# **JOINT CARERS STRATEGY 2018 – 2021**

# Recognising, Valuing and Supporting Carers in Leicester, Leicestershire and Rutland













# **Contents**

1.	Our Local Vision for Carers	4	ļ
2.	Who is the Strategy for?	5	;
3.	Impact of caring	7	7
	Relevant policy and legislation	10	)
5.	Profile of carers in LLR	12	<u>?</u>
6.	Current carer support	14	ļ
7.	What LLR Carers say	15	5
8.		19	)
	Priority 1. Carers are identified early and recognised	21	Ĺ
	Priority 2. Carers are valued and involved	21	L
	Priority 3. Carers Are Informed	22	<u>)</u>
	Priority 4. Carer Friendly Communities	22	<u>)</u>
	Priority 5. Carers have a life alongside caring	<b>2</b> 3	}
	Priority 6. Carers and the impact of Technology Products and the living space	24	ļ
	Priority 7. Carers can access the right support at the right time	24	ļ
	Priority 8. Supporting Young Carers	26	j
9.	Monitoring progress	26	5

10. Conclusion	 . 2
Appendix 1 – Adult Social Care Outcomes Framework	. 2
Appendix 2: Effect on Carers' Health	2
Appendix 3: Carers ethnicity breakdown and Young Carers statistics	3
Appendix 4: Poppi data	. 3

#### 1. Our Local Vision for Carers

This Carers Strategy has been developed in partnership with carers across Leicester, Leicestershire and Rutland, and with the support of a number of local voluntary sector organisations, Healthwatch and local health providers. The organisations signed up to this strategy have committed to work together to deliver our local vision for carers:

'Family members and unpaid carers, including young people across Leicester, Leicestershire and Rutland will be identified early, feel valued and respected. They will receive appropriate support wherever possible to enable them to undertake their caring role, whilst maintaining their own health and wellbeing'.

Throughout this strategy we refer to 'the partnership' or 'partners'. Specifically, this refers to the Carers Delivery Group, a sub-group of the Leicester, Leicestershire and Rutland Sustainability and Transformation Partnership which is responsible for overseeing a plan to improve the health and social care services to reduce inefficiencies. Supporting carers has been identified as a key area of work in Better Care Together (the Sustainability and Transformation Plan for Leicester, Leicestershire and Rutland). The Carers Delivery Group sits within the Prevention (Home First) workstream of the Sustainability and Transformation Partnership, and also links to the workstreams for integration, urgent and emergency care, and resilient primary care.

Individual members of the Carers Development Group will share this strategy with their own organisation, who will develop a delivery plan based on a set of guiding principles, as detailed in section 2 and key priorities and associated actions as detailed in section 9. Delivery plans will be tailored to suit each the diverse needs of carers in their locality and to reflect the available resources for each organisation.

Partners include: Leicester City Council, Leicestershire and Rutland County Councils, East Leicestershire and Rutland, West Leicestershire and Leicester City Clinical Commissioning Groups, voluntary and community sector organisations (notably organisations delivering carers services and speaking for carers), and Healthwatch Leicestershire.

#### 2. Guiding Principles

The strategy is underpinned by a number of guiding principles that reflect both the national and local requirements of carers

1. **Carer Identification** - We will work together across the statutory and voluntary sector organisations in Leicester, Leicestershire & Rutland to identify carers and to ensure they are signposted to relevant information and services if they require assistance. This includes young people under the age of 18 who may be caring for a family member.

- 2. **Carers are valued and involved** We will listen to carers and involve carers in the development of services that enable them to continue to provide their caring role.
- 3. **Carers Are Informed** We will ensure that accurate advice, information and guidance are available to assist carers to navigate health and social care services.
- 4. **Carer Friendly Communities** Communities will be encouraged to support carers through awareness-raising within existing community groups.
- 5. **Carers have a life alongside caring-** We will ensure that health checks for carers are promoted as a means of supporting carer to maintain their own physical and mental health and wellbeing and encouraged to have a life outside of their caring role.
- 6. Carers and the impact of Technology Products and the living space We will work with housing and other organisations to ensure the needs of carers are considered in terms of the provision of technology, equipment of adaptations that may assist a carer with their caring role.
- 7. Carers can access the right support at the right time We will respect and promote the needs of carers and ensure they have access to carer's assessment, which will determine if social care services have a statutory duty to provide assistance. The carers' experience will be considered during the assessment and any subsequent reviews.
- 8. **Supporting young Carers -** we will ensure that the needs of young carers are also considered and that families/cares with a child with special needs are supported through the transitions process, which can also be difficult to navigate their child transitions into adult services.

The above principles have been translated into key priority and actions as detailed in section 9 and each partner organisation will be expected to build upon them in the development of their individual delivery plans.

Although funding in relation to carers is not directly addressed within this strategy, the financial position faced by both health and social care organisations cannot be ignored. Therefore, the available resources for each organisation will be reflected in the individual plans that will be developed by the partners, which will underpin this strategy and the guiding principles.

#### 3. Who is the Strategy for?

This strategy is aimed towards all unpaid carers who are caring for someone that lives in Leicester, Leicestershire and Rutland (LLR) including but not limited to:

- Working Carers
- Older Carers
- Parent/ Family Carers
- Multiple Carers
- Young Carers
- Sandwich carers (those with caring responsibilities for different generations, such as children and parents)

It seeks to understand and respond to the issues related to caring that have been highlighted locally and inform carers how the partners signed up to this Strategy will work together to ensure the role of carers is recognised, valued and supported.

The Strategy also aims to highlight to a broad range of organisations, local communities and individuals the prevalence of caring, the significant impact it can have on carers lives, and what we can all do to support carers more effectively.

#### Who is a carer?

A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, substance misuse or a mental health need cannot cope without their support.

A young carer is someone under 18 who cares, unpaid, for a friend or family member who due to illness, disability, substance misuse or a mental health need or an addiction cannot cope without their support.

Carers are sometimes referred to as unpaid carers, or family carers.

It is recognised that individuals often do not relate to the term 'carer' and see the caring responsibilities they carry out as part of another relationship or role i.e. as a wife, daughter, friend etc. However, for the purpose of this strategy all those providing unpaid additional support to individuals who could not cope without their support will be referred to as Carers.

#### 4. Impact of caring

Over six and a half million people in the UK are carers. Looking after a person that you care about is something that many of us want to do. Caring can be very rewarding, helping a person develop or relearn skills, or simply helping to make sure your loved one is as well supported as they can be.

"When the person we care for really struggles to do things works really hard and is then able to do something it can make us feel really happy." Local Carer

Across Leicester, Leicestershire and Rutland carers contribute around £2 billion worth of support every year<sup>2</sup> which has a significant positive impact on demand experienced across the health and social care sector. However, some carers can be affected physically by caring through the night, repeatedly lifting, poor diet and lack of sleep. Stress, tiredness and mental ill-health are common issues for carers. In addition, carers can often be juggling and adapting to many changes in circumstances such as, in the condition of the cared for person or the impact of a new diagnosis.

Carers often lead on arranging care provision for the person they care for, which can include communicating with a range of departments and services. Challenges that carers face include knowing which service or department to contact, which can be especially difficult when the individual they care for is transitioning through a change in service/ organisational boundaries. It is widely recognised that carer identification is an issue as carers either do not identify themselves as carers or have a reluctance to identify due to stigma, potential bullying or pressure from the cared for person not to disclose.

The home environment can have an influence on carer stress and their ability to continue in their role. The key issues that have been recognised nationally have included: Where to go for help, Housing lettings policies involving carers, Inheritance issues for carers living in rented property, equipment, adaptations, repairs and improvements, housing support and technology to help carers and families stay in the home, options for moving home, funding and affordability. <sup>3</sup>

"We have grab rails and a slope put in has made life so much easier" Local Carer

#### **Older Carers**

• The 2011 Census (UK Census, 2011) revealed that there are over 1.8m carers aged 60 and over in England<sup>4</sup>.

<sup>&</sup>lt;sup>1</sup> Carers UK Policy Briefing | August 2015 | Facts about carers

<sup>&</sup>lt;sup>2</sup> VALUING CARERS 2015 The rising value of carers' support

<sup>&</sup>lt;sup>3</sup> Carers and housing: addressing their needs

<sup>&</sup>lt;sup>4</sup> Carers Trust Retirement on Hold Supporting Older Carers

Current data trends suggest that by 2035 there will be an increase of over 30% in the number of carers aged between 60-79, a 50% rise for carers aged 80-84 and carers over 85 will increase by 100%.<sup>5</sup> (Appendix 5) Older adult carers may experience health issues themselves, and in some cases experience loss of strength and mobility, and tire more quickly.

#### **Working Carers**

- 3 million people in the UK juggle paid work with unpaid caring responsibilities<sup>6</sup>. Caring can affect the type of work which carers are able to take on, aiming to find local, flexible work which can fit around caring.
- Research<sup>7</sup> has indicated that over 2.3 million people have given up work at some point to care for loved ones and nearly 3 million have reduced working hours.

"We need flexibility and understanding in the workforce" Local Carer

#### **Parent/ Family Carers**

- One in three parents report that their child outliving them and not being able to care for themselves, or oversee their professional care, is their biggest concerns.<sup>8</sup>
- (78%) of those providing care to a child with a disability said they have suffered mental ill health such as stress or depression because of caring.<sup>9</sup>
- Over 1,500 parents with disabled children took part in a 2014 online survey for Scope. Two thirds (69%) of respondents had problems accessing the local services for their children, with eight in ten parents admitting to feeling frustrated (80%), stressed (78%) or exhausted (70%) as a result.<sup>10</sup>

"I constantly worry about the future" – Local Parent Carer

#### **Multiple/Sandwich Carers**

- Most carers (76%) care for one person, although 18% care for two, 4% for three and 2% care for four or more people<sup>11</sup>. Sandwich carers find themselves caring for both younger and older generations.
- Carers with multiple caring roles report feeling exhausted and sometimes guilty that they have insufficient time to devote to their children or other close relatives in need of support.

<sup>&</sup>lt;sup>5</sup> www.poppi.org.uk version 10.0

<sup>&</sup>lt;sup>6</sup> EFC Briefing | Jan 2015 | The business case for supporting working carers

<sup>&</sup>lt;sup>7</sup> Carers UK and YouGov (2013) as part of Caring & Family Finances Inquiry UK Report (2014) Carers UK

<sup>&</sup>lt;sup>8</sup> "Who will care after I'm gone?" An insight into the pressures facing parents of people with learning disabilities Fitzroy transforming lives

<sup>&</sup>lt;sup>9</sup> CUK- State of Caring 2017

<sup>&</sup>lt;sup>10</sup> https://www.scope.org.uk/media/press-releases/sept-2014/parents-disabled-children-battle-support

<sup>&</sup>lt;sup>11</sup> CUK- State of Caring 2017

#### **Young Carers**

- Data from the 2011 Census reveals that **166,363 children in England are caring for their parents, siblings and family members**, an increase of 20% since 2001.
- A quarter of young carers in the UK said they were bullied at school because of their caring role (Carers Trust, 2013).
- One in 12 young carers is caring for more than 15 hours per week. Around one in 20 misses school because of their caring responsibilities.<sup>12</sup>
- Young adult carers aged between 16 and 18 years are twice as likely not to be in education, employment, or training (NEET)<sup>13</sup>

"They might be scared to admit it in case they get bullied. Social workers and schools should help them understand they are a young carer." Local Young Carer

**Top worries about becoming a carer** are being able to cope financially e.g. afford the care services or equipment and home adaptations required (46%) and coping with the stress of caring (43%).<sup>14</sup> Although finances are cited as a concern many carers do not claim benefits that they are entitled to, £1.1 billion of Carer's Allowance goes unclaimed every year in the UK<sup>15</sup>.

The 2016 national GP patient survey found that 3 in 5 carers have a long-term health condition, this compares with half of non-carers. This pattern is even more pronounced for younger adults providing care – 40% of carers aged 18-24 have a long-term health condition compared with 29% of non-carers in the same age group. <sup>16</sup> Carers report 'feeling tired' and experiencing 'disturbed sleep' as a result of their caring role, only 10% of carers have no effect on health because of their caring role (Appendix 2).

"Feeling that we can't rest because we are on call to look after the person we care for all of the time can make us tired and unhappy." Local Carer

When a person becomes a carer, they give up many of the opportunities that non-carers take for granted. Carers' can find their caring role limits the opportunities they have for a life outside their caring role. It is important we recognise the impact of caring in order to support carers to allow them to maintain caring relationships, and enjoy good mental and physical health.

<sup>&</sup>lt;sup>12</sup> Hidden from view: The experiences of young carers in England

<sup>&</sup>lt;sup>13</sup> Supporting Young Carers in School: An Introduction for Primary and Secondary School Staff

<sup>&</sup>lt;sup>14</sup> Research summary for Carers Week 2017

<sup>&</sup>lt;sup>15</sup> Need to know | Transitions in and out of caring: the information challenge

<sup>&</sup>lt;sup>16</sup> CUK- State of Caring 2017

#### 5. Relevant policy and legislation

Although much has been achieved in relation to the previous Leicester, Leicestershire and Rutland Strategy (2012 – 2015), there have been significant changes in government policy, including the creation of Clinical Commissioning Groups, the Care Act 2014 and the Children and Families act 2014. Whilst the new National Carers Strategy is expected soon, a new local strategy is necessary to reflect on these changes and to ensure new local priorities can be identified and addressed that are fit for now and the future.

We intend that this new strategy builds on the achievements of the previous one; some of these are:

- A Carers Charter, developed with carers, in place in all Leicester, Leicestershire and Rutland locations
- Commissioning Carers Support Services which help deliver the Care Act Early Intervention and Prevention duties, and which include a Carers Outreach Service in GP surgeries
- Developing carers registers in Primary and Adult Social Care
- Focused work in BAME communities to support people to identify as carers
- Offering Carers Assessments
- Provision of flexible respite and short breaks
- Agreement to a Memorandum of Understanding between Adult Social Care and Children's' Services in respect of Young Carers
- Partners offering information in a variety of formats, hard copy, web based, face to face
- Providing training for carers
- Providing advocacy for carers

There remain ongoing challenges which will be picked up by this new strategy. Notably these are:

- Continuing to raise awareness of carers issues and promoting early identification of carers
- Making information easy to find
- Ensuring that carer registers are robust
- Involving carers at an individual and strategic level
- Making communities carer friendly

#### Care Act 2014

The Care Act 2014 came into effect from April 2015 and replaced most previous law regarding carers and people being cared for. Under the Care Act, local authorities have new functions. The Act gives local authorities a responsibility to assess a carer's needs for support, where the carer appears to have such needs. Local authorities must consider the impact of the caring role on the health and wellbeing of carers. If the impact is significant then the eligibility criteria are likely to be met. Local authorities should work with other partners, like the NHS, to think about what types of service local people may need now and in the future.

The Care Act 2014 also places a duty on local authorities to conduct transition assessments for children, children's carers and young carers where there is a likely need for care and support after the child in question turns 18. The assessment should also support the young people and their families to plan for the future, by providing them with information about what they can expect.

#### The Children and Families Act 2014

The Act gives young carers more rights to ask for help. Councils must check what help any young carer needs as soon as they know they might need help, or if the young carer asks them to. In the past, young carers always had to ask first if they wanted their council to check what help they needed. Local authorities, carrying out a young carer's needs assessment must consider the extent to which the young carer is participating in or wishes to participate in education, training or recreation or employment.

The Act also says that councils must assess whether a parent carer within their area has needs for support and, if so, what those needs are. This check is called a 'Parent Carer's Needs Assessment'. In the past, parents always had to ask first if they wanted their council to check what help they needed to look after a disabled child.

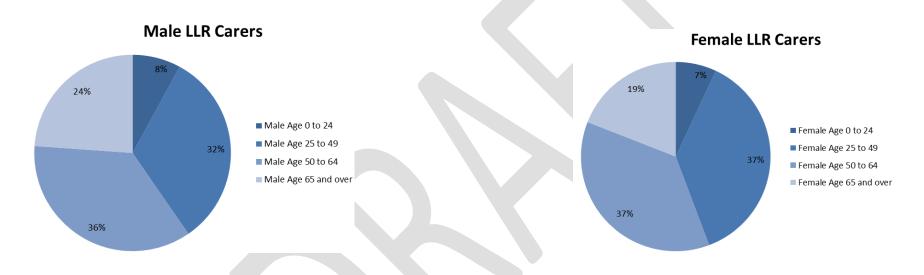
#### **NHS England's Commitment for Carers**

The Department of Health set out in its mandate to NHS England 'that the NHS becomes dramatically better at involving carers as well as patients in its care'. In May 2014 they published NHS England's Commitment for Carers, based on consultation with carers. Based on the emerging themes NHS England has developed 37 commitments around eight priorities, which include raising the profile of carers, education, training and information, person centred well co-ordinated care and partnership working.

Care Act 2014 - <a href="http://www.legislation.gov.uk/ukpga/2014/23/contents">http://www.legislation.gov.uk/ukpga/2014/23/contents</a>
The Children and Families Act 2014 - <a href="http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted">http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted</a>
<a href="https://www.england.nhs.uk/wp-content/uploads/2014/05/comm-carers.pdf">https://www.england.nhs.uk/wp-content/uploads/2014/05/comm-carers.pdf</a>

#### 6. Profile of carers in Leicester, Leicestershire and Rutland

Census data tells us that there are over 105,000 carers across Leicester Leicestershire and Rutland (LLR). Nearly 2000 of the 105,000 (2%) LLR carers are aged between 0-15 years, and 203 of these young carers provide 50 or more hours of unpaid care per week (Appendix 3). Overall, 67% of carers provide care for 1-19hrs a week. 57% of LLR carers are female, the highest provision of care for both sexes is provided by those aged 25-64.



Across Leicestershire over 90% of carers are from a white ethnic background and in Rutland it is 99%, however in Leicester City this figure is just over 50% with the remaining majority of carers coming from an Asian/Asian British background. See also Appendix 3.

A further source to help us understand the local carer population is the number of people in the area claiming carers' allowance:

	Carers in receipt of Carer's Allowance	Total value of Carer's Allowance received (p/a) (£)	Total estimated number eligible	Total estimated value of benefit eligibility (p/a) (£)	Total estimated number of carers missing out	Total estimated value of unclaimed benefit (p/a) (£)
Leicester	4,750	14,758,250	7,308	22,705,000	2,558	7,946,750
Leicestershire	4,990	15,503,930	7,677	23,852,200	2,687	8,348,270
Rutland	180	559,260	277	860,400	97	301,140

Source: Carers UK (2013)

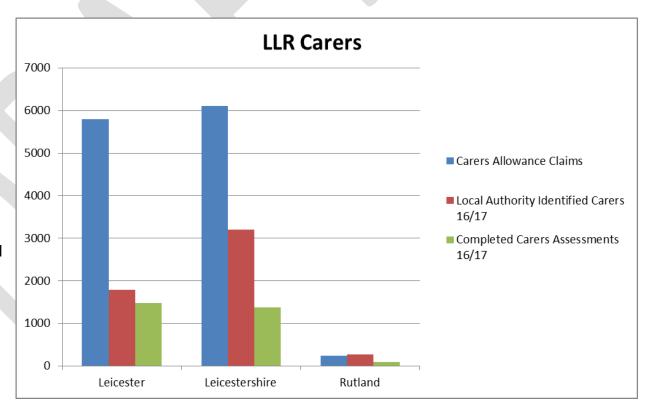
There are a variety of reasons people do not claim carers allowance – not identifying as a carer can be an issue alongside not having appropriate information or advice regarding the claim process and general benefit entitlements.

Local figures are in line with national claim rates with an average of 35% of carers missing out on claiming carers' allowance.

Although a higher proportion of carers are identified on Leicestershire systems, a smaller proportion are accessing carers' assessments in comparison to Leicester City.

When compared to the number of carers receiving carers allowance locally it is clear that a high proportion is not known to their Local Authority.

The Adult Social Care Outcomes Framework (ASCOF) uses data from a number of national sources including the Survey of Adult Carers in England (SACE) to measure how well care and support services achieve the outcomes that matter most to people. These measures are used by Leicester, Leicestershire and Rutland to monitor performance across the LLR.



As illustrated in Appendix 1, responses are varied across Leicester, Leicestershire and Rutland. Overall satisfaction with social services is high in Rutland in addition to the high proportion that feel they have been included and consulted in discussions about the person they care for. All areas have seen a small increase in the proportion that find it easy to find information about services, however less than a third of carers across LLR felt they had as much social contact as they would like. Results are static for Leicester and Leicestershire however this is a significant reduction for Rutland who reported 46% in 2014/15. Leicester City and Rutland have improved the proportion of carers who have been included or consulted about the person they care for however Leicestershire have a clear drop. This highlights opportunities to learn from local best practice, but also evidences a need to improve local carer experience.

Every two years local authorities conduct a postal survey of unpaid carers, The Survey of Adult Carers in England (SACE). The survey asks questions about quality of life and the impact that the services they receive have on their quality of life. In October 2016 surveys were sent to a selection of 1812 carers, 771 responses were received. Responses from these surveys feed into the ASCOF scores.

#### 7. Current carer support

A range of carer support services are commissioned across Leicester, Leicestershire and Rutland including support groups, advocacy, support to complete a carer's assessment form, and information and advice for carers including information on local services, and services specifically for young carers. Through an assessment process carers may also receive a personal budget, and councils can provide respite to give carers a break from caring (including breaks for parent carers).

In addition to the services common across Leicester, Leicestershire and Rutland, Leicestershire County Council also commissions online forums where carers can meet other local carers and a telephone befriending service specifically for carers. Rutland County Council has dedicated adult social care carer's workers who specifically carry out carers assessments, and funds fortnightly carers support and drop in sessions for carers and parent carers. Leicester City Council commissions a range of services for carers, including peer support and training and opportunities for social interaction which give carers a break from caring, and some specific services for carers of people with mental health needs and learning disabilities from black and ethnic minority backgrounds.

Leicester, Leicestershire and Rutland Clinical Commissioning Groups have implemented carers' charters and promote carer support throughout services and in partnership with local authorities. There are a number of hospital social work teams aiming to bridge the gap between health and social care services to provide a fluid service. Rutland operates a fully integrated service where therapists and health professionals are also able to carry out carers assessments.

Across Leicester, Leicestershire and Rutland there have been a range of approaches including but not limited to awareness raising talks and presentations, media work; stands and stalls at events. This provider undertakes young carers statutory assessments and is implementing a family based support plan, to include as required: service co-ordination, one to one support, advocacy, support with education, employment and training, grants, inclusion work, access to holidays, ID card, signposting and referral to other agencies, under 12's group work, decorating and garden challenges.

Throughout 2016/17 work was undertaken to raise the profile of young carers across Leicestershire the aim of this work was to build carer friendly communities, promote the issues young carers face, support recognition of the signs of young caring, and strengthen the shared responsibility between services and the resources available to support young carers.

The education system was targeted from primary level right up to university and each educational establishment visited was asked to have a 'named' member of staff (to be known as 'Young Carers Champion') who proactively promotes the young carers agenda, thus increasing the likelihood of young carers being identified. This has created a network of Young Carer Champions.

#### 8. What Leicester, Leicestershire and Rutland Carers say

The challenges a carer faces will be dependent on numerous factors and are individual to that carer. In order to attain a richer insight into the experiences of local carers, a range of engagement approaches were adopted in addition to analysis of survey and performance data already available.

Events were held over the summer of 2017 to ensure carer experiences and views were captured from a diverse range of carers within different caring roles and at varying stages of their caring journey. Fifteen workshops and focus groups were conducted. Numerous questionnaires and an online survey also ensured carers were given the opportunity to have their voice heard.

Through these events and further focus groups, workshops and questionnaires, over 300 carers have shared their views and experiences based around issues that we know are important to carers, such as recognition, identification, health and wellbeing, having a life outside of caring and supportive communities.

The carers were from a range of backgrounds: including parent carers, carers of different ethnic origins, young carers, older carers and working carers. Contributions were received through numerous partners, including, Leicestershire District Councils, Healthwatch, and from a number of local voluntary sector organisations. Outcomes were captured, coded and themed, in order for the most common experiences, concerns and potential solutions to be drawn from the variety of sources. In brief, key areas highlighted include:

Access to appropriate information and advice: carers lacked clarity in relation to where to look for information, not having access to digital information and provision of information not only for the carer but

information that supports the cared for individual.

"Getting correct information that is up to date can be an issue"

"Making clear the support that is available, so that a person with a disability knows they can cope without a carer"

"Temples/faith groups /clubs help with social isolation"

Access to good quality services for both carers and the cared for: Carers want good quality services for both themselves and the cared for person. Before they are happy to access any type of service for themselves they need to know the cared for person is being appropriately supported.

"Need better quality support services for carers and family"

"Need some joint services for carers and cared for so we can get out together"

**Increasing understanding in society of what a carer is:** There is a need to increase early identification of carers but also to ensure that once identified people understand the issues they face and value the contribution they make.

"Being listened to as a family carer as someone who knows some of the problems the person has and recognising how the caring impacts on us as carers."

"Carers don't recognise being a carer as a separate role"

"Need to educate people on what a carer is"

The carers' engagement work provided a real insight into the things that are important to carers locally, and their views on things that needed to be improved. It was clear that carers needed support, breaks from caring, and the opportunity to take care of themselves more, but it was also clear that small changes organisations can easily make could have a big impact on valuing carers.

"We need to feel valued and respected as people who provide help. This means that we have a lot of knowledge that is important about the person we care for and how they need help."

"Carers who are willing and able to care for their vulnerable family or friends need to be considered as co-partners in the delivery of care and support". Healthwatch Leicestershire Carers Lead

In addition to the engagement activity, a focussed research activity has been undertaken specifically considering issues faced by 30 women carers between the ages of 45-65 (the group that provides the highest amount of unpaid care) findings from the research were in line with the findings from engagement activity undertaken.

Alongside wishing for more help in their caring role, family background and values, culture and religion played a part as to why these women were caring. Asian and Asian British participants of the study described cultural and moral expectations from local communities that they provided the care required themselves and reported they would feel ashamed if they paid someone else to do it<sup>17</sup>.

The research confirmed that those in caring roles who work will reduce or compress their working hours to accommodate their caring duties, some participants reported staying longer than they would have liked to have done in their existing roles because of their working pattern and ability to manage their caring alongside employment.

However, there were examples where the caring role had prompted what they termed as positive changes in their working lives, including limiting the number of hours worked per week but at the same time progressing their career development.

"... I've spoken to people in the past who are carers who are wanting to go back to work and they don't see that they have any skills... "hang on a minute, you run a house, you liaise over 4 kids and after school clubs and you do this, that and the other. You know you've got huge organisational skills.... it's having that wherewithal to think 'well actually what I did now converts to x, y and z'. ...Because there is a huge skill set in caring,

-Research participant

Recommendations from the research paper include that organisations and carer services manage diversity and not equality – personalising support and opportunities as although they may be perceived to be in similar situations what support is needed may be different for individuals. Health and Social Care organisations should have policies that support working carers and they should be supported to gain further skills required for caring if necessary.

<sup>&</sup>lt;sup>17</sup> Oldridge L (forthcoming), Care(e)rs: An examination of the care and career experiences of mid-life women who combine formal employment and informal caring of a dependent adult, to be submitted as a PhD Thesis 2017, De Montfort University, UK

In 2015 West Leicestershire Clinical Commissioning Group undertook some qualitative research across Leicester, Leicestershire and Rutland on behalf of Better Care Together. Responses reflect the key themes identified in the 2017 engagement work, but also highlighted as key issues the lack of recognition of carers' knowledge and expertise and their non-inclusion in planning and decision-making regarding the persons they care for, and the impact of the end of the caring role.



#### 9. Key priorities and associated actions

Partners across LLR have drawn together national guidance, local data, the key themes from the engagement activity undertaken, and considered the local carers offer to determine key areas of development and improvement during the lifetime of this strategy. They are illustrated as key priorities, and for each priority high level partnership actions have been determined.

More detailed action plans incorporating individual organisational actions will be developed during the consultation phase of this strategy.

# Leicester, Leicestershire and Rutland Guiding Principles

1	2	3	4	5	6	7	8
Carer Identification	Carers are valued and involved	Carers Are Informed	Carer Friendly Communities	Carers have a life alongside caring	Carers and the impact of Technology Products and the living space	Carers can access the right support at the right time	Supporting young Carers

#### **Underpinning Partnership response**

Raising staff	Recognition of	Awareness raising	Embedding carer	Promoting carers	Involving carers	More effective	Focus on whole
awareness	carers at	and targeted	awareness	within our	in housing	partnership	family
across partner organisations  Proactive communications to the wider public	appropriate points of the pathway  Involvement of carers in service changes and new initiatives	training for frontline staff.  Improving access to Information and Advice	Support the development of local initiatives	organisations and other employers  Support carers through flexible policies  Benefits advice  Flexible and responsive carer respite	related assessments, understanding carers perspectives Simplifying processes and ensuring information is consistent	working  Support offer that is flexible and appropriate to needs	Awareness raising and early identification  Transitioning to adult services

What we found	What we will do
Carer identification was a key theme. Services that work with carers reported a difficulty in	All partners will seek to support carers to identify themselves as appropriate
etting carers to recognise themselves as carers.	LLR Clinical Commissioning Groups will include information on
arers described not accessing support until they eached crisis point as they had not recognised temselves as carers before that point.	carers and increase carer awareness in practice staff inductions. They will aim to increase the number of carers identified on GP practice registers.
·	<ul> <li>Individual partners will work to make their carer registers robust.</li> </ul>

- Increase in identified carers GP registers, council systems, carers recorded to be accessing other commissioned services
- Increase in carers referred to carer support services
- Increase in the number of carers assessments offered

Priority 2. Carers are valued and involved - Caring today and in the future		
What we found	What we will do	
Carers do not feel supported, valued or empowered in their caring role, often not being kept informed, or not seen as a key partner in care.	<ul> <li>Health and social care professionals will seek the input of informal carers at appropriate key points on the health and social care pathway in order to secure the best possible outcomes for the cared for. This joined up approach is particularly focussed on avoiding inappropriate hospital discharge and enabling timely discharge.</li> <li>Commissioners will ensure that carers' views are sought and reflected in commissioning exercises.</li> <li>Good practice in carer training will continue to be shared across partners.</li> </ul>	
How will we know if it has worked		
<ul> <li>Increased satisfaction level from carers within t</li> </ul>	he next national carers survey	

What we found	What we will do
There was recognition through engagement that information about carer issues was difficult to find and carers needed to actively seek out support and information rather than it being offered.	<ul> <li>Partners will review their information offer for carers to improve its accessibility.</li> <li>All Partners will seek opportunities to raise awareness of local carers services</li> </ul>
How will we know if it has worked	

• Increase in numbers accessing carer support

What we found	What we will do
Feedback included carers wanting services and support available "in smaller pockets within localities as access to services is often difficult due to the obscure shape of the localities".  Other feedback from carers included "help should be offered rather than having to ask for it"  Those in minority or geographically isolated groups need support too.	<ul> <li>Commissioners will take the views of carers into account in future commissioning exercises. This will include consideration of geographic and demographic profiles.</li> <li>Encourage communities to support carers through awareness raising within existing community groups</li> </ul>
How will we know if this has worked	

What we found	What we will do
Carers feel their caring role is not valued at work and flexibility was a key factor in the ability to continue to work  Carers cite financial worries as one of their biggest concerns.  Carers highlighted that they often neglect their own health and wellbeing  Carers also felt respite was essential to enable to them to continue within their caring role.	<ul> <li>As employers themselves, partners will review their carer friendly policies and aim to set a good example to others.</li> <li>The assessment process will consider the use of flexible and responsive respite provision to enable carers to have a break, including short beaks to families with a child with Special Educational Needs and Disability.</li> <li>CCG's will continue to encourage carers to take up screening invitations, NHS Health checks and flu vaccinations, where relevant.</li> </ul>
How will we know if it has worked?	

What we found	What we will do
The home environment plays a key part in enabling a carer to undertake their caring role. A carer's perspective should be considered throughout relevant assessment processes. Although most workers would consult carers and some positive feedback was received the approach was not consistent.  It was also found across LLR local authorities do not hold enough information on carers and their tenure status.	The partnership will seek to involve professionals from housing, equipment and adaptations in work to improve the carers' pathway This should include raising awareness of the issues facing carers with those organisations.
Some Leicestershire carers found equipment often took a long time to be acquired due to the longevity and inconsistency in processes followed, having a real impact on their ability to care.  How will we know if it has worked	

Χ

Priority 7. Carers can access the right support at the right time - Services and Systems that work for carers			
What we found	What we will do		
Carers wanted to receive support that recognised their individual circumstances, and sometimes	Assessments will take a strength based approach		
needed support to navigate through the system.	<ul> <li>Each partner will look at its carer's pathway to reduce the potential for a disjointed approach.</li> </ul>		
Throughout all engagement work carers felt access			
to services was challenging due to lack of integration	Opportunities for closer working between agencies will be		

(with the exception of many carers based in Rutland) and felt the services they received were often disjointed due to interdepartmental transfers or change in funding streams.

Some carers felt confused about which organisation is responsible for what, and felt health and social care should work better together.

considered at appropriate points in service reviews.

People will be signposted to sources of support post-caring

#### How will we know if it has worked

• Improvements in carer reported quality of life and satisfaction with social services.



What we found	What we will do
Young carers identified the need for services to be more integrated. This is particularly significant at the point of transition from children's to adult services.  Young Carers often miss education due to their caring responsibilities this can impact on them when it comes to employment.  Young carers identified the need to be 'young people'	<ul> <li>All partners will take the needs of young carers into account in planning and assessment processes.</li> <li>The assessment process will take a whole family approach</li> </ul>
rather than in the carer role all the time, leading to the need for 'time off' or respite time.	

- The impact of caring on young carers is taken into account in assessments and transition planning.
- Young carers report improved outcomes at home, school or in employment.

#### 10. Monitoring progress

As part of the Sustainability and Transformation Plan (STP) governance structure, the Carers Delivery Group have led on the development of this strategy and recognise the impact that positive carer support can have across all workstreams. The group will work alongside other partners to ensure the carers perspective is considered and responded to.

During the consultation phase more detailed action plans will be developed to further capture both partnership and ensure all key activities, timescales and measures of impact are in place. These action plans will be overseen by the Carers Delivery Group which will report progress to the Home First Programme Board.

In order to ensure the involvement of carers in overseeing delivery of the strategy, a carer's reference group will be created which will track progress against key milestones.

#### 11. Conclusion

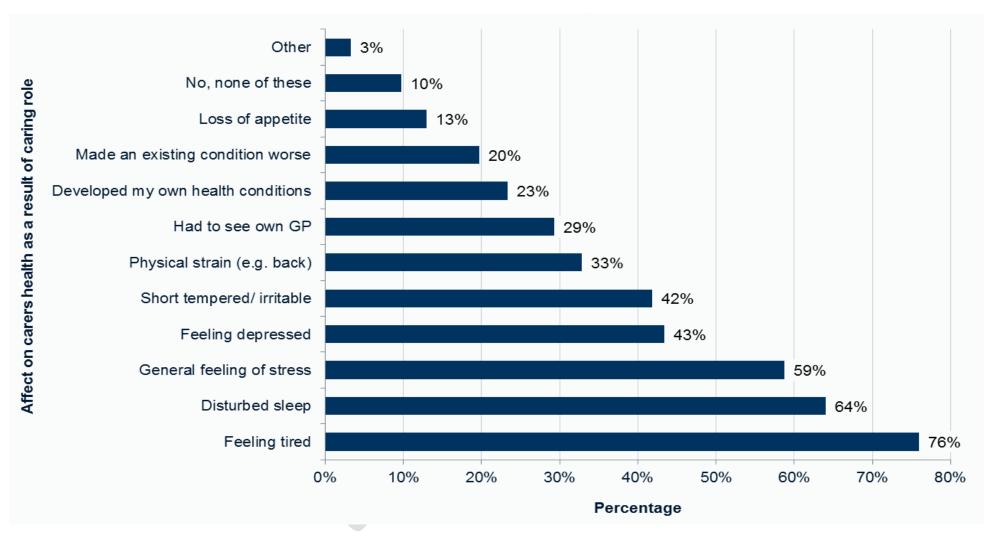
Whilst recognising the significant contribution that carers make across the health and social care economy, it is clear from our review of evidence and through significant engagement undertaken, that more can be done to recognise, value and support carers across Leicester, Leicestershire and Rutland.

This strategy recognises that improvements in carer support will not only contribute to improved health and wellbeing for those with caring responsibilities, but will also help the local health and social care economy rise to the challenges of a changing local population.

# **Appendix 1 – Adult Social Care Outcomes Framework**

	Measure	2012-13		2014-15	2016-17
1D Carer reported Quality of Life	Carron romantad Ovalita, of Life	NATIONAL	8.1	7.9	
		LCC	7.9	7.4	7.5
	Carer reported Quality of Life	CITY	7.1	7.2	7.2
		RUTLAND	9.0	8.4	7.9
11 (2)	% of carers who felt they had as much social contact as they would like	NATIONAL	N/A	38.5 %	
		LCC	N/A	32.5%	31.4%
		CITY	N/A	31.9%	31.0%
		RUTLAND	N/A	46%	31.1%
3В	Overall satisfaction of carers with social services	NATIONAL	42.7	41.2 %	
		LCC	43.3%	41.2%	31.2%
		CITY	37.9	37.7%	43.5%
		RUTLAND	62.4	55.8%	62.1%
3C	The proportion of carers who report that they have been included or consulted in discussions about the person they care for	NATIONAL	72.9	72.3 %	
		LCC	75.6%	72.5%	68.5%
		CITY	63.5	68.5%	70.7%
		RUTLAND	92.6	76.7%	84.6%
3D (2)	The proportion of carers who find it easy to find information about services	NATIONAL	71.4	65.5 %	
		LCC	65.5%	58.4%	63.5%
		CITY	52.5	55.5%	57.3%
		RUTLAND	78.0	76.8	79.5%

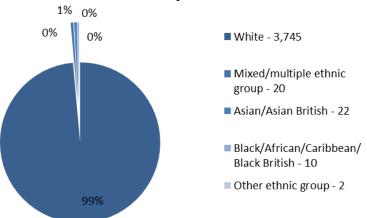
#### **Appendix 2: Effect on Carers' Health**



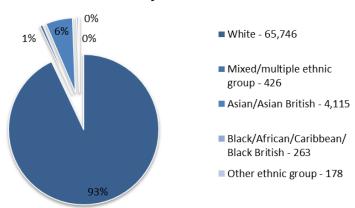
Source: SACE, NHS Digital

#### **Appendix 3: Carers ethnicity breakdown and Young Carers statistics**

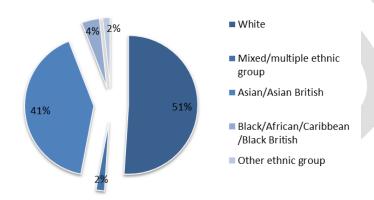
# **Carers Ethnicity Rutland**



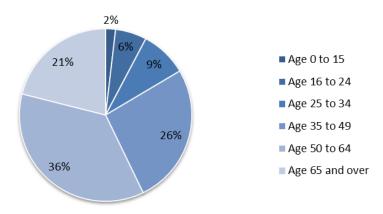
#### **Carers Ethnicity Leicestershire**



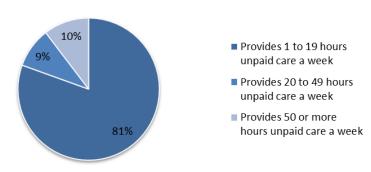
### **Carers Ethnicity Leicester**



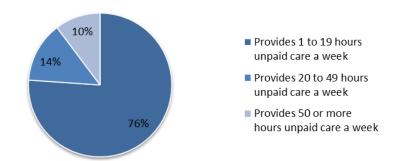
# **Age of LLR Carers**



# LLR Young Carers Age 0 to 15



# LLR Young Carers Age 16 to 24



# Appendix 4: Poppi data

