: The Carers Trust

Sempik and Becker (2013c) ‘Young Adult Carers and Employment’ London: The Carers Trust


8. Glossary

**ACS:** Adult and Community Services are a commissioner and provider of adult social care and support services in Suffolk. The Directorate’s aim is to ensure adults of all ages and abilities that live in Suffolk have opportunities to access leisure activities, learning or work that assist them to develop and sustain their economic, health and social wellbeing, remain independent, and exercise choice and their right to dignity in a safe environment.

**Adult Carer:** An adult carer is anyone 18+ who spends a significant proportion of their time providing unpaid support to a family member, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.

**ADASS:** The Association of Directors of Adult Social Services (ADASS) represents all the directors of adult social services in England as well as senior managers who report to them.

**ASCOF:** The Adult Social Care Outcomes Framework (ASCOF) is used both locally and nationally to set priorities for care and support, measure progress and strengthen transparency and accountability.

**CAF:** The Common Assessment Framework (CAF) is a national standard for assessing needs of children and young people and deciding how best to meet them through a simple process.

**CCG:** Clinical Commissioning Groups are groups of GP Practices, working with other healthcare professionals and in partnership with local communities and Local Authorities are responsible for commissioning the majority of NHS services for patients within their local communities. They have a duty to work with Local Authorities in relation to health and adult social care, early years services, public health.

**CIN:** Under Section 17 (10) of the Children Act 1989, a child is a **Child in Need** if:

a) He/she is unlikely to achieve or maintain, or have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him/her of services by a local authority;

b) His/her health or development is likely to be significantly impaired, or further impaired, without the provision for him/her of such services; or

c) He/she is a Disabled Child.

**CYPS:** Children and Young Peoples Services are a commissioner and provider of children, young people and families care and support services in Suffolk.

**DoH:** The Department of Health (DoH) is a ministerial department, supported by 23 agencies and national bodies. The department helps people to live better for longer and leads, shapes and funds health and care in England, ensuring people have the support, care and treatment they need, with the compassion, respect and dignity they deserve.
Epidemiology: is the branch of medicine which deals with the incidence, distribution, and possible control of diseases and other factors relating to health.

GY&WCCG: Great Yarmouth and Waveney Clinical Commissioning Groups (HealthEast) services a population of 230,000 people. Their patch is broadly aligned with Great Yarmouth Borough Council and Waveney District Council. The CCG works in partnership with other organisations, such as local councils and the voluntary sector, to improve the health and wellbeing of the residents of Great Yarmouth and Waveney.

HASCI: is an acronym for Health and Social Care Integration and an umbrella term for local programmes of work which focus on unplanned care and community services integration.

IDeA: The Local Government Improvement and Development Agency (IDeA) was formed in 1998 to work in partnership with all councils in England and Wales, to serve people and places better, to enhance the performance of the best local government authorities, accelerate the speed of improvement of the rest, and develop the sector as a whole.

IESCCG: NHS Ipswich and East Suffolk Clinical Commissioning Group is a group of 41 GP practices in Ipswich and the eastern part of Suffolk. The CCG was established in April 2012 and has responsibility for approximately 385,000 patients.

LA: A local authority is an administrative body in local government

Prevalence: is the total number of cases of a disease in a given population at a specific time.

RCGPs: The Royal College of General Practitioners is the professional membership body and guardian of standards for family doctors in the UK, working to promote excellence in primary healthcare.

SCC: Suffolk County Council

WSCCG: NHS West Suffolk Clinical Commissioning Group are a team of GPs and health professionals working on behalf of all GPs in West Suffolk. The WSCCG have full responsibility for a budget of £268.6 million to buy and manage health care for the 240,621 local residents in the WSCCG area, which stretches from Sudbury, Haverhill, Brandon and Stanton to Botesdale, Woolpit and Newmarket.

Young Carer: The term young carer should be taken to include children and young people under 18 who provide regular or ongoing care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances. A young carer becomes vulnerable when the level of care-giving and responsibility to the person in need of care becomes excessive or inappropriate for that child, risking impacting on his or her emotional or physical well-being or educational achievement and life chances’
**Young Adult Carer:** Young adult carers are those people that bridge the young carer and young adult carer cohorts and include those with caring responsibilities as an adolescent who are transitioning into adulthood. Young adult carers are categorised in Suffolk as being aged 16-24 years.
Appendix A: Corresponding CCG Level Data

Main Report Graph 1 & 13: Estimated number of people providing unpaid care in Suffolk by CCG (adapted from ONS, 2013a)

<table>
<thead>
<tr>
<th>CCG</th>
<th>Number of people of all ages providing unpaid care</th>
<th>Usual resident population of all ages at 2011 Census</th>
<th>% of population providing unpaid care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Great Yarmouth &amp; Waveney CCG</td>
<td>24,556</td>
<td>212,531</td>
<td>11.6%</td>
</tr>
<tr>
<td>Ipswich &amp; East Suffolk CCG</td>
<td>42,759</td>
<td>393,548</td>
<td>10.9%</td>
</tr>
<tr>
<td>West Suffolk CCG</td>
<td>21,335</td>
<td>219,361</td>
<td>9.7%</td>
</tr>
<tr>
<td>East of England</td>
<td>69,759</td>
<td>5,846,965</td>
<td>10.2%</td>
</tr>
<tr>
<td>England</td>
<td>5,430,016</td>
<td>53,012,456</td>
<td>10.2%</td>
</tr>
</tbody>
</table>

Main Report Graph2: Percentage of resident population providing unpaid care by CCG (adapted from ONS, 2013a)
Main Report Graph 5: Provision of unpaid care by number of hours per week and CCG (adapted from ONS, 2013a)

![Graph showing Provision of unpaid care by number of hours per week and CCG](image)

Main Report Graph 6: General health of people providing unpaid care in Suffolk by CCG (adapted from ONS, 2013a)

![Graph showing General health of people providing unpaid care in Suffolk by CCG](image)
Main Report Graph 7: Provision of unpaid care by age group and CCG as a percentage of population (adapted from ONS, 2013a)

Main Report Table 4: Provision of unpaid care by age group and CCG – All Persons (adapted from ONS, 2013a)

### NHS Great Yarmouth and Waveney

<table>
<thead>
<tr>
<th>Carer</th>
<th>All categories: Age</th>
<th>Age 0 to 24</th>
<th>Age 25 to 49</th>
<th>Age 50 to 64</th>
<th>Age 65 and over</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>209,749</td>
<td>59,190</td>
<td>61,871</td>
<td>42,539</td>
</tr>
<tr>
<td></td>
<td>Provision of unpaid care</td>
<td>185,245</td>
<td>57,659</td>
<td>54,474</td>
<td>33,610</td>
</tr>
<tr>
<td></td>
<td>Provides no unpaid care</td>
<td>24,504</td>
<td>1,531</td>
<td>7,397</td>
<td>8,929</td>
</tr>
<tr>
<td></td>
<td>Provides unpaid care: Total</td>
<td>14,092</td>
<td>1,100</td>
<td>4,332</td>
<td>5,725</td>
</tr>
<tr>
<td></td>
<td>Provides 20 to 49 hours unpaid care a week</td>
<td>3,335</td>
<td>220</td>
<td>1,031</td>
<td>1,157</td>
</tr>
<tr>
<td></td>
<td>Provides 50 or more hours unpaid care a week</td>
<td>7,077</td>
<td>211</td>
<td>2,034</td>
<td>2,047</td>
</tr>
</tbody>
</table>

### Ipswich and East Suffolk CCG

<table>
<thead>
<tr>
<th>Carer</th>
<th>All categories: Age</th>
<th>Age 0 to 24</th>
<th>Age 25 to 49</th>
<th>Age 50 to 64</th>
<th>Age 65 and over</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>385,627</td>
<td>110,125</td>
<td>123,835</td>
<td>78,298</td>
</tr>
<tr>
<td></td>
<td>Provision of unpaid care</td>
<td>342,994</td>
<td>107,610</td>
<td>111,160</td>
<td>61,482</td>
</tr>
<tr>
<td></td>
<td>Provides no unpaid care</td>
<td>42,633</td>
<td>2,515</td>
<td>12,675</td>
<td>16,816</td>
</tr>
<tr>
<td></td>
<td>Provides unpaid care: Total</td>
<td>28,950</td>
<td>1,929</td>
<td>8,489</td>
<td>12,699</td>
</tr>
</tbody>
</table>
Provides 20 to 49 hours unpaid care a week | 4,816 | 328 | 1,547 | 1,684 | 1,257
Provides 50 or more hours unpaid care a week | 8,867 | 258 | 2,639 | 2,433 | 3,537

West Suffolk CCG

<table>
<thead>
<tr>
<th>Carer</th>
<th>All categories: Age</th>
<th>Age 0 to 24</th>
<th>Age 25 to 49</th>
<th>Age 50 to 64</th>
<th>Age 65 and over</th>
</tr>
</thead>
<tbody>
<tr>
<td>All categories: Provision of unpaid care</td>
<td>214,967</td>
<td>61,471</td>
<td>72,145</td>
<td>41,243</td>
<td>40,108</td>
</tr>
<tr>
<td>Provides no unpaid care</td>
<td>193,762</td>
<td>60,132</td>
<td>65,655</td>
<td>33,228</td>
<td>34,747</td>
</tr>
<tr>
<td>Provides unpaid care: Total</td>
<td>21,205</td>
<td>1,339</td>
<td>6,490</td>
<td>8,015</td>
<td>5,361</td>
</tr>
<tr>
<td>Provides 1 to 19 hours unpaid care a week</td>
<td>14,244</td>
<td>1,028</td>
<td>4,391</td>
<td>6,012</td>
<td>2,813</td>
</tr>
<tr>
<td>Provides 20 to 49 hours unpaid care a week</td>
<td>2,403</td>
<td>177</td>
<td>789</td>
<td>782</td>
<td>655</td>
</tr>
<tr>
<td>Provides 50 or more hours unpaid care a week</td>
<td>4,558</td>
<td>134</td>
<td>1,310</td>
<td>1,221</td>
<td>1,893</td>
</tr>
</tbody>
</table>

Main Report Graph 8: People providing 1-19 hours of unpaid care a week by age group and CCG*
Main Report Graph 9: People providing 50+ hours of unpaid care a week by age group and CCG*

Main Report Graph 11: Proportion of unpaid carers by gender and CCG*
Appendix B: Care Act 2014 Clause Analysis

Wellbeing principle: section 1

<table>
<thead>
<tr>
<th>New in law and practice</th>
<th>New in law but not new in policy</th>
<th>Consolidating or modernising existing law</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will impact on local authorities</td>
<td>Impact will depend on local practice</td>
<td>X</td>
</tr>
</tbody>
</table>

This section creates a new statutory principle which applies to all the functions under Part 1 of the Act (including care and support and safeguarding), and means that whenever a local authority makes a decision about an adult, they must promote that adults' wellbeing.

The well-being principle is a new legal requirement, but existing practice in relation to care and support functions should already be compliant with the principle. Local authorities should consider reviewing their compliance with the principles of this general duty.

Prevention: section 2

<table>
<thead>
<tr>
<th>New in law and practice</th>
<th>New in law but not new in policy</th>
<th>Consolidating or modernising existing law</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will impact on local authorities</td>
<td>Impact will depend on local practice</td>
<td>X</td>
</tr>
</tbody>
</table>

Section 2 requires local authorities to ensure the provision of preventative services - that is services which help prevent or delay the development of care and support needs, or reduce care and support needs (including carer’s support needs).

This duty builds upon existing requirements to provide certain preventive services (e.g. under Schedule 20 to the NHS Act 2006) and supports other duties, such as those to undertake joint strategic needs assessments. This expands current legal requirements, to reflect best practice in relation to local approaches to preventing and delaying needs.

Integration: section 3

<table>
<thead>
<tr>
<th>New in law and practice</th>
<th>New in law but not new in policy</th>
<th>Consolidating or modernising existing law</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will impact on local authorities</td>
<td>Impact will depend on local practice</td>
<td>X</td>
</tr>
</tbody>
</table>

This section establishes a duty on local authorities to carry out their care and support functions with the aim of integrating services with those provided by the NHS or other health-related services (for example, housing).

Information and advice: section 4

<table>
<thead>
<tr>
<th>New in law and practice</th>
<th>New in law but not new in policy</th>
<th>Consolidating or modernising existing law</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will impact on local authorities</td>
<td>Impact will depend on local practice</td>
<td>X</td>
</tr>
</tbody>
</table>

Section 4 provides for an information and advice service to be available to all people in the local authority’s area regardless of whether or not they have eligible care needs.
This replaces existing duties in relation to information and advice, and updates those requirements to specify more detail on what a universal information and advice service must include. This is based on existing best practice.

**Diversity and Quality of provision (Market Shaping): section 5**

<table>
<thead>
<tr>
<th>New in law and practice</th>
<th>New in law but not new in policy</th>
<th>Consolidating or modernising existing law</th>
</tr>
</thead>
<tbody>
<tr>
<td>Will impact on local authorities</td>
<td>Impact will depend on local practice</td>
<td>X</td>
</tr>
</tbody>
</table>

This section describes a general duty for local authorities to promote diversity and quality in the market of care and support providers for people in their local area. In particular, local authorities must act to ensure that there is a range of different providers of services available, offering a range of services shaped by the demands of individuals, families and carers, and that those services are of a high quality, in order to meet the needs and preferences of people wanting to access services.

This is a new duty, which reflects existing responsibilities of local authorities and policy with regard to the promotion of the market of local services.

**Cooperation: sections 6-7**

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Sections 6 and 7 describes a general duty to cooperate between the local authority and other relevant authorities which have functions relevant to care and support. This includes a duty on the LA itself to ensure cooperation between its adult care and support, housing, public health and children’s services.

These duties replicate existing cooperation duties, and provide a new ability to require cooperation from a relevant partner, in relation to an individual case.

**How to meet needs: section 8**

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This section gives examples of the ways in which a local authority may meet a person's needs under this statute. It relates to adults who need care and carers, and is an illustration of how needs could be met, to ensure there is flexibility.

This section is a new provision, however it does not create an impact on local authorities in its own right.
Assessment regulations: section 12

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Section 12, which also applies to carers, allows for regulations to specify further detail about the assessment process, including requiring the assessment to be appropriate and proportionate, specialist assessments, self-assessment, and considering the needs of the whole family. Regulations may also specify when a local authority should refer a person for assessment by the NHS when they believe that the person has NHS continuing healthcare needs.

Regulations will replace existing Directions in relation to assessment, with additional detail to provide further clarity on a number of issues, based on existing practice.

Carers assessment: section 10

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Section 10 creates a single duty for local authorities to undertake a 'carer's assessment', on the basis of the appearance of a need for support. This is a lower threshold for assessment than under the current law. It removes the existing requirement that the carer must be providing "a substantial amount of care on a regular basis". This will mean many more carers are able to access an assessment, and that the duty is similar to that for the people they support i.e. it is on the appearance of need.

The duty to assess carers replaces and expands on existing requirements. The duty lowers the threshold for assessment, meaning that more carers will be entitled to an assessment of their needs. Requirements of the assessment process are also updated, to create a parallel to the process for users of care and support.

Eligibility: section 13

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This section requires local authorities to determine whether a person has eligible needs after they have carried out a needs assessment or a carer's assessment. It provides for regulations which will set out the eligibility criteria, including the minimum level of eligibility at which local authorities must meet a person's care and support needs.

The duty to determine eligible needs replaces an existing requirement to do so, following the assessment. The description of eligible needs within regulations will create a national minimum threshold, which replaces existing local thresholds and current statutory guidance.
**Duty and power to meet carers’ needs: section 20**

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Section 20 establishes a legal obligation to meet a carer’s needs for support, on a similar basis to those needing care in section 18. The key conditions for a carer’s entitlement is that they have assessed eligible needs for care and support and that the person for whom they care is ordinarily resident in the local authority area (or present there but of no settled residence).

The duty to meet a carer’s needs is a new entitlement to support for carers. This replaces the existing discretionary power for local authorities to provide services to carers, with a requirement based on meeting eligible needs. This will have a substantial impact on local authorities, which will vary based on their current arrangements for carers.

**Steps to take: section 24**

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Section 24 sets out the steps local authorities must take after carrying out the needs assessment or carer's assessment (and the financial assessment where relevant).

The duty to prepare a care and support plan is a new legal duty, which reflects established practice in local authorities and existing case law.

The requirement to inform the person about direct payments replicates a current requirement in regulations.

The duty to provide an independent personal budget is a new requirement, linked to the new funding reforms and capped costs system.

**Care and support plans: section 25**

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Section 25 details requirements for inclusion in the care and support plans and carers’ support plans. The required detail of the plans reflects existing best practice in care planning. The requirement to include a personal budget reflects both practice and agreed policy priorities. The impact on local authorities will vary depending on existing arrangements.
Review of C/S Plan: section 27

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Section 27 requires local authorities to keep care and support plans and carers' support plans under review generally, and to carry out an assessment where they are satisfied that the person’s circumstances have changed. The adult can also make a reasonable request to have a review.

The duty to review care and support plans and carers' support plans is a new legal duty, which reflects existing practice and case law in relation to the local authorities ongoing responsibilities towards an individual whose needs it is meeting.

Direct payments: sections 31-33

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Sections 31-33 consolidate the existing legislation on direct payments. People with capacity can request a direct payment, and where they meet the conditions set out in this section the local authority must provide direct payments to meet their assessed eligible needs.

The sections also place a duty on local authorities for adults who lack capacity. It requires local authorities to make a direct payment to an authorised person who requests one, provided five conditions set out in the section are met.

These provisions replace and update existing duties in relation to direct payments (under the Health and Social Care Act 2001 and the 2009 regulations).

Continuity of care: sections 37-38

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Section 37 sets out the duties that local authorities are under when an individual, and potentially their carer, notifies them that they intend to move from one local authority area to another.

Section 38 applies when the second authority has not carried out the assessment before the person moves. It requires the second authority to provide services based on the care and support plan provided by the first authority. The second authority must continue to provide this care until it has undertaken its own assessment.
These sections set out new legal duties, to provide for a new arrangement for notification, information-sharing and assessment, when a person moves between areas. The new duty to ensure continuity of care will impact on local authorities when a person moves to/from their area under the rules set out.

**Transition from childhood: sections 58-66**

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These sections create new legal duties to carry out transition assessments for the three groups identified, and to take certain additional steps. They are new in law and reflect best practice in relation to preparation for adulthood and joint working between local authorities' adult and children's services departments.

The section:

- establish a duty for local authority to assess a child, young carers or child's carer before they turn 18, in order to help them plan if they are likely to have needs once they (or the child they care for) turn 18 and if it will be of "significant benefit"
- gives local authorities a power to meet the needs of an adult caring for a child with needs for care and support and allows regulations to be made in relation to the exercise of this power.
- include a power to make regulations about assessment for young carers and also provides that an assessment can be carried out jointly with another assessment.
- provide continuity so that where a young person is receiving children's services those services will not stop abruptly when the person turns 18, but must continue until adult services have a plan in place

**Independent advocacy support: sections 67-68**

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This section places a duty on local authorities, in certain specified circumstances, to arrange an independent advocate to be available to facilitate the involvement of an adult or carer who is the subject of an assessment, care or support planning or review.

This is a new duty to provide an independent advocate in specified circumstances. This reflects best practice in local authorities, but will extend practice in many areas to require the advocate to be provided

**Delegation: section 79**

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The Act provides a power for local authorities to authorise a third party to carry out certain care and support functions. This section provides for a new power for local authorities to delegate certain care and support functions to a third party. This is a new discretion for local authorities, to be determined locally.