

# LEICESTERSHIRE JOINT STRATEGIC NEEDS ASSESSMENT (DRAFT)

## Carers

Autumn 2024

Leicestershire County Council

Business Intelligence Service



**Public Health and Adult Social Care Intelligence**

Business Intelligence Service  
Leicestershire County Council  
County Hall, Glenfield  
Leicester LE3 8RA

Tel 0116 305 4266

Email [phi@leics.gov.uk](mailto:phi@leics.gov.uk)

Produced by the Business Intelligence Service at Leicestershire County Council.

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## FOREWORD

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The purpose of the Joint Strategic Needs Assessment (JSNA) is:

To improve the health and wellbeing of the local community and reduce inequalities for all ages.

To determine what actions the local authority, the local NHS and other partners need to take to meet health and social care needs, and to address the wider determinants that impact on health and wellbeing.

To provide a source of relevant reference to the Local Authority, the Integrated Care System (ICS) and NHS England for the commissioning of any future services.

The Local Authority and the Integrated Care Board (ICB) have equal and joint statutory responsibility to prepare a Joint Strategic Needs Assessment (JSNA) for Leicestershire, through the Health and Wellbeing Board. The Health and Social Care Act 2012 amended the Local Government and Public Involvement in Health Act 2007 to introduce duties and powers for Health and Wellbeing Boards in relation to JSNAs.

This JSNA chapter has reviewed the population health needs of the people of Leicestershire in relation to carers and their support needs. This has involved looking at the census and a wide variety of data related to carers, the policy and guidance relating to carers and existing services supporting them. The unmet needs and recommendations that have arisen from this needs assessment are discussed.

The JSNA offers an opportunity for the Local Authority, ICS and NHS England's plans for commissioning services to be informed by up-to-date information on the population that use their services. Where commissioning plans are not in line with the JSNA, the Local Authority, ICS and NHS England must be able to explain why.

Please note, the majority of indicators presented in this needs assessment are from national sources so are subject to a time lag due to the time required for data collection, data analysis and publication. Where possible, comparisons have been made to national averages and local context has been included. The term significance is used throughout the report and refers to statistical significance. This examines if the result presented is different to the national result, due to something other than chance. Most often, this is calculated using 95% confidence intervals.

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## EXECUTIVE SUMMARY

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Carers play an essential role in our communities, often without recognition of the commitments they make and the substantial impact that their selfless commitment to others can have on their own wellbeing. They provide a form of effective 'early intervention,' supporting the most vulnerable citizens and preventing the people they care for from requiring greater degrees of health and social care support. The 2021 Census identified that nationally 4.7 million people in England were providing unpaid care, representing 9% of the population. Because many carers do not self-identify, the true figure is likely to be much higher.

A carer is not a volunteer who has been placed in a caring role by a voluntary organisation, nor someone who is paid as a care worker or personal assistant. It is estimated that three in five people are carers at some point in their lives. Most carers in this country are not in touch with social care.

By supporting carers, services can improve the carer's quality of life and support the cared-for citizens to remain in their own homes, maintaining their independence and reducing chances of hospital admissions or residential care.

The Care Act 2014 aims to improve people's independence and wellbeing. It states that local authorities must provide or arrange services that help prevent people developing needs for care and support or delay people deteriorating such that they would need ongoing care and support. The Act relates mostly to adult carers, people over 18 years of age, who are caring for another adult. The Children and Families Act gives young carers (and parent carers) similar rights to assessment as other carers have under the Care Act.

The recent **population and morbidity trends** indicate that care needs for the elderly population in Leicestershire are increasing and likely to raise further in the future. Firstly, demographic data show that the older (65+) population of Leicestershire is growing at a faster rate than nationally (28% vs 20% between 2011 and 2021). Secondly, it is projected that, by 2033, the number of those aged 80 and above will rise by 47% (nearly 19 thousand) and those aged between 65 and 79 by 16% (nearly 18 thousand). It is estimated that 82% of the older population will suffer from at least two, and a quarter from four or more chronic conditions.

As a result of these trends, even with age-specific incidence rates remaining constant, the demand for paid and unpaid care will increase, particularly for conditions such as dementia or heart failure.

All unpaid carers are at higher risk of poorer health and disability. Responses to the 2021 Census have shown that general health of carers deteriorates incrementally with the increasing hours of care provided (nearly 38% of those caring for more than 50 hours per



week reported their health was 'not good', and 35% were disabled). In addition to long-term physical conditions, mental health, social isolation and economic inequality, through cost of living or lack of employment, all play a part.

Several groups of carers have additional risk factors and unique challenges including. Ethnic minority carers have higher rates of financial difficulties and loneliness, there are higher rates of mental health issues and financial difficulties among carers from LGBTQ+ community, while young carers have additional educational, developmental and social needs. Those caring for younger adults may have employment problems while providing high volume of care and additional burden of care is experienced by those caring for people with learning difficulties or mental health conditions. Other risk groups include those caring for people with dementia or those with substance misuse.

According to Carers UK, 26% of UK adults providing some form of unpaid care in 2023, which would indicate a broad estimate of 156,000 adult carers in Leicestershire.

However, **Census 2021 data** show a total of 61.3 thousand of respondents, aged 5 years and above, declaring that they provided unpaid care (9% of population). The highest rate of caring population was among those aged 45 to 64 (15%), followed by those 65 to 84 (11.3%), with women predominating in all but the eldest (aged 85 years and above) group of carers. Same as nationally, the highest rates of unpaid care for ethnic groups were for white Gypsy or Irish Travellers (13.2%, compared to 9.4% for white English, Welsh, Scottish and Northern Irish). There is some geographical variation with of carers highest rate in Oadby and Wigston (9.8%) and lowest in Harborough (8.3%), although this is unadjusted for age. The rate of employment among carers were slightly higher in Leicestershire compared to the national average, with slightly lower unemployment rate (2% vs 3%).

More than a half (54%, 33.2 thousand) of 61.3 carers provided less than 20 hours of care per week, and 28% (17.1 thousand) provided 50 or more hours per week. In the latter group, the majority (93%; N=15,800) of households comprised of at least one disabled person, including 6.2 thousand carers who declared their own health being poor.

Broad indicators of social isolation and quality of life of unpaid carers by the Office for Health Improvement and Disparities (OHID), show no significant departure from national average, except for social isolation among the older population (65 and above) being lower (better than average) and rate of self-directed support and direct payments higher (better).

Local data confirm that only a proportion of carers are in **contact with services**. In July 2024, there were less than 6,800 carers registered with the Support for Carers service in Leicestershire. The number of young carers identified by schools in Leicestershire in 2024 is 255 (0.6% of secondary school population), with 72% of schools reporting no young carers -

Census 2021 data report 1,185 carers aged 5-17 years in Leicestershire (1.1% of the population in this age group). Furthermore, only about 1-2% of patients registered with GPs are reported as carers on the LLR Carer Registration Dataset indicating a significant gap to the 9% from Census 2021.

The **Leicestershire Carers Survey** for 2023/24 (1,064 sampled carers with 40% response rate), showed a lower level of dissatisfaction with services (4.8%, compared to the national average of 8%).

One in four (25%) of respondents cared for more than 20 years. The proportion of those caring for more than one hundred hours per week increased from 30% in 2021/22 Survey to 36% in 2023/24.

Less than half (46%) of respondents reported they could look after themselves, while over 17% felt they were neglecting themselves, compared to 20% nationally. Carers' ability to look after themselves has been declining at the national level as well as locally.

Almost one in ten (9% vs 10% nationally) of Leicestershire carers report having substantial financial difficulties as result of their caring role. This finding also shows a negative trend.

Caring can have significant effect on health and wellbeing of the carer, their personal finances and employment prospects. Unpaid care also has a profound **impact** on the wider economy. This was particularly evident during the COVID-19 pandemic of 2020-2021.

According to Rowntree Foundation report, 28% of people with caring responsibilities were in poverty in 2021/22; those in paid employment experience an average £5,000 pay penalty per year. In 2024, 1.4 million people claimed Carers Allowance, a 4% increase on the previous year.

Many carers juggle caring responsibilities with paid employment; in 2022 a third of NHS employees also provided unpaid care. It is estimated that more than a half of carers in paid employment provide more than 35 hours of care per week. However, increasing caring responsibilities often lead to reduction in working hours or leaving employment with subsequent financial implications for the carer and their family.

The contribution of unpaid care for the national economy is estimated to be equivalent to the total NHS budget – circa £162 billion per year.

Overreliance on unpaid care may lead, on larger a scale, to a reduction in productivity and economic output (through staff or skill shortages), increased social and health care cost over time.

Rates of disability are high among unpaid carers, particularly in older age groups (65 and above), with 40% of carers providing over 20 hours of care per week who are disabled

themselves.

In Leicestershire, age-specific rates of ill-health or disability among carers are similar or lower than national average; the local population is not statistical outlier in this respect.

It is estimated that the onset of COVID-19 pandemic caused additional 4.5 million people in the UK to become carers overnight, while existing unpaid carers experienced increased burden of caring (58% of carers reported providing more care during the pandemic), increasing feeling of loneliness, mental ill health and stress. The pandemic had a particular impact on young carers; with closure of educational settings many young carers lost regular forms of contact and support.

Under the Care Act 2014, carers are entitled to support from their local authority, with eligibility assessed through Carers Assessment. In Leicestershire, it can be completed through customer service portal, by calling the **Adult Social Care (ASC)** Customer Service Centre or VASL Support for Carers. Carers may be entitled to a personal budget to support their health and wellbeing and provide respite from their caring responsibilities. Carers can receive a Direct Payment from ASC to support in their caring role. The number of carers in receipt of a weekly Direct Payment on any given day has been increasing over the last 3 years (by 32%).

A Parent Carer Assessment can be requested for those families where the parent or carer is the main carer for a child or young person up to the age of 18 that has either a physical or learning disability and/or has a mental disorder.

Voluntary Action South Leicestershire (VASL) **Support for Carers** is a free service commissioned by Leicestershire County Council. Support for Carers offers carers a variety of different services to support unpaid carers including issuing a Carers Passport, providing information and advice, financial and emotional support, befriending service, and local support groups to give carers the opportunity to connect with other carers.

Under the Children and Families Act of 2014 and Health and Care Act of 2022, the Local Authority has a statutory responsibility to identify young carers across the county and to the right to an assessment. The dedicated **Young Carers Team** which comprises of one Young Carers Co-ordinator and one Young Carers Youth Worker (two full-time equivalent). Young Carers Passport has been introduced to support children in working with their schools, GP's and other professionals. Only 288 young carers were so far identified in secondary schools in Leicestershire: 0.6% of school population. As reference, Census 2021 reports 1.1% of 5-17 year olds as carers.

The University Hospitals of Leicester (UHL) are undertaking a variety of projects in support of carers, including development of new Carers Strategy, with a focus on carers identification, involving carers and keeping carers informed. UHL developed their Carers Passport, which is

being rolled out throughout the Trust. UHL is also reviewing the Family, Carers and Friends Feedback Form.

There has been a number of initiatives in primary care including the development of GP Carer Registration Form, establishing the LLR GP Carer Registration Dataset, ongoing work to improve carer identification, developing support pack, carer awareness training and carer awareness raising with ICB staff involved in service transformation.

Leicestershire Partnership NHS Trust (LPT) developed a National Carers Trust Triangle of Care (TOC) programme, including introduction of a Carers Pack, Systmone Carers dashboard, carer awareness training.

There are many independent voluntary sector organisations, such as Age UK or Carers UK, providing a variety of help, information and advice to carers. The support may include home respite, benefits checks and advice, support with domestic tasks and personal care, domestic help, friendship and support and dementia and memory services.

The service section of the report is not a comprehensive service directory, rather a summary of services provided by different sectors.

**In summary**, a substantial proportion of carers remain unidentified, or do not identify themselves. The demographic trends, increasing number of the elderly and those with long-term conditions, indicate rising need for care. Leicestershire carers have some additional risk factors, particularly in areas of rural deprivation, through social isolation, poor access to transport and services. For a high number of carers (over 22.7 thousand) the volume of care exceeds a full time job and the proportion of carers caring for someone long-term (over 20 years) have been increasing in the recent survey. One in ten local carers report having financial difficulties linked their caring role; this rate has been increasing recently.

One in twenty of carers surveyed recently in Leicestershire were dissatisfied with services, but this rate much lower than national average (4.8% vs 8%).

Data collected by the local services indicate rising demand for financial support – the number of Leicestershire carers receiving weekly direct payments has increased by almost a third between 2021 and 2024.

## 1. Introduction and Overview

The Leicester, Leicestershire and Rutland (LLR) Joint Carers Strategy<sup>1</sup> defines a carer as, “anyone who supports and cares, unpaid, for a family member or friend living with a disability, long-term illness, substance misuse or a mental health need, who would not manage without their help”.

Carers play an essential role in our communities, often without recognition of the commitments they make and the substantial impact that their selfless commitment to others can have on their own wellbeing. They are effectively a form of ‘early intervention’, supporting the most vulnerable citizens and preventing the people they care for from requiring greater degrees of health and social care support. Carers look after family, partners or friends in need of help because they are ill, frail or have a disability and the care they provide is unpaid. This includes adults looking after other adults, parent carers looking after disabled children and young carers under 18 years of age looking after siblings, parents or other relatives.

By supporting carers, services can improve the carer’s quality of life and support the cared-for citizens to remain in their own homes, maintain independence and reduce their incidences of requiring hospital admissions and residential care.

Local authorities have a duty under The Care Act 2014 to proactively identify, assess and look at how they can meet the needs of carers, including the carers of citizens who are not receiving social care support. The Care Act requires local authorities and Integrated Care Systems to work to bring together Health and Social Care services to provide tailored support for citizens.

A carer is not a volunteer who has been placed in a caring role by a voluntary organisation, nor someone who is paid as a care worker or personal assistant. It is estimated that three in five people are carers at some point in their lives. It is widely acknowledged that most of carers in this country are not in touch with social care.

Throughout the document, the term ‘carer’ is used to signify an ‘unpaid carer’, i.e. those for whom the caring role is not part of their paid employment.

## 2. Who is at Risk and Why?

Caring responsibilities are linked to many health and wellbeing problems, particularly with the increasing age of the carer and the complexity of issues and the condition of the cared-for person. Carers can experience significant economic, social and health inequalities, social isolation and poor social functioning, increased mental and physical morbidity, and even

increased mortality.

Consequently, all carers are an ‘at risk’ group, with some potentially at a higher risk (or with specific needs) such as older carers, young carers, ill or disabled, or ethnic minority carers.

This section of the report looks at the relevant demographics of Leicestershire population, its social and health profile, followed by a discussion of risk factors shared by all carers and a more detailed description of specific at-risk groups.

## 2.1. The Population of Leicestershire

The latest (2023) population estimates show that, compared to England and the East Midlands Region, Leicestershire has a higher percentage of people aged 65 years or more (Table 1). In Leicestershire, 21% of the population is aged 65 or over, compared to 18.7% across England. The ratio of those over 65 to the 15-64 age group is 33.5, compared to 29.2 for England (‘old age dependency ratio’\*).

*Table 1. Broad age group population comparison between Leicestershire, East Midlands and England (mid-2023 population estimates, ONS 2024)*

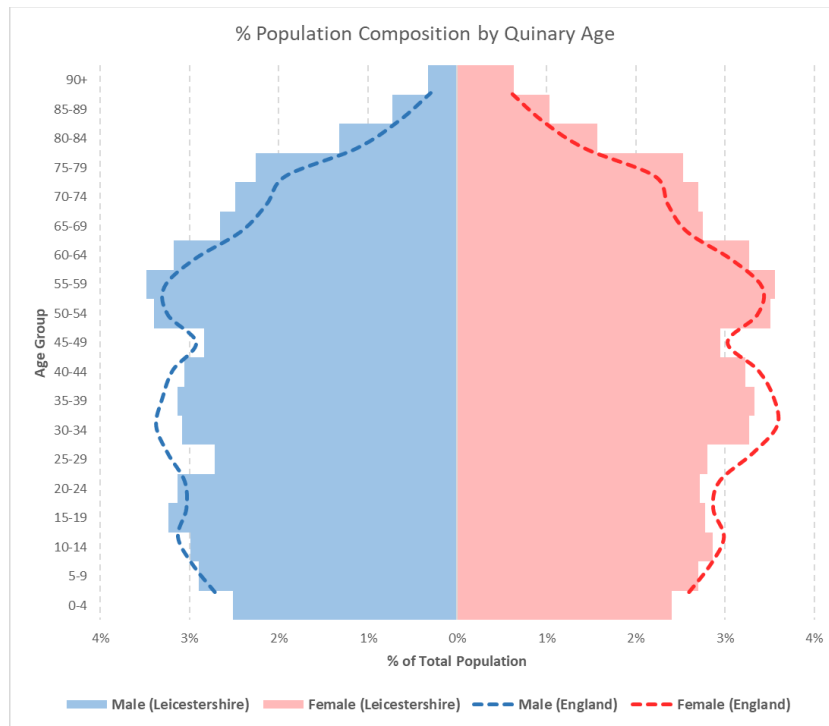
Area	0-14		15-64		65-79		80+		Total
	No*	%	No*	%	No*	%	No*	%	
England	9,942	<b>17.2</b>	36,965	<b>64.1</b>	7,860	<b>13.6</b>	2,923	<b>5.1</b>	<b>57,690</b>
East Midlands	840	<b>16.8</b>	3,164	<b>63.4</b>	727	<b>14.6</b>	260	<b>5.2</b>	<b>4,991</b>
<b>Leicestershire</b>	120	<b>16.4</b>	460	<b>62.7</b>	113	<b>15.4</b>	41	<b>5.6</b>	<b>734</b>

\* thousands

Leicestershire has proportionately more residents in older age groups, when compared to England. Conversely, there are less children and younger adults.

\* Proportion of dependents (aged over 64 years) per 100 working age population

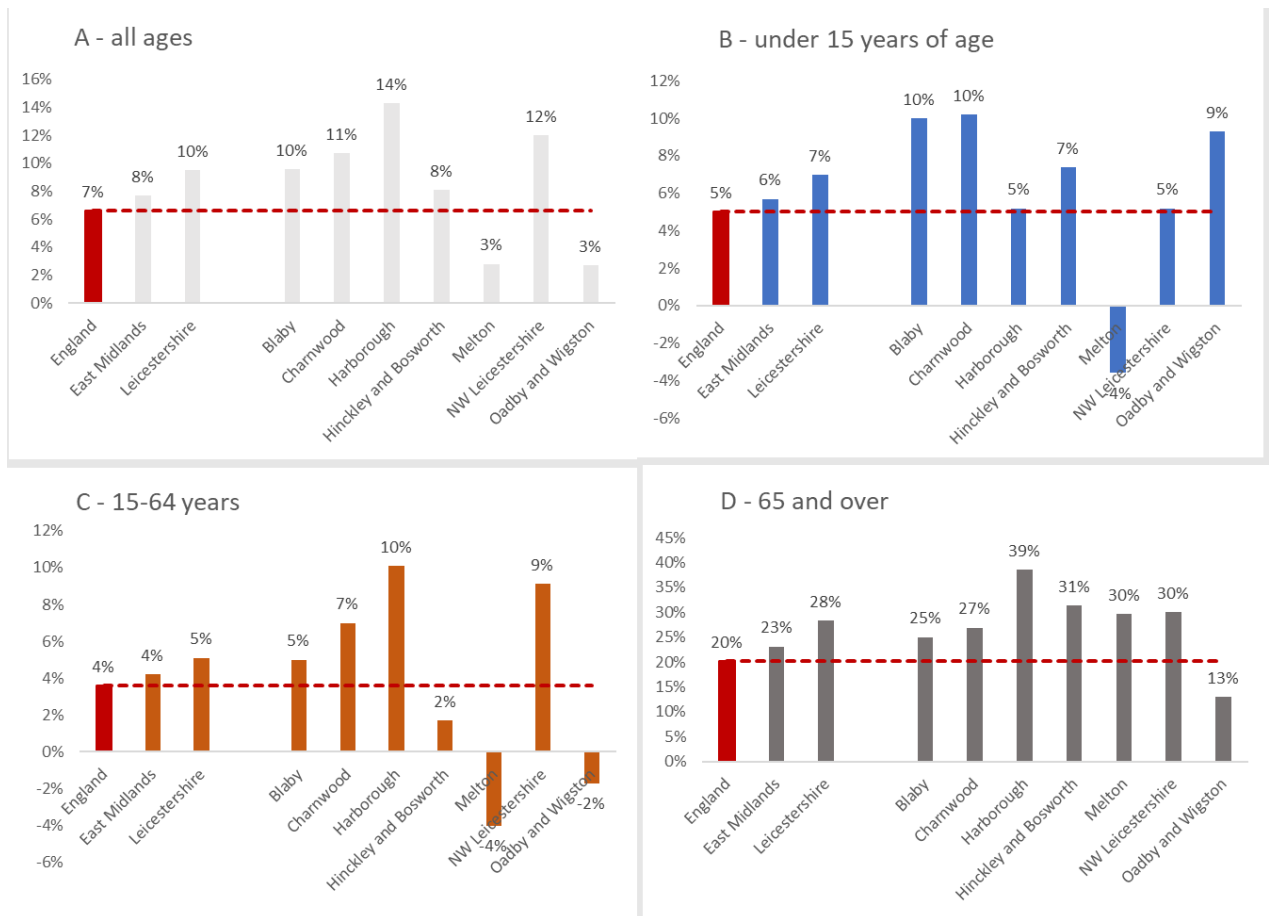
Figure 1. Age structure of Leicestershire population - mid-2023 estimates



Source: Office for National Statistics 2024

The population of Leicestershire has grown at a faster rate than England or the East Midlands since 2011, 10% increase in the overall numbers vs 7% nationally (Figure 2). Except for Melton and Oadby and Wigston (both 3%), rates were comparatively high in all districts, highest in Harborough (14%). Looking across three broad age groups, by far the highest growth rate was among those aged 65 and over, 28% vs 20% nationally and as high as 39% in Harborough (Figure 2 D). Of note is that Melton recorded a growth of 30% among the elderly, on a background of a drop in the number of both children and working age adults by 4% (Figure 2 B and C).

Figure 2 Population growth between 2011 and 2021 Census for main population groups in Leicestershire



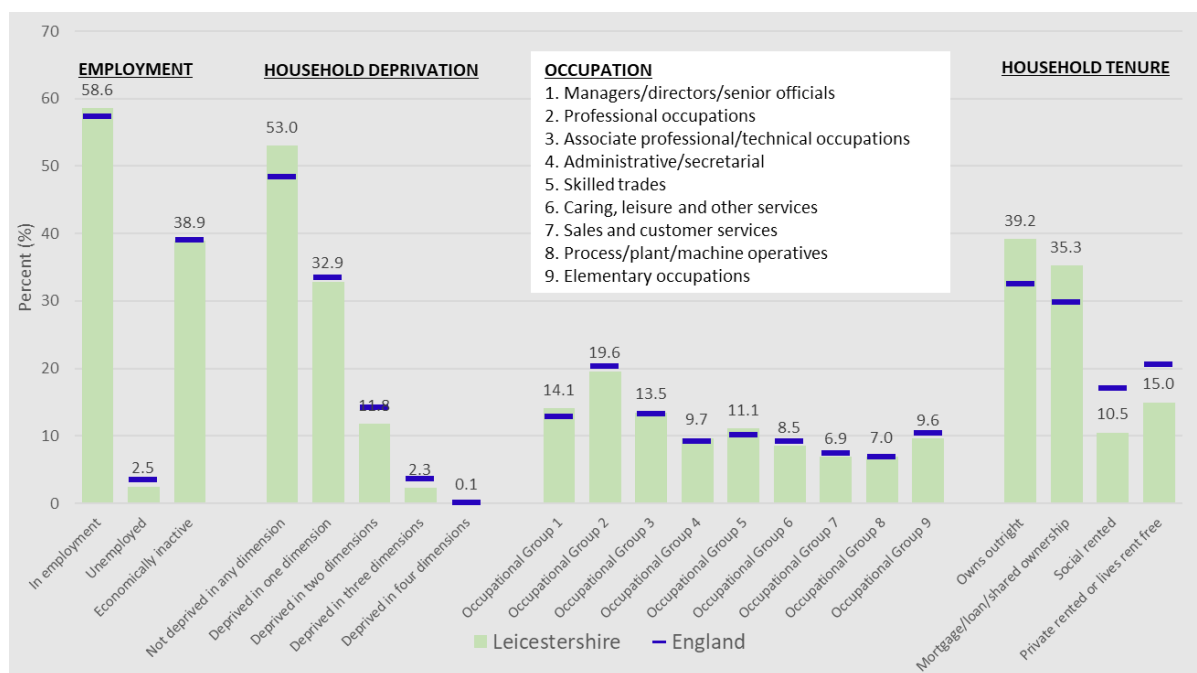
Source: Office for National Statistics 2023

### 2.1.1. Socio-economic deprivation

The broad socio-economic profile of Leicestershire population, based on Census 2021, shows a higher proportion of households as not deprived in any dimension (53% vs 48% nationally), and less of those deprived in two or more dimensions. Also, a higher proportion of Leicestershire population owned their homes outright or through mortgage or loan, with lower than national average rates of social or private renting (household tenure). Other indicators show a broadly similar patterns to the national average (Figure 3).



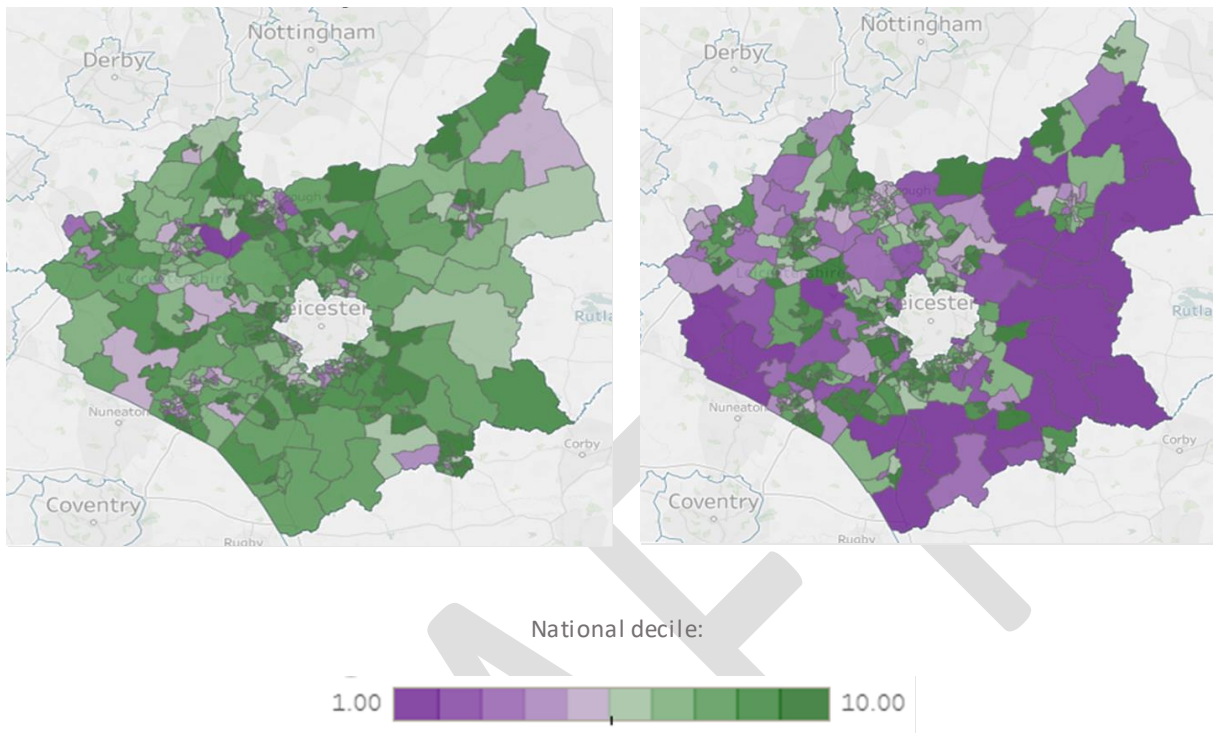
Figure 3 Summary of socio-economic indicators form Census 2021



Source: Office for National Statistics 2023

The average levels of deprivation across Leicestershire measured by the Indices of Multiple Deprivation (IoD)<sup>2</sup> are not high when compared to the national figures, but there are pockets of deprivation across the county particularly in North West Leicestershire and Charnwood. Although a useful measure at a larger scale, IoD is known to be biased towards urban deprivation. As a large proportion of Leicestershire is rural in character, it has specific issues expressed better through the Barriers to Housing and Services domain of the IoD. Within this domain predominantly rural areas show significant problems rooted in poor access to housing and services (Figure 4).

Figure 4. Deprivation in Leicestershire by lower super-output area (LSOA) – the overall IoD 2019 (left) and Barriers to Housing and Services domain (right).



### 2.1.2. Ethnicity

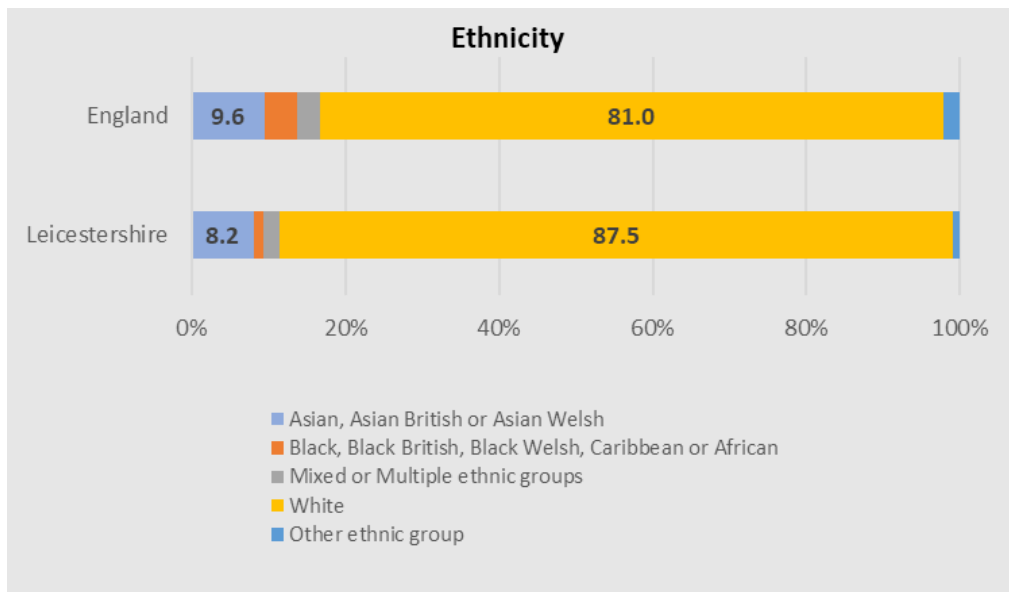
In 2021, the largest proportion (87.5%, N=632,426) of the Leicestershire population was of a white<sup>†</sup> ethnic background which is significantly more than the average for England (81%) (Figure 5). The total number in other ethnic groups was 88,938, with the proportion of Asian<sup>‡</sup> population (8.2%), followed by mixed groups (2.2%), black<sup>§</sup> (1.1%) and other population groups (1%). In the decade since 2011 the size of the ethnic minority population of Leicestershire has increased from 55,722 to 88,938 (a 60% rise).

<sup>†</sup> Includes the following categories – white English/Welsh/Scottish/Northern Irish/British, Irish and other white

<sup>‡</sup> Includes Asian or Asian British groups – Bangladeshi, Chinese, Indian, Pakistani or other

<sup>§</sup> Includes black and black British, African, Caribbean and other black groups

Figure 5 Ethnic profile of population of Leicestershire in 2021



Source: Office for National Statistics 2022

The picture varies across Leicestershire districts with lowest ethnic minority proportion in Melton (3.1%) and highest in Oadby and Wigston (36.6%) (Table 2).

Table 2 Ethnicity of Leicestershire districts' populations (Census 2021)

	Asian	Black	Mixed or Multiple	White	Other
Blaby	8.3	1.5	2.7	86.2	1.3
Charnwood	12.4	1.5	2.5	82.3	1.2
Harborough	5.4	0.7	2.1	91.0	0.8
Hinckley and Bosworth	2.8	0.6	1.8	94.3	0.6
Melton	1.2	0.4	1.3	96.9	0.3
North West Leicestershire	1.5	0.6	1.5	95.9	0.5
Oadby and Wigston	27.9	2.2	3.2	63.4	3.3
<b>Leicestershire</b>	<b>8.2</b>	<b>1.1</b>	<b>2.2</b>	<b>87.5</b>	<b>1.0</b>
<b>England</b>	<b>9.6</b>	<b>4.2</b>	<b>3.0</b>	<b>81.0</b>	<b>2.2</b>

(Source: ONS)

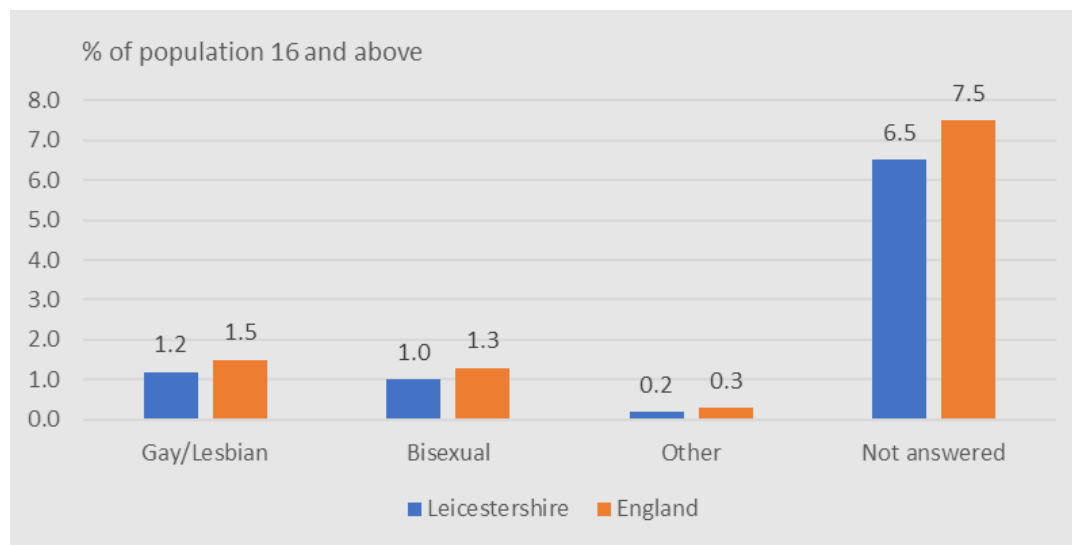
### 2.1.3. Sexual orientation and gender reassignment

In Census 2021 a slightly lower proportion of adult Leicestershire population declared themselves to be gay/lesbian or bisexual when compared to the national average; of note is a better response rate (only 6.5% not answered, compared to 7.5% in England) (Figure 6).

There was a total of around 7 thousand gay/lesbian and 6 thousand bisexual Leicestershire residents and 2.4% of adults declaring sexual orientation other than heterosexual (3.1%

nationally) (Table 3).

Figure 6. LGBTQ population - Census 20



(Source: ONS)

Table 3 Sexual orientation - Census 2021

	Gay/Lesbian		Bisexual		Other		No answer
	Number	%	Number	%	Number	%	%
Blaby	1,055	1.3	690	0.8	150	0.2	6.1
Charnwood	1,970	1.3	2,070	1.4	440	0.3	7.2
Harborough	925	1.1	620	0.8	140	0.2	6.0
Hinckley & Bosworth	1,105	1.2	865	0.9	195	0.2	5.9
Melton	480	1.1	405	0.9	75	0.2	6.2
North West Leicestershire	1,070	1.2	865	1.0	200	0.2	6.1
Oadby & Wigston	420	0.9	425	0.9	120	0.3	7.8
<b>Leicestershire Total</b>	<b>7,030</b>	<b>1.2</b>	<b>5,940</b>	<b>1.0</b>	<b>1,320</b>	<b>0.2</b>	<b>6.5</b>

(Source: ONS)

In Census 2021 a total of 735\*\* Leicestershire adults declared their gender was different to their sex at birth (0.15% of adult population, compared to the 0.25% national average). This number includes 375 trans women and 360 trans men. Other categories include 280 non-binary adults and 144 in other gender identity groups.

\*\* All numbers in this section were rounded to nearest 5

#### 2.1.4. Rural and urban populations

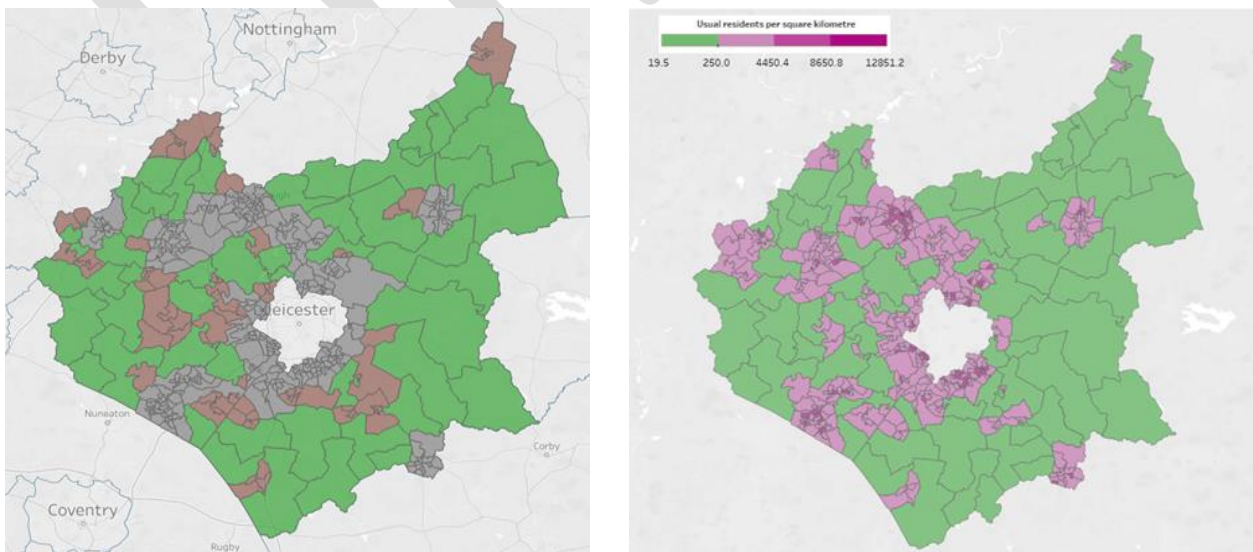
According to data from Census 2011<sup>3</sup>, more than a third of the Leicestershire population lived in areas classified as rural ('town and fringe' 18.4% and 'village and dispersed' 12.1%), with the remaining 69.5% residing in 'urban city and town' areas (Figure 7). This profile is defined as 'urban with significant rural' component. Some of the issues affecting the health and wellbeing of rural communities include low-paid work, unemployment of young people, high costs of housing and fuel poverty, poor access to health services and lack of public transport.

Figure 7. Population by rural-urban classification (Census 2011 data)

Population (percent, all ages)		Urban city and town	Rural town and fringe	Rural village and dispersed
All People		69.49%	18.38%	12.13%

Awaiting the updated urban-rural classification, Figure 8 presents the Census 2021 population density, for comparison. The rural-urban classification relies on geographical data, namely the relationship between the built-up areas and the lowest census geographical units (Output Area or OA), assigning OAs either to the urban or the rural domain then classifying higher geographical levels (Lower SOAs, Middle SOAs and Local Authorities) using the mix of their component OAs. Population density, on the other hand, is simply the number of usual residents in 2021 per square kilometre in the given LSOA.

Figure 8. Census 2011-based rural-urban classification (left) and Census 2021-based population density (right) of Leicestershire LSOAs

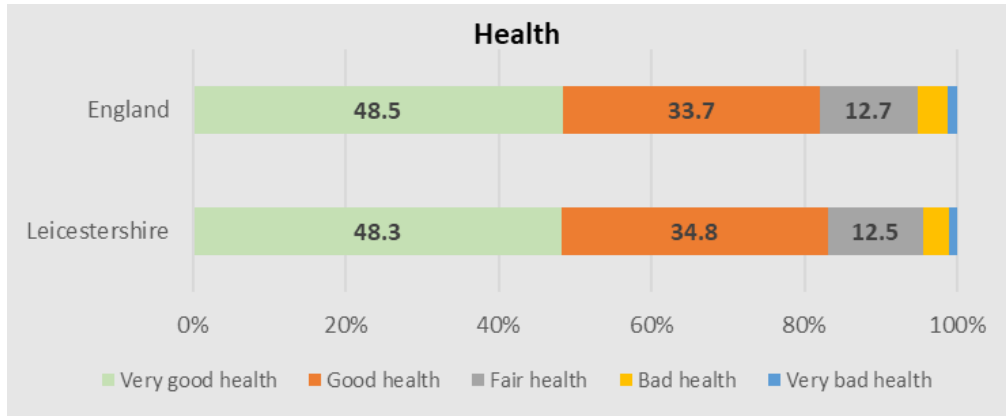


Source: ONS 2016 and 2022

### 2.1.5. Health and disability

The broad health profile from Census 2021 does not indicate major departures from national average, although these rates have not been standardised for age, which would be important given the somewhat different age structure of Leicestershire's population (Figure 9).

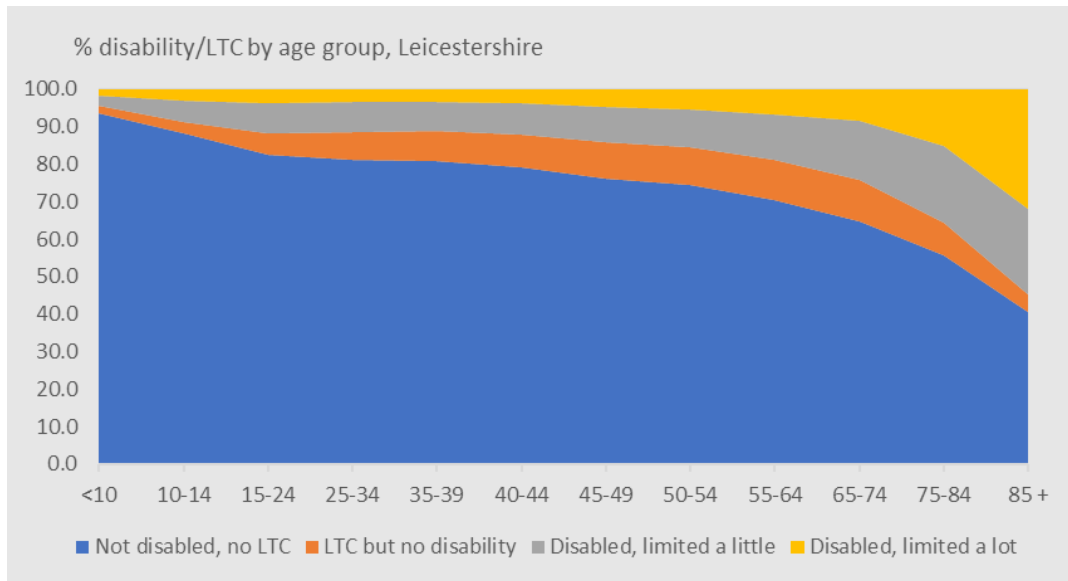
Figure 9. Health profile of Leicestershire population in 2021



Source: Office for National Statistics 2022

In Census 2021, 16.2% of Leicestershire population (N=113,470) declared they were disabled under the Equality Act, with 6% (N=43,222) saying that they were limited a lot in their daily activities. As comparison, for England these proportions were 16.9% and 7%. In addition, 7.8% (N=54,258) of Leicestershire population, although not disabled, had a long-term physical or mental health condition, which is higher than the national average of 6.9%. These proportions are highly dependent on age, with rates of disability and chronic disease rising steeply in older population. More than half of people aged 85 and over are disabled in Leicestershire (Figure 10).

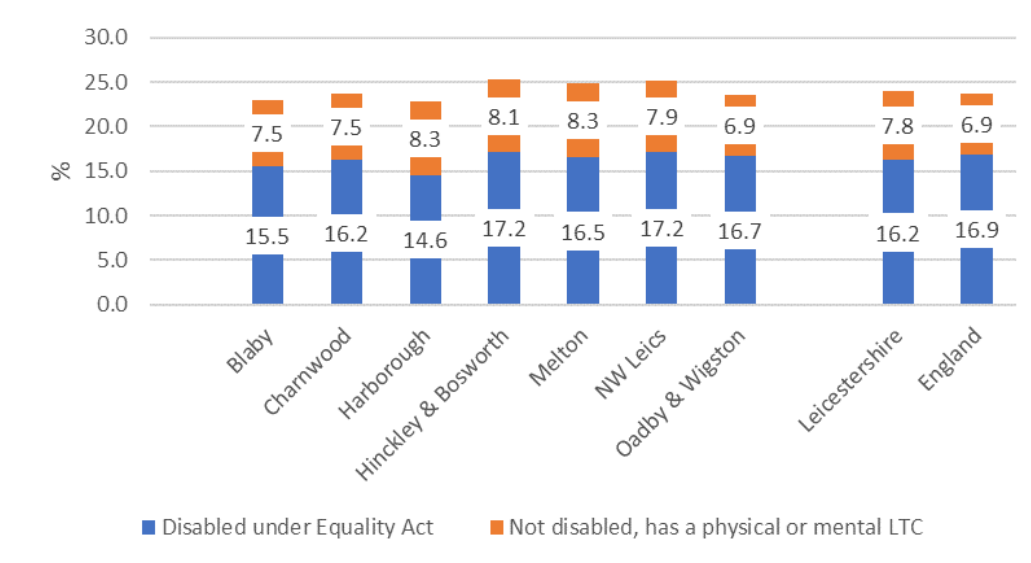
Figure 10. Disability and long-term conditions (LTC) - Census 2021



Source: Office for National Statistics 2022

There is a degree of local variation – rates of disability are higher than national average in Hinckley and Bosworth and North West Leicestershire. However, the rates of long-term disease without disability are generally high across local districts (higher than the average for England, except for Oadby and Wigston) (Figure 11). As these are crude rates, a variety of factors are involved, such as demographics, mainly age, and deprivation.

Figure 11. Proportion of population with a disability or a long-term condition (LTC) across Leicestershire districts - Census 2021 (Source: ONS)



Source: Office for National Statistics 2022

#### 2.1.6. Population growth and future morbidity

The currently available projections are based on 2018 population estimates published by the ONS<sup>4</sup>, which in turn are based on Census 2011 population figures. These projections are likely to be rebased by the ONS using Census 2021 results, with planned release in Spring 2025. With this caveat in mind the following is expected by 2032<sup>5</sup> (Table 4):

- The population of Leicestershire is projected to increase by a 10% to over 803,000 in the next decade, an increase of over 70,000 people. This is two and a half times higher than the average for England (4%), and significantly higher than the East Midlands (6%).
- The greatest change is expected in the oldest population group (80 and above), accounting for nearly 18,900 (47% increase) additional elderly people. This is above the projected average for England of 36% growth. There is also a projected significant increase (16%) in the numbers of residents aged 65 to 79 - by over 17,700 in the next ten years, in line with the wider, national trend.
- While nationally there is a forecast reduction in population under 40 (by 1.7% for under 20s and a small decrease for those in their 20s and 30s), both these groups are projected to grow in Leicestershire (by about 6%).
- Although the presented projections are based on the previous (2011) population census, the 2011-based projection for year 2021 was relatively close to the actual



Census 2021 population count, the former just 1.5% higher than the latter, which goes some way to support the validity of the overall methodology.

*Table 4. Leicestershire population projections 2022-32 (source: ONS 2022)*

Year / Age:	2022	2024	2026	2028	2030	2032	Local Growth*		England Growth*	
	Number (000s)						# (000s)	%	# (000s)	%
0-19	166.0	169.8	172.9	174.8	176.4	176.7	10.7	6.5	-227	-1.7
20-39	172.3	174.4	176.4	179.0	180.9	182.5	10.3	6.0	-29	-0.2
40-64	239.5	242.7	245.4	247.2	249.1	252.1	12.5	5.2	227	1.2
65-79	113.1	115.9	119.6	121.5	125.8	130.9	17.8	15.7	1,265	16.0
80+	40.0	43.5	46.8	52.6	56.3	58.8	18.8	47.2	1,074	36.4
<b>Total</b>	<b>732.9</b>	<b>748.3</b>	<b>763.1</b>	<b>777.2</b>	<b>790.6</b>	<b>803.0</b>	<b>70.1</b>	<b>9.6</b>	<b>2,310</b>	<b>4.0</b>

\* Change between 2022 and 2032

Source: Office for National Statistics 2022

The population projections and current morbidity trends point toward a significant rise in the numbers of people with several chronic conditions (both mental and physical) in the near future<sup>6</sup>. In addition to the overall population increase over the next ten years, statistical models based on national surveys<sup>7</sup> allow for approximate projections of morbidity and multi-morbidity in the Leicestershire population. According to the ONS 2018 population projections, the local population (65 and above) is likely to increase between 2023 and 2033 by at least 37 thousand.

It is estimated that the vast majority (82% or 30.3 thousand) will have at least two chronic conditions, with more than a quarter (26%, nearly 9.6 thousand) projected to suffer from four or more chronic diseases (Figure 12).

In addition to the older population increase, these models predict the percentage rise in the prevalence of specific chronic conditions. For Leicestershire, it is estimated that, by 2033, there could be an additional 27 thousand residents (aged 65 and over) suffering from arthritis, 22 thousand with hypertension, 15 thousand additional cases of cancer, 14 thousand with respiratory conditions and 11 thousand with diabetes. Depression is the only condition for which a small decrease in this age group is predicted (Figure 13).

Figure 12. Projected increase in morbidity and multi-morbidity for Leicestershire population aged 65 and above in the decade between 2023 and 2033.

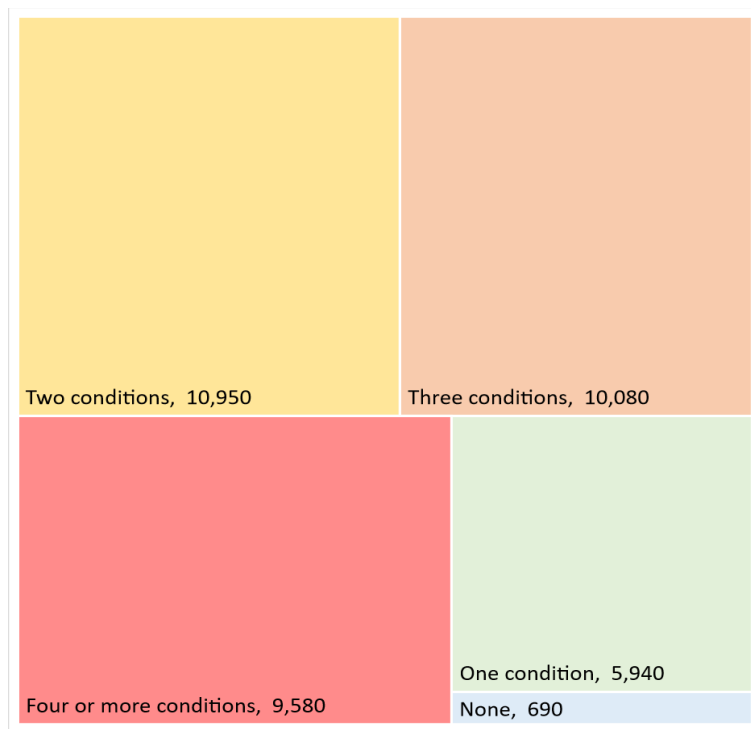
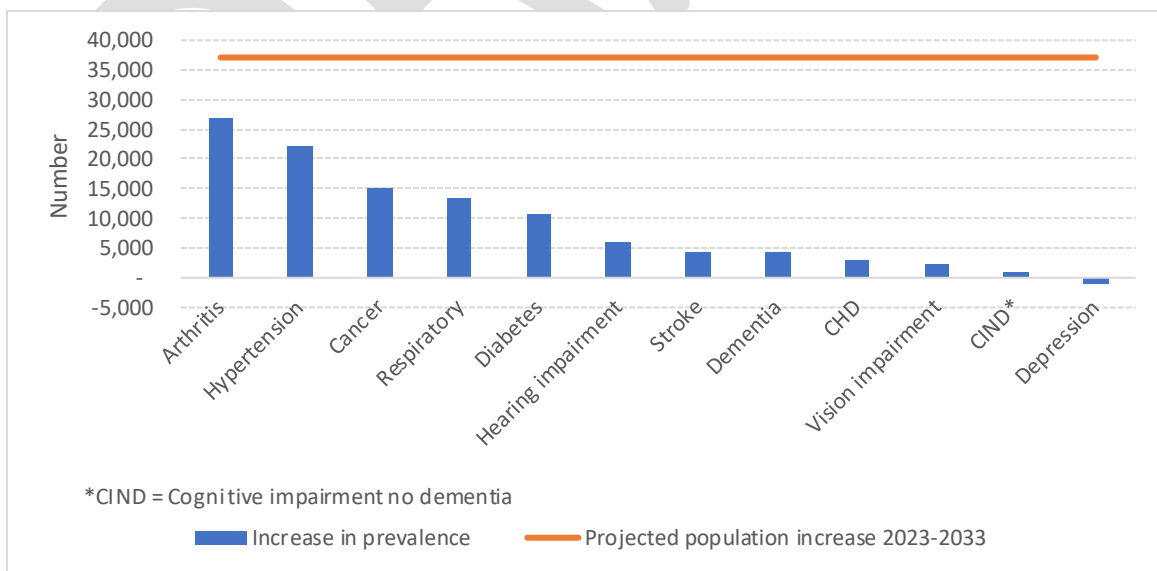


Figure 13. Projected additional burden of chronic disease among the 65 and older population of Leicestershire by 2033.



The projected prevalence of dementia in England<sup>8</sup> indicates an overall rise in prevalence in older people by about a third between 2015 and 2040 (from 6.7% to 8.8%), with nearly doubling in the rate of severe dementia (from 303 thousand in 2015 to 909 thousand in 2040 in England, prevalence of 3.1% to 5.9%).

For Leicestershire, the national rate for 2040 translates into 18,600 older people with dementia, two thirds severe (12,500, 67%) and a fifth moderate (3,800 or 20%). The cost of unpaid care for dementia in 2040 is projected to reach £22.3K per person per year, second only to the social care cost of £28K.

It is estimated that the rates of unpaid dementia care will rise by 81% and the numbers of people with dementia receiving both unpaid and formal care will double in that period. However, this projection assumes that the supply of unpaid care will match the demand, while demographic trends (particularly the observed higher rates of childlessness of future cohorts of older people) would indicate lower supply in the future, putting a higher burden on formal health and social care.

The Health Foundation<sup>9</sup> currently predicts that by 2040, in England, people aged 85 and above will have, on average, 5.7 diagnosed conditions, compared to 5.2 in 2019. Their recent forecasts highlight that, although the age-specific disease incidence rates are not likely to rise to a large degree<sup>††</sup>, the projected total numbers of diagnosed cases are likely to increase substantially in that period, primarily due to increasing numbers of older people. Thus, the highest relative increases are in heart failure (by 92%), atrial fibrillation (51%), diabetes (49%) and dementia (49%). The most prevalent conditions – chronic pain, diabetes, and anxiety and depression – are likely to increase by 32%, 49% and 16%, respectively.

On a background of the projected higher life expectancy overall (83.1 years in 2040 compared to 81.7 in 2019), the number of years spent disease-free is likely to decrease (from 44.9 years to 44.1 in 2040) while time spent with major illness is likely to increase from 11.2 years in 2019 to 12.6 in 2040.

The figures in this section are presented mostly for illustrative purposes, to highlight the importance of the projected rising burden of disease and potential impact on carers and services. All forecasts and predictions are model based with inherent caveats and substantial levels of uncertainty.

Further details of on demographic and economic picture of Leicestershire population is available in the Leicestershire JSNA 2022-25 Demography chapter.

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<sup>††</sup> With exception of asthma

## 2.2. Groups at Risk

### 2.2.1. Risk factors shared by all carers

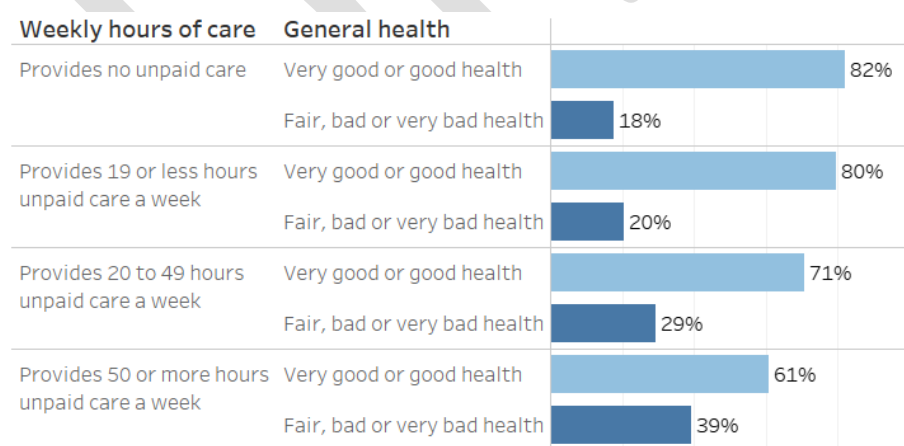
The 2021 Census identified that nationally 4.7 million people in England were providing unpaid care, representing 8.8% of the population, with 51% of carers providing 20 or more hours of care a week<sup>10</sup>. As many carers don't self-identify the true figure is likely to be substantially higher.

Carers are more likely to be female than male, with an approximate three female carers for every two male carers. The number and percentage of people providing any unpaid care are both lower than in the previous Census (2011). The Office for National Statistics (ONS) have put forward possible explanations for the reduction which include the COVID-19 restrictions in force at the time of the Census and changes to the question wording between 2011 and 2021. The numbers and percentages of people providing 20 to 49 hours and 50 or more hours of unpaid care each week have both increased since 2011.

On Census Day 2021 in England more unpaid carers were disabled (27.5%) compared with non-carers (17.8%).

It is clear from the 2021 Census that the general health of carers deteriorates incrementally with the increasing hours of care provided. 39% of those providing 50 or more hours of unpaid care each week reported their own health as 'not good' (Figure 14).

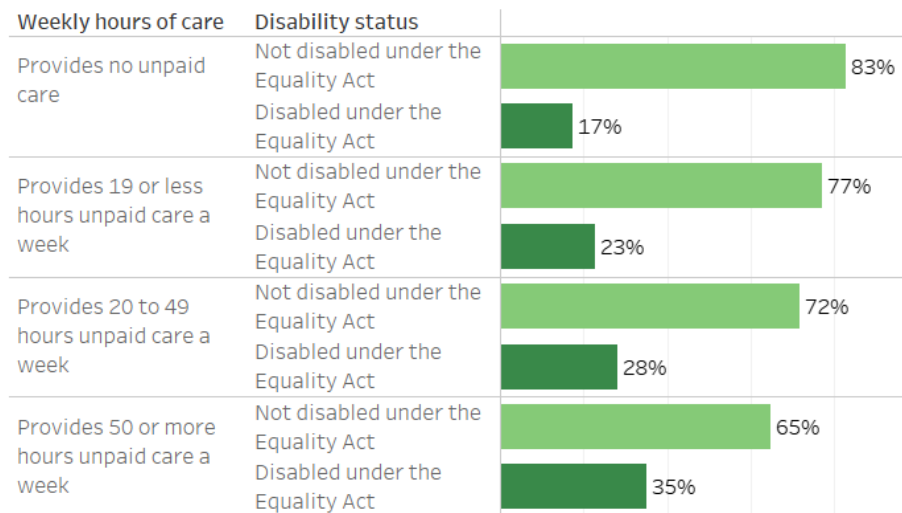
*Figure 14. Carers self-reported perception of health (as a % of the total in each category) in relation to the number of hours of unpaid care provided (England)*



The Census 2021 data also shows that those who provide more hours of unpaid care are more likely to have assessed their day-to-day activities as limited by long-term physical or mental

health conditions or illnesses and are considered disabled (Figure 15).

*Figure 15. Carers self-reported limiting long term illness (as a % of the total in each category) in relation to the number of hours of unpaid care provided (England)*



The State of Caring 2023<sup>11</sup> provides a snapshot of caring through a survey completed by 11,667 across the UK. The report estimates 26% of UK adults were providing unpaid care to an older, disabled or ill relative at the height of the pandemic although numbers were expected to have decreased slightly after this. Applying this rate to the Leicestershire population would result in over 156 thousand carers, and whilst only a guide, this shows the potential scale of the carer population in the County. As a comparison, Census 2021 recorded a much lower number of unpaid carers, just over 61,000 (see section 3.1 for more details).

A report by Carers UK<sup>12</sup> using data from the 2021 GP Patient Survey looked closer at the health of carers compared to non-carers. The key findings from the survey relating to inequality are presented below (Figure 16). It is of note that in that survey 18% of the 850,000 respondents reported some unpaid care responsibilities.

Figure 16 Summary of health inequalities experienced by carers

Long-term conditions, disability and illness	Mental Health	Social isolation
<ul style="list-style-type: none"> <li>● <b>60% of carers stated they had a long-term condition, disability or illness compared to 50% of those who weren't caring.</b> The most likely were arthritis, back or joint problems and high blood pressure.</li> <li>● <b>69% of those providing 50 hours or more</b> reported having a long-term condition compared to <b>58% providing less than 35 hours.</b></li> <li>● <b>Older and retired carers were also most likely to report having a long-term condition, 79% and 76% respectively.</b></li> </ul>	<ul style="list-style-type: none"> <li>● <b>27% of carers not in work</b> declared they had a mental health condition compared to <b>12% of working carers and 5% of retired carers.</b></li> <li>● <b>26% of carers under the age of 25</b> had a mental health condition, compared to <b>5% of carers over 65.</b></li> <li>● <b>36% of lesbian, gay and bisexual carers</b> had a mental health condition compared to <b>13% of heterosexual carers.</b></li> </ul>	<ul style="list-style-type: none"> <li>● <b>18% of carers reported feeling isolated</b> compared to 14% of those who weren't caring.</li> <li>● <b>Feeling isolated increased during COVID-19,</b> from 8% in 2019, 9% in 2020 and 18% in 2021.</li> <li>● <b>32% of carers aged under 25</b> reported feeling isolated over the last 12 months, <b>compared to 12% over 65.</b></li> </ul>

Source: Carers UK, Carer's health and experiences of primary care. Data from the 2021 GP Patient Survey

Carers over the age of 55 in England had significantly worse (lower) levels of physical activity (14%) than all adults (54%). 46% of carers were inactive, compared to 33% of all adults, with the remaining fairly active. The greatest barriers were limited time, lack of motivation, affordability and not having anyone to go with. 76% of carers did not feel that they can do as much physical activity as they'd like to do and this rate was highest in carers who are disabled, lonely or struggling financially<sup>13</sup>.

A review of evidence by the National Institute for Health and Care Research<sup>14</sup> found that caring can have a serious financial impact with many needing to give up or reduce their employment, rely on charities for basic necessities and pay for expensive services or equipment to support their loved one, with 1 in 5 carers worried about being able to cope financially. The review suggests online resources (due to difficulties in people attending in person), support for daily tasks such as managing medication, supporting carers into work through initiatives such as flexible working hours for example and active engagement with carers e.g., when they attend clinical appointments, often with the person they care for, can all help to improve the health of carers.

While 55% of female adult carers and 44.9% of male adult carers reported they were economically active, only 12.1% of women and 9.3% of men were working full-time alongside caring responsibilities and only 1.2% of women and 1% of men reported they were in full-time employment while providing 50 hours or more care a week.

Irrespective of background, gender and age it is usually the condition of the cared-for person that most impacts on the health and wellbeing of the carer. Conditions such as mental health problems, dementia, learning disabilities, physical and sensory impairments and substance misuse contribute to increased use of health and social services and increased social isolation for both the carer and the cared for. Such circumstances also affect the quality of care given due to the increased burden they place on the carer.

Carers UK's 'The State of Caring' annual surveys and the Caring and Family Finances Inquiry (2014)<sup>15</sup> evidenced that many carers of working age feel forced to give up work to care and after a period of absence many find it difficult to return to the labour market. The State of Caring survey in 2011 found that of carers who had given up work or reduced their working hours to care, a fifth were £10-15k a year worse off and a further fifth were losing £15-20k annually. Many older working carers aged 55-64 years of age were likely to lose at least £30k a year.

According to Carers UK the highest level of carers' needs were reported among carers with mental health problems of their own, Asian/British Asian carers, those under the age of 64 and long-term carers, usually between 15 and 20 years.

### 2.2.2. Ethnic minority carers

Previous research had shown that ethnic minority carers provide more care proportionately than white British carers, putting them at greater risk of ill-health, loss of paid employment and social exclusion. Certain groups also experience greater levels of isolation, namely Pakistani and Bangladeshi carers. It is likely that data may only represent a fraction of carers in ethnic minority populations. There may be familial expectations of caring in some cultures, where caring is seen as a normal function of the family, the carers may not self-identify and therefore do not receive any support, advice or carer's assessments. A report by Barnardo's on young carers from ethnic minority groups highlighted that this group have long been recognised as particularly vulnerable<sup>16</sup>. It is commonly expected that help for older or ill relatives remains within the family rather than relying on strangers. As many as 40% of young carers report mental health problems as a result of their experience of caring.

The Carers UK State of Caring 2023 survey data for ethnic minority carers<sup>17</sup> show that:

- Ethnic minority carers are more likely to be struggling financially, with 34% of ethnic minority carers struggling to make ends meet, compared with 29% of white carer and 69% worried about living costs and whether they can manage in the future, compared with 60% of white carers. They are also more likely to be cutting back on things, including the essentials (37% of ethnic minority carers had cut back on essentials like food or heating compared with 33% of white carers).

- Nearly two thirds (74%) of ethnic minority carers said the increase in the cost-of-living was having a negative impact on their physical or mental health, compared with 63% of white carers. A similar proportion (73%) worry that rising cost of living would be a challenge over the coming year, compared with 67% of White carers.
- A slightly higher proportion of ethnic minority carers say they need more financial support compared with white carers (55% vs 49%, respectively)
- Ethnic minority carers are more at risk of loneliness (55% said they feel lonely compared with 51% of white carers). Fifty-seven percent of ethnic minority carers said they needed more breaks or time off from their caring role compared with 48% of white carers. They may also need more support from the NHS (47% compared with 42% of white carers), including better recognition from the NHS of their needs as a carer.
- Ethnic minority carers were more likely to feel unsatisfied with social care services (32% dissatisfied, compared with 24% of white carers).

In Census 2021, of all ethnic groups in England, the “White: Gypsy or Irish Traveller” ethnic group had the highest age-standardised percentage of unpaid carers in females (16%) and males (12%); compared to 12% for females and 9% for males in the main white group (English, Welsh, Scottish, Northern Irish or British) and the lowest proportion (6% and 5%, respectively) for the Chinese population.

### 2.2.3. LGBT carers

Lesbian, gay, bisexual or transgender (LGBT) carers can face additional challenges in relation to their caring role, and barriers to accessing services which have been examined in Carers UK ‘State of Caring’ and other surveys. They tend to be, on average, younger than their heterosexual counterparts but more disadvantaged financially, and with higher levels of anxiety, feelings of loneliness and isolation. Trans carers are likely to be further disadvantaged and have their own unique challenges, although survey sample size from these surveys too small to provide meaningful data for this group<sup>18</sup>.

The Carers UK State of Caring 2023 survey data for LGB+ carers<sup>19</sup> provides up-to date evidence:

- LGB+ carers are more likely to be struggling financially, 40% said they were struggling to make ends meet, compared with 28% of heterosexual carers. Two-thirds (74%) of LGB+ carers said they were worried about living costs and whether they can manage in the future, compared with 60% of heterosexual carers. They are also more likely to be cutting back on things (53% vs 46%) with 41% having to cut back on essentials like



food or heating compared with 33% of heterosexual carers.

- LGB+ carers were more likely to say the cost-of-living crisis was affecting their health. 76% of LGB+ carers said the increase in the cost-of-living was having a negative impact on their physical or mental health, compared with 63% of heterosexual carers. LGB+ carers were more likely to say they needed more financial support. 60% of LGB+ carers said they needed more financial support compared with 49% of heterosexual carers.
- LGB+ carers were more likely to say that caring had impacted on their mental health. This includes slightly higher rates of stress and anxiety (84% vs 79%), depression (56 vs 49%), and loneliness (59% vs 50%), with 43% of LGB+ carers needing support to prevent/reduce their loneliness/social isolation compared with 35% of heterosexual carers. 68% of LGB+ carers said they needed more support to look after their own health and wellbeing compared with 63% of heterosexual carers.
- LGB+ carers were more likely to say they needed a break (52% vs 48% of heterosexual carers) and they were more likely to have concerns around services not meeting their needs and more likely to feel unsatisfied with social care services (34% vs 24% of heterosexual carers). They were also more likely to say they needed more support with planning for the future.

The 2021 Census found a higher percentage of unpaid carers who identify with a lesbian, gay, bisexual or other (LGB+) sexual orientation - 3.9% compared with non-carers (3.0%).

#### 2.2.4. Young carers

A young carer is a child or young person under 18 who provides care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances. The term young carer does not apply to everyday or occasional help that may occur in all families. It is specific to care that is relied upon in maintaining the health, safety or day to day wellbeing of the person receiving support or care.

Young carers (aged under 18) can experience feelings of loneliness and isolation, and report feeling stigmatised by teachers and by their peers. Young carers can experience substantial physical, emotional or social problems, and encounter difficulties in school and elsewhere<sup>20</sup>. The amount and type of care that young carers provide can vary greatly and does not predict how far the health or well-being of each young carer may be affected. In addition, young carers have significantly lower educational attainment at GCSE level and are more likely than the national average to be not in education, employment or training (NEET) between the ages of 16 and 19<sup>21</sup>.

YouGov conducted a survey on behalf of Barnardo's in December 2017 of young carers aged

7 to 24 receiving their support<sup>22</sup>. This survey found the following:

- Two thirds of the young carers stated that they began caring whilst they were still in primary school and 1 in 8 had started caring at the age of 5.
- Most young carers are caring for their mother.
- Over 50% of young carers are giving emotional support, shopping, attending medical appointments and completing household chores as part of their caring role.
- Over half of young carers are looking after someone with mental or physical disabilities and a third for someone with a long-term illness or disease. 10% are caring for someone with a drug and/or alcohol misuse problem.
- The average age of a young carer in the UK is 12, with some children as young as four caring for members of their family.
- A quarter of young carers surveyed completed more than 30 hours of care per week. 27% were unable to estimate how many hours they give.
- Nine out of ten teachers surveyed were concerned that some young carers remained 'unidentified and unsupported'.
- Over 90% of our young carer practitioners surveyed said that they believed there were young people who did not want to be identified.

An analysis of data from UK Household Longitudinal Study (2013 to 2017) and Health Survey for England carried out by the NIHR<sup>23</sup> found that:

- Young people (16 to 25) who provided care were found to be: less likely to be in employment, have lower earnings from paid employment, and have poorer mental and physical health than equivalent young people who did not provide care.
- Costs to the state were an estimated £1 billion a year. Individual young carers also experienced financial costs.
- The association between receipt of care for the person with care needs and the impacts of providing care on young people's lives was mixed.
- Services could have negative as well as positive effects and, in many cases, were not in the sufficient amount or the right type to prevent young people from carrying out levels of care that impacted on their employment, education and health.

#### 2.2.5. Carers of younger adults

Unpaid carers of younger adults (ages 16-64) experience worse outcomes in some areas than carers of older people. They are less likely to be satisfied with services and more likely to have

financial difficulties and not be in paid employment because of their caring role<sup>24</sup>. This group includes people with caring responsibilities for a child, for example due to disability. They could constitute around 20% of carers providing care within their household, they are more likely to be younger, on average 47, and often (41%) caring for more than 50 hours per week<sup>25</sup>.

#### 2.2.6. Carers of people with learning difficulties

Carers of people with learning difficulties, who may now be an adult, are often parents or other relatives. These carers often face a life-long caring role as the life expectancy of people with learning disabilities has increased significantly, and more people with learning disabilities are now expected to outlive their parents.

A survey<sup>26</sup> of unpaid carers of adults with a learning disability in Scotland found that:

- Unpaid caring roles for adults with learning disabilities require additional responsibilities, outside of personal care (such help with washing, dressing and eating) and include supervision to ensure safety, assisting with leisure activities, providing transport, ordering medications, and liaising with health and social care staff. Leading to higher weekly hours.
- Carers had less employment opportunities, there was more reliance on the social security system. Just over half the unpaid carers had household income below or around the poverty line.
- Scoring much lower than the national average on wellbeing measures, particularly for loneliness and burnout.
- The lifelong caring commitment creates a loss of agency and limits the long term choices unpaid carers can make.
- Urgent need for more respite and services for the person cared for.
- Carers experienced particular difficulties during the Covid-19 pandemic, filling in the gaps left by the care system, compounded by the perception that services have not returned to pre-pandemic levels.

As the person with learning difficulties ages, their needs, and the needs of their elderly parent, may lead to mutual caring situations. Often in such families the carer and the person with learning difficulties only come to the attention of Adult Social Care when a crisis occurs, for example, when the carer or adult person with learning disabilities becomes ill, or physically incapacitated, or is suffering from dementia. In order to offer support, it is important to identify this hidden population of carers before a crisis occurs.

Mencap's report 'Housing for People with a Learning Disability'<sup>27</sup> states that 83% of carers

whose son or daughter lives with them have not planned for when they are no longer able to deliver care. The report goes on to state that even older carers are not planning for the future, with 56% of carers aged over 70 years whose son or daughter lives with them having not planned for when they are no longer able to care.

#### 2.2.7. Carers of people with mental health conditions

Nationally, approximately 13% of carers care for someone with a mental health condition. Such carers can be reluctant to discuss their role due to the stigma still attached to mental health. Mental health conditions can fluctuate, are often misunderstood, and can cause considerable emotional distress to carers. The issues of confidentiality and information sharing between mental health professionals and carers are difficult and complex to resolve as healthcare staff have a duty to both patients and carers not to disclose confidential information.

Key health needs of this group of carers include:

- Mental health and emotional support for higher levels stress, anxiety and depression, experienced in their roles. This could include counselling or peer support.
- Respite care and breaks.
- Financial assistance and/or flexible employment options<sup>11</sup>.
- Training and education to manage complex needs of individuals with mental health conditions, including crisis management and navigating the healthcare system<sup>28</sup>.
- Easy access to information and resources about available services, legal rights and support networks<sup>29</sup>.

#### 2.2.8. Carers of people with dementia

Those caring for someone with dementia comprise 11% of all the carers in the UK. Dementia is one of the main causes of disability in later life and the number of people with dementia is rising yearly as the population ages. Dementia can affect people of any age but is most common in older people, particularly those aged over 65 years.

Dementia places a particular burden on carers and family members. Timely diagnosis and intervention are helpful, as it enables the person with dementia and their carer/s to come to terms with the disease and make plans for the future. Many of those with severe dementia, especially those over 85 years, have a combination of mental and physical problems. Many of the carers of older people with dementia are themselves elderly up to 60 % of whom are husbands, wives or partners.

Carers of people with dementia generally experience greater stress than carers of people with most other support needs, with nearly half having some kind of mental health problem

themselves. However, carer support and education can enable more people to live at home for longer and prevent carer breakdown, which is a major cause of people needing to move into long-term care. See section 2.1.6 for discussion of the projected increasing prevalence of dementia care.

#### 2.2.9. Carers of people with substance misuse

Around 2% of the population experience addiction in the family at some time. The contribution of families and their role in treatment/detox is recognised. Due to the stigma and shame surrounding drug or alcohol use, carers of people with substance misuse issues don't tend to engage with carer support services or carers assessments, only with substance misuse services. There is concern that young carers of parents with substance misuse issues are remaining hidden due to fear of the involvement of outside agencies, not wishing to "betray" their parents, and fear of losing their parents. Whilst parents may have concerns about their children being taken into care.

### 3. Level of Need in Leicestershire

The most recent (2021) population Census in England and Wales provides the most robust information on the numbers of carers in Leicestershire with their demographic characteristics as well as selected health and socio-economic data. As with all sources of data, there are some well-known limitations of the Census, such as not reaching some hidden populations, reliance on self-reporting, under-reporting or double counting in some instances. However, the Census provides the most reliable and detailed picture of the local population available.

The Leicestershire Carers Survey provides some more detailed data on social, financial and other circumstances faced by carers in Leicestershire and further information from the Leicestershire Carers Services is also included in this section of the document.

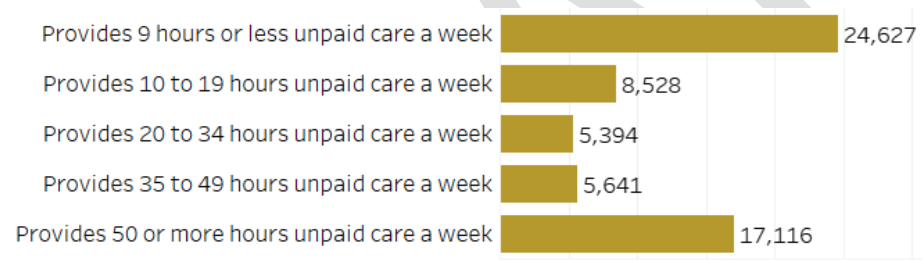
#### 3.1. Unpaid Care in 2021 (Population Census)

The population Census carried out on the 21st of March 2021 asked respondents whether they looked after, or gave any help or support to, anyone because they had long-term physical or mental health conditions or illnesses, or problems related to old age, excluding anything they did as part of their paid employment. The question varied slightly from the question asked in 2011 and Census 2021 was undertaken during the coronavirus (COVID-19) pandemic, which may also have influenced how people perceived and undertook their provision of unpaid care and therefore may have affected how people chose to respond, thus comparisons need to be made with some caution.

The Census 2021 found that while the proportion of people providing any amount of unpaid care fell slightly since the 2011 Census, the percentage of those providing at least 20 hours a week of unpaid care in England (equivalent to a typical part-time job or more) increased from 3.7% in 2011 to 4.4% in 2021. This means that those people providing the most unpaid care each week, equivalent to approximately three to seven hours per day or more on a weekly basis, has increased since 2011. Many of these people will have been providing unpaid care for over 35 hours per week, roughly equivalent to a full-time job. The North East (5.4%) and North West (4.8%) had the highest proportions of people who provided at least 20 hours per week of unpaid care in England. The East Midlands figure was 4.5%

According to the Census 2021, just over 9% of Leicestershire population (61.3 thousand people aged 5 years and over) provided unpaid care, including 4.9% (N=33,155) providing less than 20 hours of care per week, 1.6% (N=11,035) 20 to 49 hours and 2.5% (N=17,155) 50 or more hours of care per week (Figure 17). As comparison, the national average was 4.4%, 1.9% and 2.8%, respectively. Thus, there were relatively more Leicestershire carers in the under 20 hours per week category.

*Figure 17 Number of people providing unpaid care by number of hours provided.*



### 3.1.1. Demography of Leicestershire carers

Of the 61,300 Leicestershire carers (or 9.1% of total population aged 5 and above) nearly a half (29,615, or 15.4% of population in that age group) were aged between 45 and 65, with 60% more women than men in this group (Table 5). There was a relative excess of women in all carer groups, except for those above the age of 85, where men predominated by 20%.

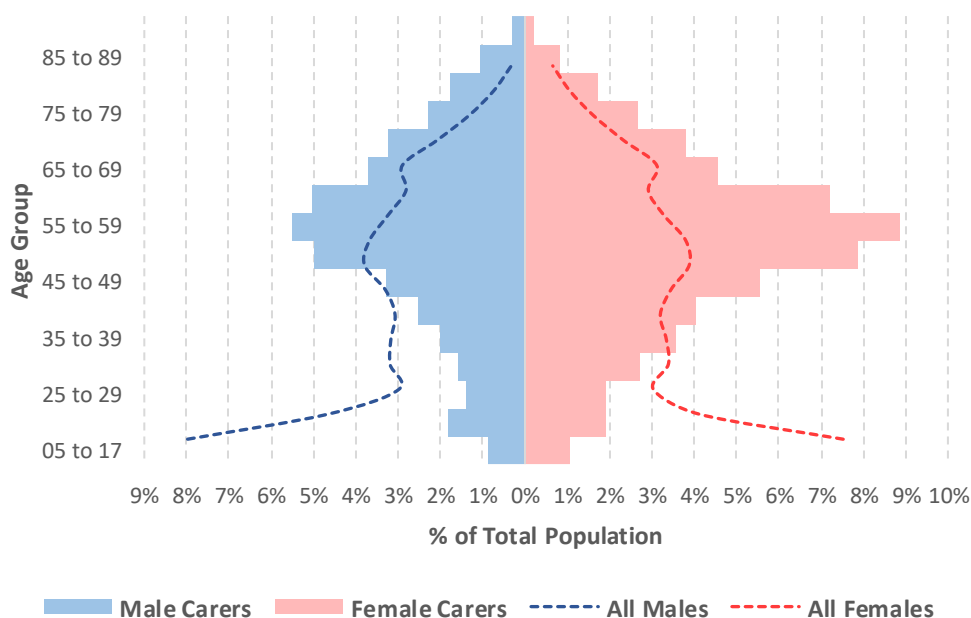
Table 5 Unpaid carers in Leicestershire - Census 2021

Age	Male	Female	Ratio (F/M)	Persons	Population	%
5 to 17	540	645	1.2	1,185	104,845	1.1
18 to 24	1,105	1,180	1.1	2,285	59,545	3.8
25 to 44	4,645	7,525	1.6	12,170	171,680	7.1
45 to 64	11,535	18,080	1.6	29,615	192,230	15.4
65 to 84	6,725	7,825	1.2	14,550	129,295	11.3
85+	835	655	0.8	1,490	18,785	7.9
<b>Total</b>	<b>25,385</b>	<b>35,910</b>	<b>1.4</b>	<b>61,295</b>	<b>676,380</b>	<b>9.1</b>

Numbers rounded to nearest 5

Figure 18 presents a more detailed age distribution of unpaid carers in Leicestershire, against the general Leicestershire population.

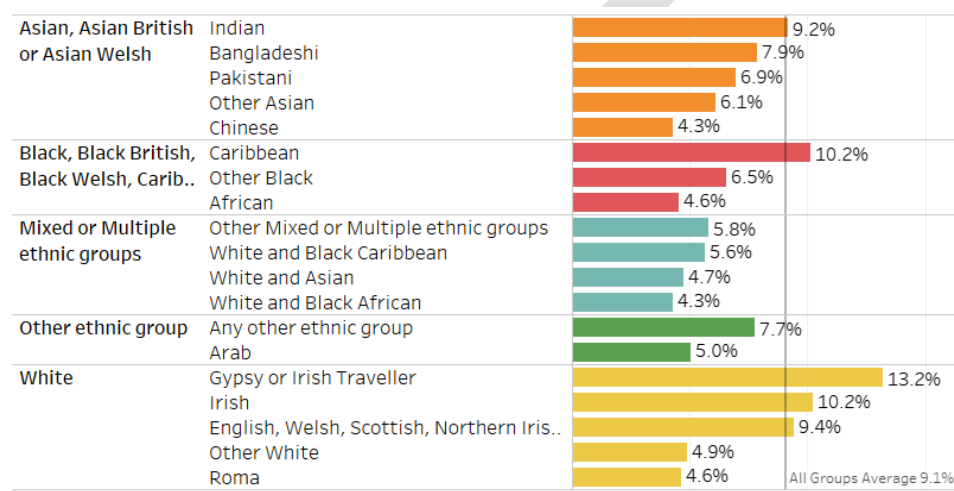
Figure 18. Age distribution of unpaid carers in Leicestershire in 2021 (Source: ONS, Census 2021)



Please note broader age groups under 25

The 2021 Census showed that in Leicestershire 7.6% of ethnic minority residents provided some unpaid care, which is lower than the 9.3% result for white residents. However, higher than average incidences of providing unpaid care are reported amongst the white Gypsy or Irish Traveller (13.2%), Black Caribbean and Irish groups (10.2%) (Figure 19). As a reference, the national patterns were similar with highest rates in the white Gypsy or Irish Traveller group (13%), but followed by mixed ethnicity groups, rather than Black Caribbean or Irish populations.

Figure 19. Percentage of each ethnic group aged 5 years and above that provide unpaid care (ONS, Census 2021)



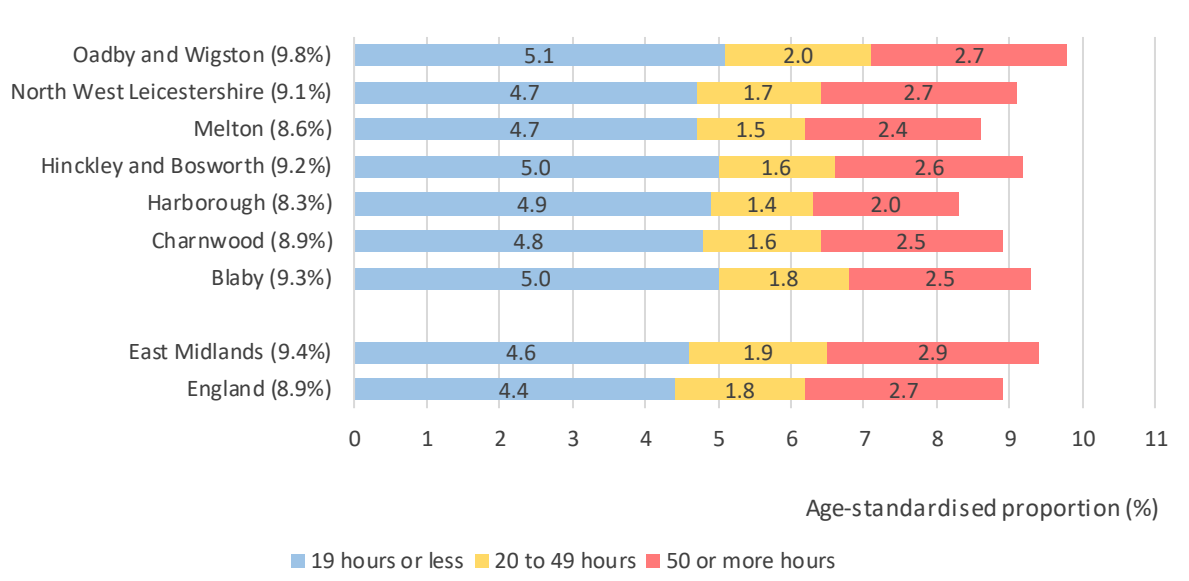
### 3.1.2. Geographical variation

The rates of unpaid care provision in Leicestershire districts, reported in Census 2021 across broad categories of weekly volume of care provided are presented in Figure 20. Generally, there are proportionately more carers in Leicestershire in the lower category (under 20 hours per week) when compared to the national and regional average, while a little less in groups providing higher volumes of care, particularly in Harborough, Melton, Charnwood or Hinckley and Bosworth, although the differences are relatively small.

The highest rates of unpaid care across all categories were in Oadby and Wigston with almost one in ten of residents providing some unpaid care per week (9.8% compared to the national average of 8.9%), including 2.7% providing at least 50 hours, which is similar to the national average. The lowest rate was in Harborough (8.3%).



Figure 20. Carers in Leicestershire districts in 2021, classified by number of hours of unpaid care provided per week (age-standardised proportion, usual residents aged 5 and above). Source: ONS 2022

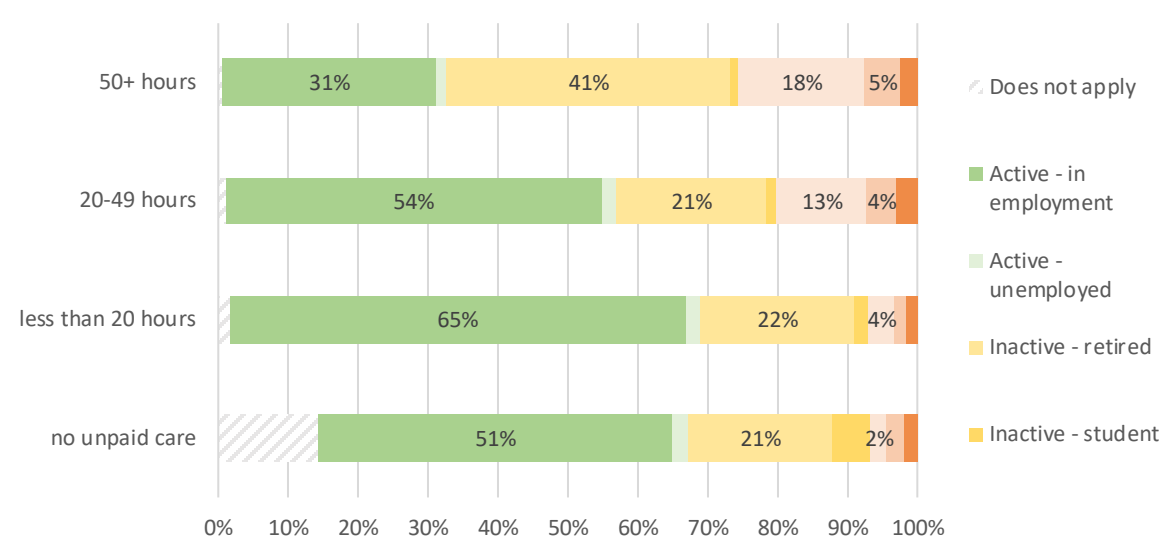


Source: ONS 2022

### 3.1.3. Employment

More than a half (54%) of carers providing 20-49 hours of care and nearly a third (31%) of those in the 50+ hours per week category were in employment in 2021 (Figure 21). This is somewhat higher than the national average of 51% and 29%, respectively. The highest proportion of those committed to more than 50 hours of care were retired in Leicestershire (41%), higher than the national average of 35%, with 21% of those in the 20-49 hours category, again higher than the national average of 17%. Proportions of unemployed carers was slightly lower than the national average (below 2% against 3% nationally).

Figure 21. Employment status of unpaid carers in Leicestershire in 2021



Source: ONS 2022

#### 3.1.4. General health and disability

Across Leicestershire population (aged 5 years and above), nearly two thirds (64%) reported to be in good health and with no disabled people in their household, with a further 19% in good health but with at least one disabled person in the household. Only 17.5% were not in good health either without (5%) or with (12.6%) someone with a disability in the household.

Looking specifically at the 61,000 unpaid care providers in households<sup>††</sup>, there is a clear positive association between rates of disability in the household and the number of hours of unpaid care provided per week. Thus the vast majority (93%) of carers providing 50 or more hours of care per week reported at least one disabled person in their household (Figure 22).

The total number of residents in this latter category in Leicestershire was 6,235 (Table 6), with the majority (N=4,426) reporting two or more disabled persons in the household; the Table provides further details. Unsurprisingly, rising numbers of hours of care provided are related to a lower proportion of carers in good health and with no one with a disability in their household.

<sup>††</sup> This segment of the analysis looks only at residents of Leicestershire in households, resulting is slightly lower total number of carers (60,998 vs 61,306 total)

Figure 22. Provision of unpaid care by general health by households with people who have a disability in Leicestershire (Census 2021)

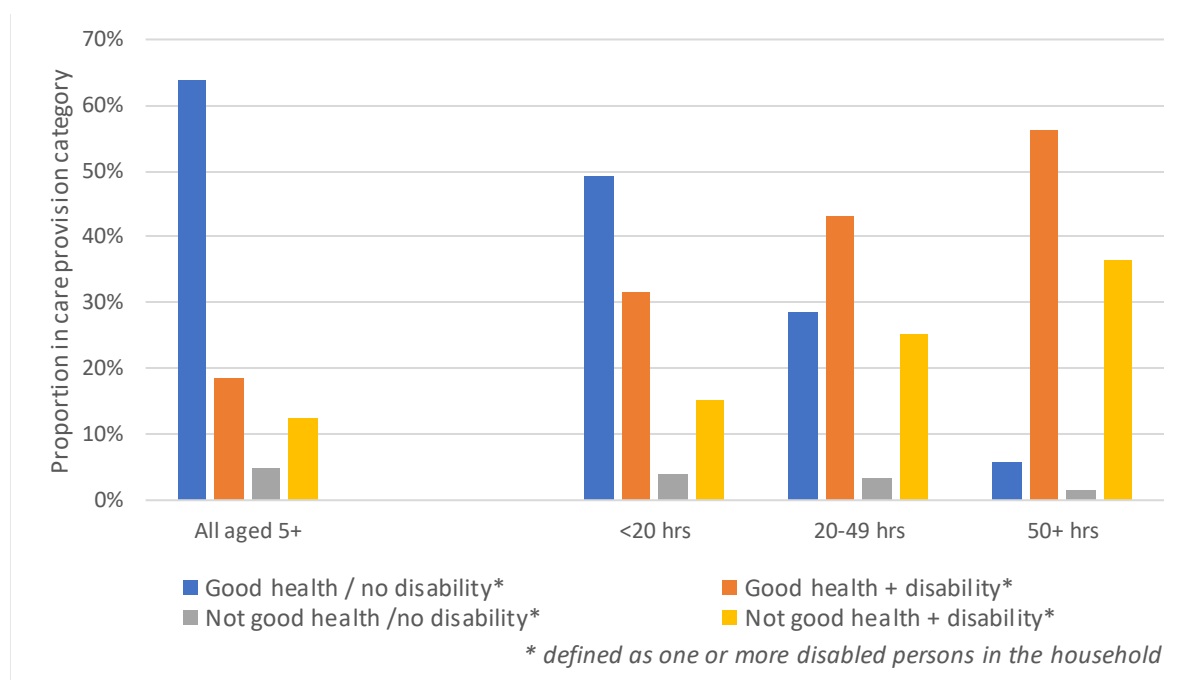


Table 6. Unpaid care, health and disability in Leicestershire (ONS, Census 2021)

Health / disability category:	Total residents*	<20 hrs**	20-49 hrs**	50+ hrs**	Any care provision
Good health and no disabled people in the household	N° 423,606	16,229	3,134	979	20,342
	% 63.9	49.2	28.5	5.8	33.3
Good health and at least one disabled person in the household	N° 123,138	10,387	4,745	9,565	24,697
	% 18.6	31.5	43.1	56.2	40.5
Not in good health and no disabled people in the household	N° 32,268	1,334	357	245	1,936
	% 4.9	4.0	3.2	1.4	3.2
Not in good health and at least one disabled person in the household	N° 83,415	5,016	2,772	6,235	14,023
	% 12.6	15.2	25.2	36.6	23.0
<b>Total number</b>	<b>662,427</b>	<b>32,966</b>	<b>11,008</b>	<b>17,024</b>	<b>60,998</b>

\*aged 5 and above in households

\*\* of care per week

Source: ONS 2022

### 3.1.5. Social isolation and quality of life

Three indicators relating to the general health and wellbeing of carers are regularly presented by the Office for Health Improvement and Disparities. These are summarised in Table 7 below.

Firstly, there is a measure of social isolation, derived for the Adult Social Care Outcomes Framework (ASCOF)<sup>§§</sup>, which measures the performance of the adult social care system as a whole. The indicator draws on self-reported levels of social contact as an indicator of social isolation for both users of social care and carers. There is a clear link between loneliness and poor mental and physical health. A key element of effective social care is to tackle loneliness and social isolation by supporting people to remain connected to their communities, friends and family.

The level of social isolation in Leicestershire seems to be statistically similar to the national average for all ages (while being slightly lower for those over 65) and comparable to other areas demographically similar to Leicestershire (CIPFA comparators<sup>\*\*\*</sup>).

Secondly, the quality-of-life score gives an overarching view based on outcomes identified through research by the Personal Social Services Research Unit. This is a current measure related to quality of life for carers looking after people with dementia and supports a number of the most important outcomes identified by carers themselves to which adult social care contributes. The 'Prime Minister's 2020 Challenge on Dementia' reports that carers of people with dementia should be made aware of and offered the opportunity for respite, education, training, emotional and psychological support so that they feel able to cope with their caring responsibilities and to have a life alongside caring. This indicator is also similar to the comparators.

Third, the rate of self-directed support and direct payments for adults can be regarded as a proxy, as indicated by research, of the satisfaction with services, personalisation and overall wellbeing of users of care and carers. The Care Act places personal budgets on a statutory footing as part of the care and support plan. This rate is significantly higher (better) than the national average of 93.2% for Leicestershire adults.

The following Table 7 contains England level and Leicestershire findings which have been reported through NHS Digital. The data has been collated from the Personal Social Services Survey of Adult Carers in England (SACE). This is a biennial survey of carers undertaken by each local authority, with findings reported to central government, and from which a range of ASCOF performance metrics are derived. Surveying carers gives vital information about the impact of people's caring responsibilities on their quality of life. This also enables a better

<sup>§§</sup> Original data collected through the Personal Social Services Survey of Adult Carers (PSS SACE).

<sup>\*\*\*</sup> CIPFA – Chartered Institute of Public Finance and Accountancy

understanding of the impact of carer support services. Due to the impact of coronavirus, the 2020-21 survey was postponed for one year and took place in 2021-22.

Table 7. OHID indicators for carers

Indicator	Leicestershire	CIPFA range	England	Sig**
	% (95% CI)*	%*	%*	
Social Isolation (all adults)	24.7 (20.7-28.7)	19.3-38.7	28.0	↔
Social Isolation (65+)	22.2 (16.9-27.5)	19.4-37.0	28.8	↓
Quality of life score for people caring for someone with dementia (adults)	7.4 (7.0-7.8)	6.8 - 8.2	7.3	↔
Rate of self-directed support and direct payments (2021/22, 18+)	95.4 (94.6-96.0)	4.3-100.0	93.2	↑

\* Except quality-of-life score

\*\* ↔ not significantly different, ↓ significantly lower, ↑ significantly higher than national average

Source: OHID 2023

### 3.2. Leicestershire Carers Survey 2023/24

#### Key findings

- Nearly four out of ten carers are satisfied, while one in twenty are dissatisfied with the service in Leicestershire. The level of dissatisfaction is lower than national average (4.8% vs 8%).
- A quarter of surveyed carers have been caring for more than 20 years, with that proportion increasing in each subsequent survey.
- Carers' ability to look after themselves has been declining at a national level, with less than a half of respondents (46.7%) being able to look after themselves and one in five (20.2%) feeling that they are neglecting themselves in the last 12 months. Similar position in Leicestershire – 45.6% and 17.3%, respectively.
- Nationally, one in ten carers (or 9% in Leicestershire) report having a lot of financial difficulties as a result of their caring role. The relative proportion of carers experiencing financial difficulties has been worsening over time.

#### Survey population and response rate

The eligible population included all unpaid carers aged 18 or more, known to the council (have

been assessed or received a service including information and advice) and who are caring for somebody over the age of 18.

The total eligible population for the 2023-24 survey in Leicestershire was 3,266, similar to 3,250 in 2018-19 but lower than 5,829 in 2021-22. From the eligible population, 1,064 carers were sampled and sent a survey, resulting on a 40.3% response rate (a total of 429 responses received). For comparison in 2018-19 the response rate was nearly 50% and in 2021-22 40.7% (similarly to the national trend).

### Information about the Carers

#### Age

The largest age band was 55-64 years, which accounted for 27.8% (slightly higher than 25.6% nationally) of the eligible population and the smallest age band was 18-24 years which accounted for 0.5% (lower than 1.6% nationally).

**Error! Reference source not found.** shows the Carers Age over the last five years which was derived from Short and Long Term (SALT) data. The largest age band for carers for the last five years was aged between 26-64 which has seen a slight increase from 49% in 2018-19 to 51% more recently. This is followed by carers aged between 65-84 which has stayed consistent over the last five years, on average equating to 42%.

*Table 8. Age Breakdown over the last four years where the age of the carer was known*

Age Group	2018-19	2019-20	2020-21	2021-22	2023-24
Carer Aged 18-25	1%	1%	1%	1%	1%
Carer Aged 26-64	49%	49%	51%	50%	51%
Carer Aged 65-84	42%	42%	41%	42%	42%
Carer Aged 85+	7%	8%	8%	7%	6%

#### Sex

Over two-thirds of those who were sent a questionnaire were female (accounting for 68.1%) compared to 51.3% of the general population of Leicestershire aged 20 or over (from the 2021 census). Male carers made up the remaining 31.9% sent a questionnaire compared to 48.7% of the general Leicestershire population aged 20 or over.

#### Ethnicity

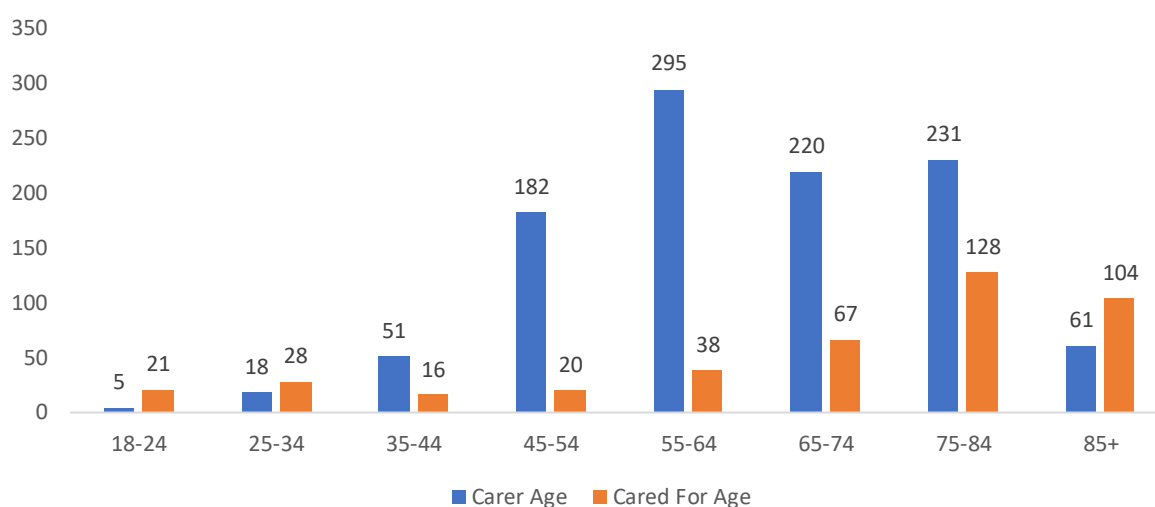
Of those who received a questionnaire and declared an ethnicity, 7.8% were Asian or Asian-

British, compared to 8.2% of the general population of Leicestershire recorded in the 2021 census. Nine out of ten (90.1%) were White, slightly higher than 87.5% recorded in the 2021 census.

### Information about people cared-for

The chart below shows the age of the carers surveyed and the age of the person they cared for.

Figure 23. Age of the carers and the age of the person they cared for

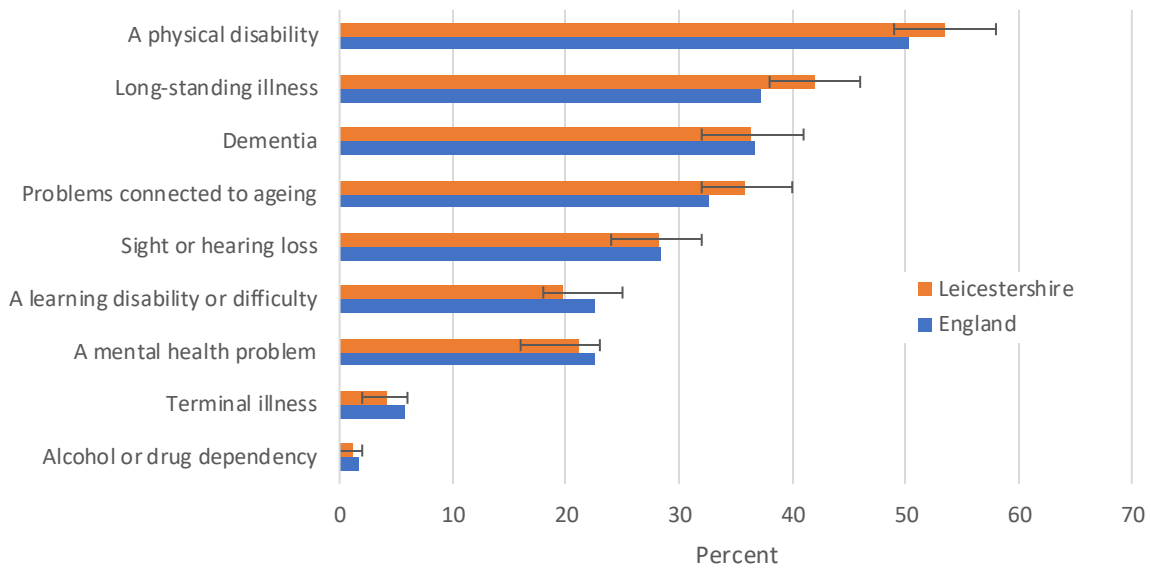


People aged 75 or over accounted for over half of those cared for – 232, or 54.9%, compared to 53.2% nationally.

### Support needs of the cared-for person

Over a half of Leicestershire respondents (53.5%), cared for somebody with a physical disability, whilst 42% for someone with a long-standing illness (statistically significantly higher than 37.3% nationally). Over a third cared for someone with dementia and/or problems of ageing. Generally, the pattern of care needs in Leicestershire was similar to the national picture with only rates of long-standing illness outside of the margin of error for Leicestershire (Figure 24).

Figure 24. Support needs of the cared-for person



Nationally, in the decade since the 2014-15 survey, there were significant increases in support needs for those with mental health issues and learning disability or difficulty, with corresponding falls in physical disability, problems connected with ageing, and long-standing illness<sup>30</sup>. The trends were similar, albeit less pronounced, locally.

Figure 25. Approximately how many hours spent looking after or helping the person you care for per week

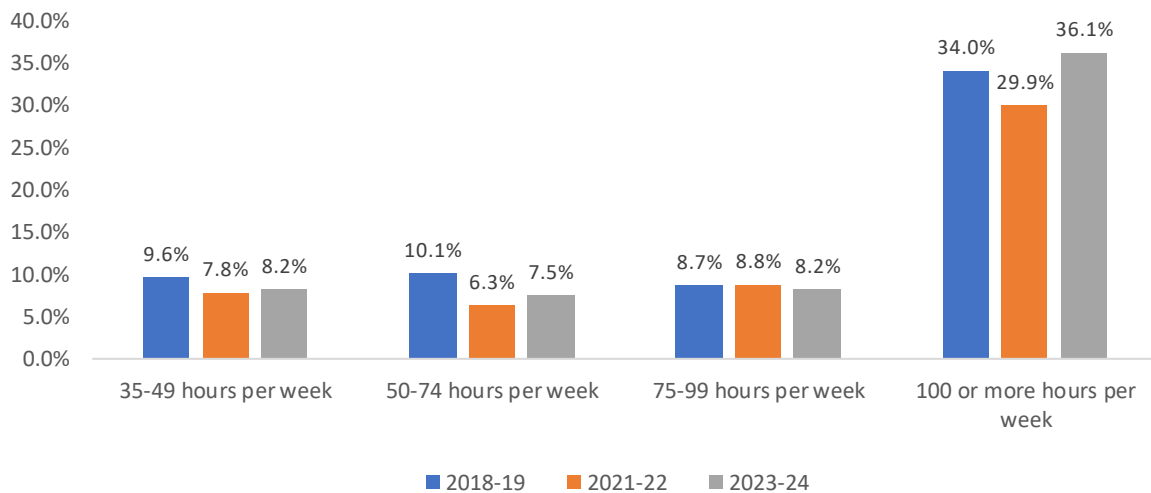


Figure 26. About how long have you been looking after or helping the person you care for?

A quarter of carers responding to the survey (25.1%) had been looking after or helping the person they care for twenty years or more. In fact, almost two-thirds (65.4%) have been caring for five years or more.



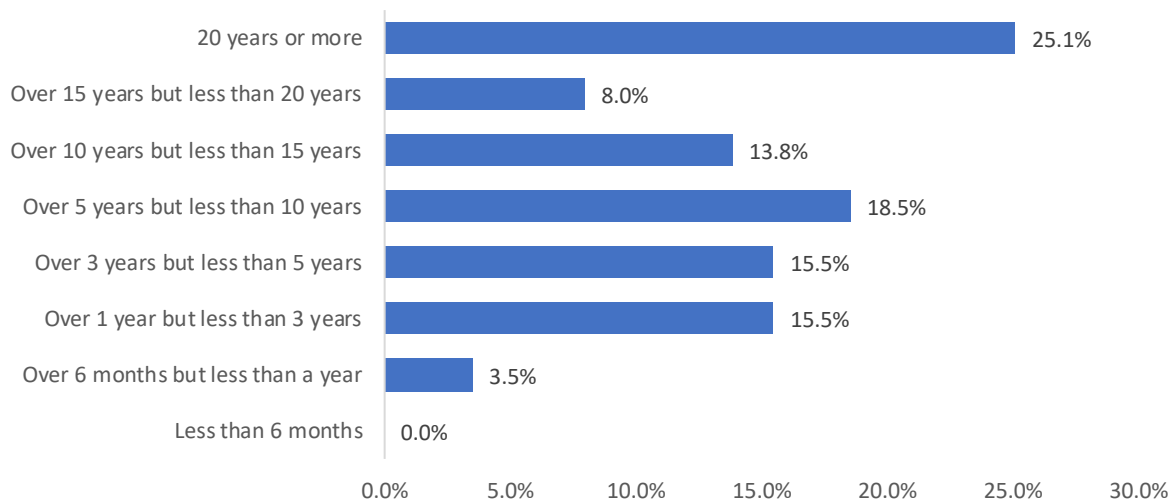
### Impact of caring and carers' quality of life

To assess the impact of caring on carers' quality of life, the survey asked respondent to quantify the time spent caring per week and the overall length of time spent looking after the person they cared for. Respondents also provided information on several aspects of their lives, including how they are able to spend their time, whether they are able to look after themselves, have quality social contacts, suffer loneliness or experience a deterioration in health. Other questions focused on carers' financial status, employment, overall control over their lives and their overall health status.

#### Time spent caring

A quarter (25.1%) of surveyed Leicestershire carers have spent 20 or more years looking after or helping the person they care for (Figure 26). The national rate is similar, with a consistent increase in proportion of carers in this group since 2014-15 survey (from 20% to 24.8%). In Leicestershire, the increase was from 21.1% in 2016-17 to 25.1% in 2023-24.

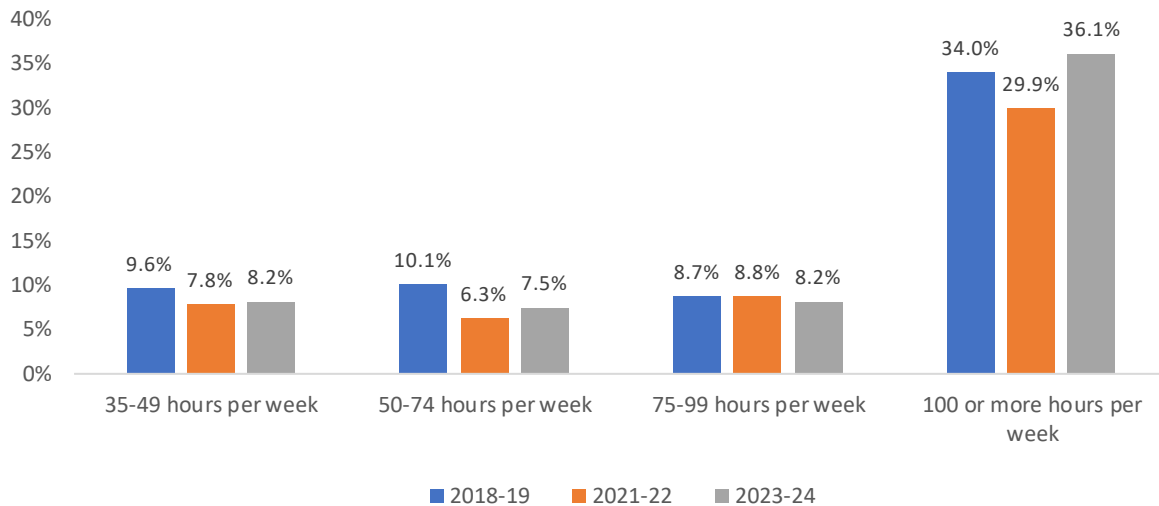
Figure 26 Length of time caring (Leicestershire)



Across the three surveys conducted since the autumn of 2018 there hasn't been a notable difference in the proportion of carers who care for 35 or more hours per week. In the most recent survey in the autumn of 2023, six in every ten (60.0%) respondents stated they spent

more than 35 hours per week in a caring role. Proportions tended to fall slightly in 2021-22 compared to the previous (pre-pandemic) survey and then return to the earlier levels in the most recent survey of 2023-24. For carers providing care for more than 100 hours per week, the proportion in the most recent survey – 36.1% in 2023-24 – was the highest of the three surveys (Figure 27).

Figure 27 Weekly time spent caring - time trends (Leicestershire)



#### Quality of life - how carers spend their time, look after themselves, social contact and loneliness

Covid-19 had a profound impact on levels of social contact across the country and this was seen in the previous carers survey, conducted in the autumn of 2021 when 24.7% of carers in Leicestershire stated they had as much social contact as they want with people they like, down from 30% prior to the pandemic. In the most recent survey, there has been little improvement, with 25.4% saying they have as much social contact as they want with people they like. Across England the equivalent measure showed a slight improvement from 28.0% pre-pandemic to 30.0% more recently.

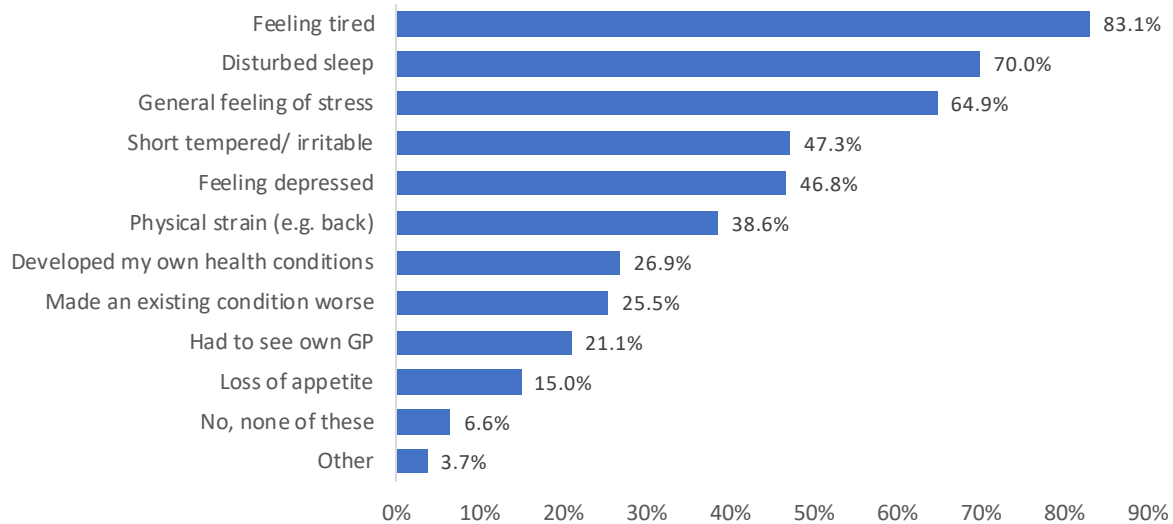
Furthermore, almost three-quarters of Leicestershire carers responding to the latest survey stated a level of loneliness with 13.2% saying this was often or always. This is a similar picture to England – 70.2% saying that they felt lonely to some extent with 13.3% saying this was always or often.

#### Impact of caring on health and health needs of carers

The most common reported health impact of caring was described by the respondents as feeling tired ( 83.1% of surveyed Leicestershire carers). This is followed by disturbed sleep 70.0%), then a general feeling of stress at 64.9% of carers (Figure 28).

Nationally there was a steady increase in percentage reported for most of health impact indicators over the last four surveys (since 2016-17).

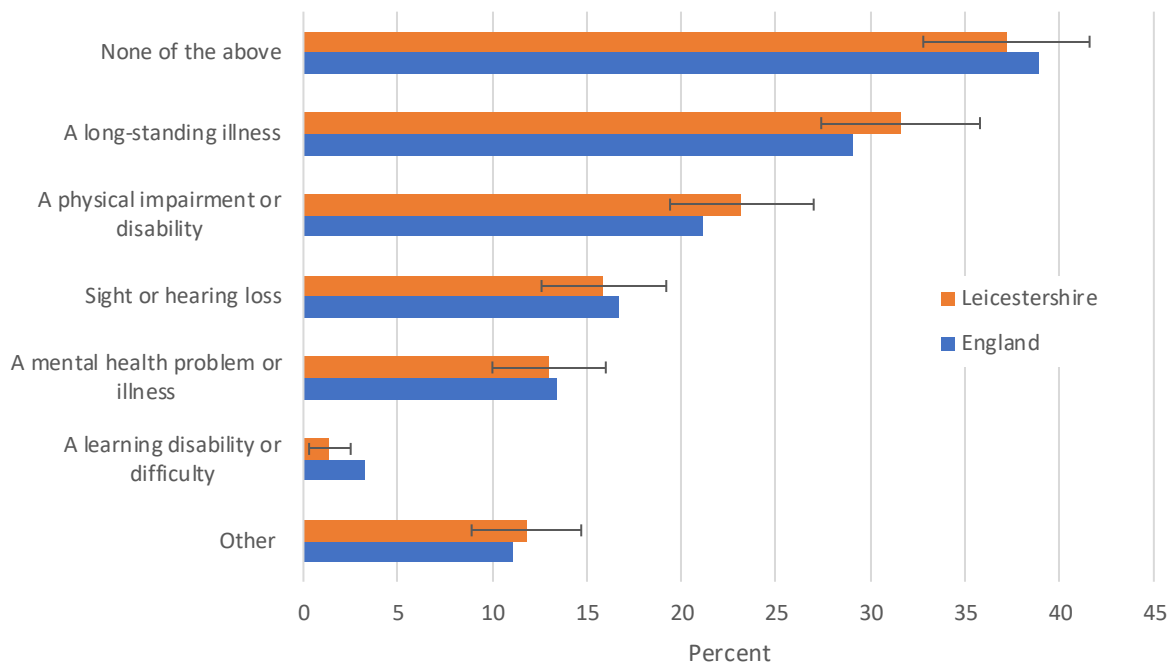
*Figure 28 Impact of caring role on carers' health*



Reporting on their own health needs, nearly four in ten (37.2%) of surveyed Leicestershire carers had none of the conditions listed in the survey, 31.6% said that they had a long-standing illness and almost a quarter (23.2%, N=760) had a physical impairment or disability (Figure 29). There was significant increase in the proportion of carers with a physical impairment or disability - from 18.6% in 2021-22 to 23.2% in 2023-24 in Leicestershire.

Except for lower prevalence of learning disability/difficulty among Leicestershire carers, the burden of other conditions is statistically similar to the national average.

Figure 29 Carers health needs



#### *Employment status, financial issues and control over life*

Nationally, one in five carers (20.4%, a slight decrease from 21.4% in previous survey) reported that they were not in paid employment due to their caring responsibilities. This proportion in Leicestershire was 17.3%, a result which is not statistically significantly lower than national average.

The proportion of Leicestershire carers in employment who felt supported by their employer was 10%, compared to 12.5% nationally (difference is not significant).

Almost four in ten (38.5%) of carers who responded to the survey stated that in the last twelve months their caring role had caused financial difficulties to some extent. A further 9% responded to say that their caring role had caused a lot of financial difficulties. The equivalent figures across England were 36.6% and 10%.

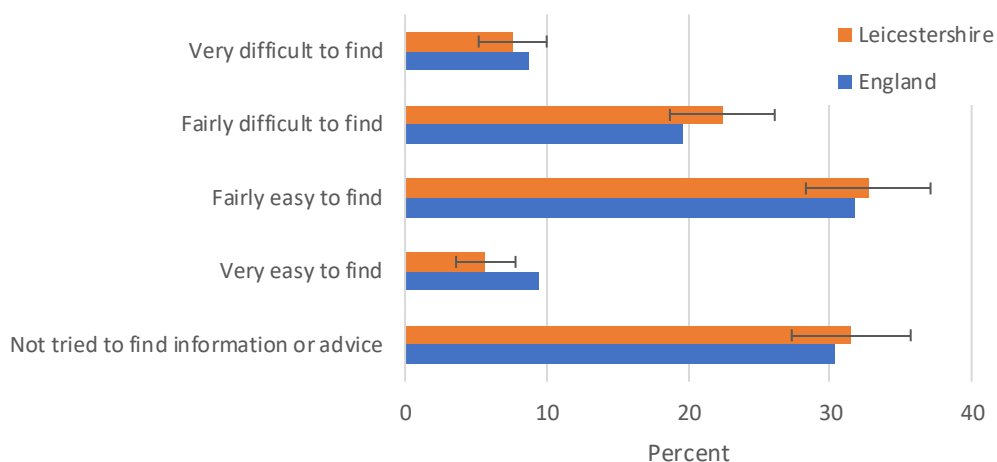
In Leicestershire, a significantly lower proportion of respondents felt that they had as much control over their daily life as they would like, when compared to England's average (17.7% vs 21.5% nationally). There was also 16.3% of carers who felt they had no control over their daily life.

### Quality of information and advice

The survey assessed several aspects of the quality of information and advice received by the respondents, including whether carers seek and receive such services, whether easy it is to find and/or helpful.

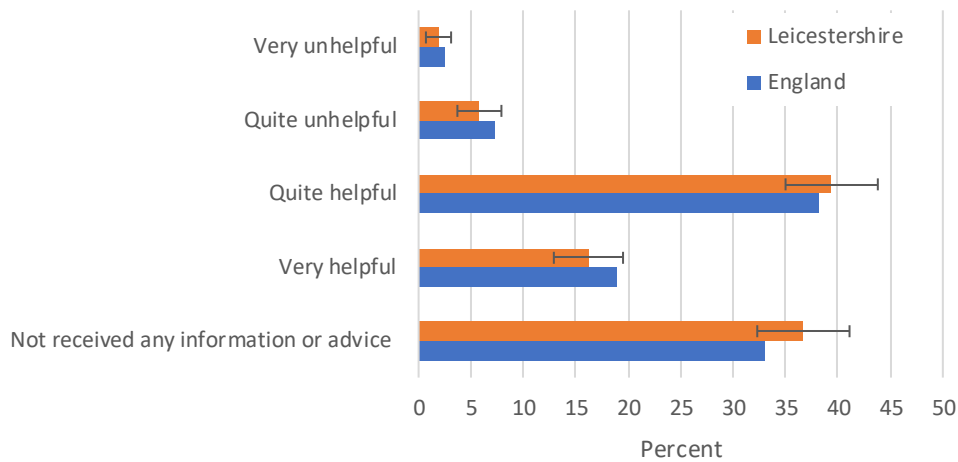
About three in ten surveyed carers did not try to find information in the last 12 months (31.5% in Leicestershire vs 30.4% nationally). Only 5.7% of Leicestershire respondents very easy to find (significantly less than 9.4% nationally), while almost a third (32.7%) were find information fairly easily (Figure 30).

Figure 30 Ease of finding information



While over a third of Leicestershire respondents did not receive any information or advice in the last 12 months, 16.2% said that they found information very helpful and only 1.9% as very unhelpful. None of the categories of information helpfulness was statistically significantly different from the national average (Figure 31).

Figure 31 Helpfulness of information



### Experience of support

The survey aims to assess the level of overall satisfaction with the support or services from Social Services, perception of encouragement and support as well as the involvement of carers in support services provided for the cared-for person.

### Overall satisfaction with support/services

One in five of surveyed carers in Leicestershire (20.7%) declared that they had not received support or services in the past 12 months. This is lower than one in four (25.6%) average across England. Among those who did receive such services the level of satisfaction (answers as 'very' or 'extremely' satisfied) was 37.7% (N=1,230), similar to the national average of 36.7%. The numbers of carers who were very/extremely dissatisfied with services was lower than national average (4.8%, N= 150, against 8% for England).

### Perception of encouragement and support by services

Almost one in three respondents in England (32.4%) felt that they were supported and encouraged in their caring role; for Leicester this proportion was just slightly lower at 29.5% (N=960).

On the other hand, one in five of carers in Leicestershire (19.8%, N=650) felt they had no encouragement or support, just below the national average of 21.1%.

### *Carers' involvement*

Over a third of carers locally (34.9%, N=1,140) were not aware about the support services provided for the person they cared for in the last 12 months. Of those who were, just over a third (35.8%) felt they were always involved while 7.4% (N=240) never felt involved.

### 3.3. Referrals to Support for Carers

Voluntary Action South Leicestershire (VASL) provides Support for Carers service funded by Leicestershire County Council. This is a free service to unpaid carers and offers a range of support including information and advice, carers assessments, benefits, financial and legal advice provide a telephone befriending service and local carers groups. See section 6.1 for further description of this service.

In March 2023 there were 5,559 registered carers, including new 1,097 carers registered in 2022/23. The total number of carers passport issued by April 2023 was 5,652, including 1,058 new carers passports issued in 2022/23. In July 2024, the total number of registered carers has risen to 6,793.

The numbers of referrals by type of support are presented in Table 9 below. The majority were for information and advice (33-40%), followed by emotional support (a quarter of all referrals).

*Table 9 Referrals to Support for Carers (January-March 2024)*

<b>Type of support</b>	October-December 2023		January-March 2024	
	<i>No.</i>	%	<i>No.</i>	%
Finance	26	2%	32	2%
Carers assessment	130	8%	124	9%
Emotional Support	435	27%	337	24%
Social Care	17	1%	14	1%
Hospital Discharge Grant	255	16%	317	23%
Information & Advice	647	40%	458	33%
Carers Passport	112	7%	98	7%
<b>Total</b>	<b>1,622</b>	<b>100%</b>	<b>1,380</b>	<b>100%</b>

*Source: VASL 2024*

### 3.3.1. Young Carers

Since 2023, schools have a responsibility to identify young carers on an annual basis and for 2024 there was a total of 255 young carers or 0.6% of the secondary school population. The majority (72% of schools) reported having no young carers.

## 4. Impact of Caring

The section below looks at the effects of caring on an individual, communities and wider society. It also considers the impact of the COVID-19 pandemic on unpaid carers.

### 4.1. Personal finances

The Carers UK State of Caring 2023<sup>11</sup> found that among over 11,000 carers surveyed in 2023, 75% of those receiving Carer's allowance were struggling with cost-of-living pressures, while almost half (46%) were cutting back on essentials, including food and heating. Furthermore, 45% were even more likely to say they were struggling to make ends meet, an increase from 39% in the previous year.

Almost three in ten (28%) people with caring responsibilities were in poverty in 2021/22. Informal carers face limited ability to work, with unpaid social-care givers experiencing an average pay penalty of nearly £5,000 a year<sup>31</sup>.

Carer's Allowance is the main carer's benefit and is £81.90 per week (2024/25 rate) for a minimum of 35 hours. It is the lowest benefit of its kind.

The Department of Work and Pensions reported that the total number of people claiming Carer's Allowance at February 2024 was 1.4 million, 3.7% higher than at February 2023. Almost a third (30% or 400,000) of carers entitled to this benefit do not receive payments, largely because they receive another benefit which equals or exceeds their weekly rate of carers allowance<sup>32</sup>.

### 4.2. Employment

According to Census 2021, in England of 9% of adults in employment over 2.3 million also provide unpaid care, 38% providing more than 19 hours and 17% more than 49 hours of care per week<sup>10</sup>. According to the 2022 NHS Staff Survey, a third of NHS staff provide unpaid care<sup>33</sup>, with rates being higher in the public sector compared to the private sector (19% vs 13%)<sup>34</sup>.

More than a half (56%) of carers juggle paid employment with 35+ hours of unpaid care. 60% of carers in employment are worried about the impact of caring responsibilities on their



finances, with over a third (34%) having cut back on essentials, such as food or heating (compared to 13% in 2021).

Caring increases the risk of leaving employment - Carers UK estimated that, prior to 2019, 600 people a day were leaving work to care – with nearly half a million people leaving work to provide unpaid care in two years pre-pandemic. Women are more likely to leave employment than men. For 7% of carers in employment their caring role has a negative impact on their work, potentially increasing the risk of reduction in income and poverty later in life<sup>34</sup>.

The most useful interventions, according to the survey respondents, were supportive employers, flexible working and additional paid care leave between five and ten days<sup>30</sup>.

#### 4.3. Wider economy

Unpaid care has a profound and complex impact on the wider economy, manifesting in a variety of ways, including its economic value, employment and productivity, health and social care, economic inequalities:

- The monetary contribution to wider economy - estimated at £445 million per day or £162 billion per year for England and Wales. This is equivalent to the whole NHS budget (£164 billion funding in 2020/21)<sup>35</sup>. Its replacement costs (i.e., the state replacing unpaid care with paid services) would be astronomical.
- Impact on employment - many unpaid carers reduce their working hours or leave employment altogether to provide care. This reduction in workforce participation can lead to a significant loss of productivity and economic output (see 4.2 above). In addition, the wider economy may suffer from the loss of skilled workers who leave the workforce to become full-time carers, particularly those sectors that are already experiencing skill shortages; employers may suffer increased costs due to absenteeism and/or high staff turnover<sup>11</sup>. Implementing supportive and flexible employment policies for carers can mitigate some of these impacts but may require investment.
- Health and social care costs - over-reliance on unpaid care may lead to delayed professional intervention, higher long-term costs. Effective signposting and to early professional assessment may prevent of escalation of health and social problems<sup>36</sup>.
- Economic inequalities - unpaid carers often face financial hardship (see 4.1 above), and his financial strain can contribute to broader economic inequality and affect the overall economic stability of households. Women are more likely to take on unpaid caregiving roles, which exacerbates gender disparities in income and employment<sup>11</sup>.

Addressing these issues through targeted policies and support services is crucial for mitigating these impacts and supporting both carers and the wider economy.

#### 4.4. Health Impact

The impact of caring can be detrimental to carers' health owing to a number of factors, including stress related illness or physical injury. Carers UK's 'In Poor Health', found carers who provide high levels of care for sick, or disabled relatives and friends, unpaid, are more than twice as likely to suffer from poor health compared to people without caring responsibilities.

Caring can have a significant impact on health and wellbeing. Sixty percent of carers report a long-term health condition or disability compared to 50% of non-carers<sup>37</sup>.

In 2023, eight out of ten carers reported stress and anxiety, almost half (49%) said that they felt depressed, and a similar proportion said they felt lonely. A high proportion (54%) reported that their physical health had suffered, and two out of ten said that caring had caused them injuries<sup>38</sup>. There is a growing consensus that caring should be considered a social determinant of health<sup>39</sup>.

See also Figure 16 in paragraph 2.2 on carer health inequalities.

#### Disability and poor health

Census 2021 data show that, in Leicestershire, the rate of disability among carers is overall much higher than among the non-carers, and more than twice as high among those providing more than 50 hours of unpaid care per week (35% vs 16%). The rates are highest in the older carer (65+) population – over 40% of all those providing more than 20 hours of care are themselves disabled, compared to 33% among the non-carers. The rates are also relatively high among the young carers - nearly a half of carers under 16 providing 50 or more hours of care are disabled, compared to just a 7.5% rate among those not providing care (Table 10).

*Table 10 Number and proportion of Leicestershire residents with reporting disability in Census 2021 by age group and unpaid care provision*

Age group	Not providing care		Less than 20 hrs		20-49 hours		50+ hours	
	No	%	No	%	No	%	No	%
5-15	6,646	7.5	88	15.8	41	36.6	45	47.4
16-24	8,255	11.3	362	21.5	135	18.6	96	31.6
25-34	8,683	10.8	497	21.8	273	22.2	382	32.2
35-49	13,792	11.6	1,274	19.2	652	24.3	1,069	30.0
50-64	20,881	17.1	2,820	18.3	1,007	25.0	1,384	29.1
65 +	42,895	32.5	2,095	31.8	896	39.9	2,926	40.5
<b>Total</b>	<b>101,152</b>	<b>16.4</b>	<b>7,136</b>	<b>21.5</b>	<b>3,004</b>	<b>27.2</b>	<b>5,902</b>	<b>34.5</b>

Source: ONS 2023

Similarly, the rates of poor (bad or very bad) health are overall twice as high in the population of carers when compared to non-carers (10% vs less than 5%), and they are highest in the older population (Table 11).

*Table 11 Number and proportion of Leicestershire residents reporting 'bad or very bad health' in Census 2021 by age group and unpaid care provision*

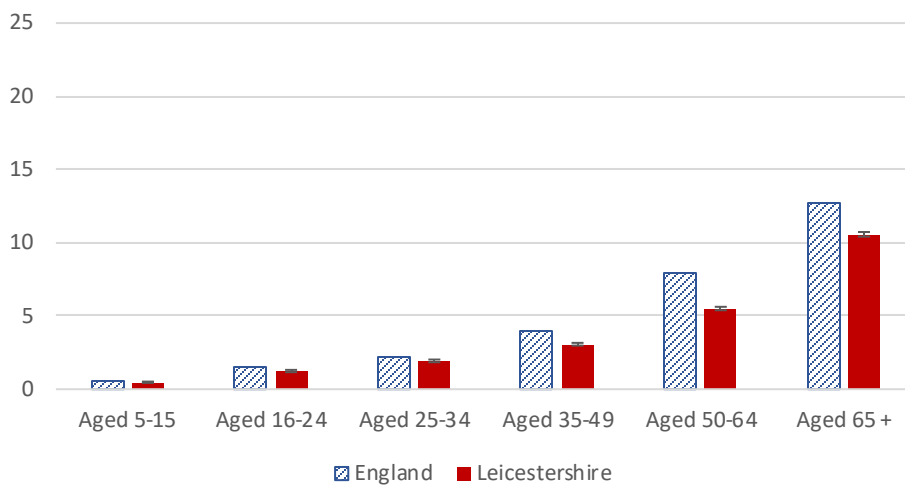
Age group	Not providing care		Less than 20 hrs		20-49 hours		50+ hours	
	No	%	No	%	No	%	No	%
5-15	401	0.5	8	1.4	*	0.9	11	11.6
16-24	842	1.2	47	2.8	25	3.4	20	6.6
25-34	1,454	1.8	65	2.8	49	4.0	77	6.5
35-49	3,381	2.8	208	3.1	170	6.3	297	8.3
50-64	6,875	5.6	461	3.0	264	6.5	473	9.9
65 +	14,087	10.7	434	6.6	251	11.2	892	12.4
<b>Total</b>	<b>27,040</b>	<b>4.4</b>	<b>1,223</b>	<b>3.7</b>	<b>760</b>	<b>6.9</b>	<b>1,770</b>	<b>10.3</b>

Source: ONS 2023

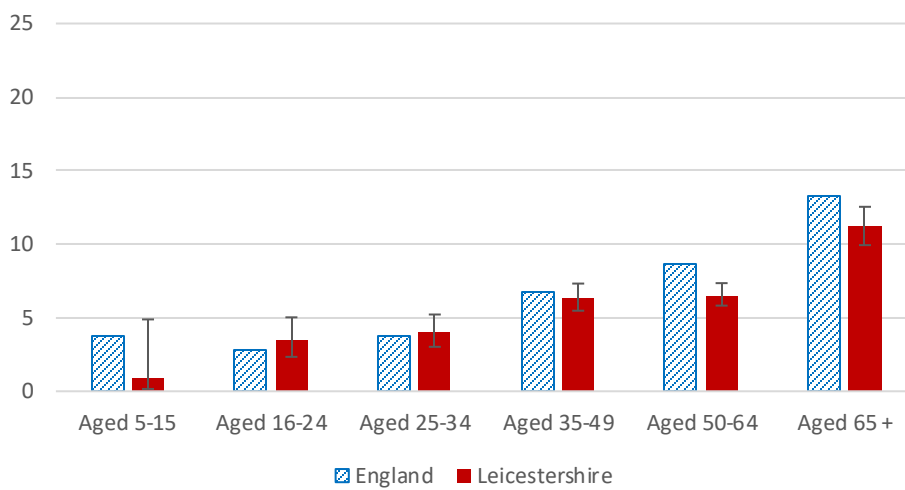
Figure 32 and Figure 33 below compare age-specific rates of poor health and disability among Leicestershire carers to the national (England) average. For most age groups, the local rates were statistically similar or lower than national average.

Figure 32 Rates of bad or very bad health among people providing unpaid care (Census 2021)

A. Population ill-health rate (%)



B. Ill health of carers providing 20-49 hours of care per week (%)



C. Ill health of carers providing 50+ hours of care per week (%)

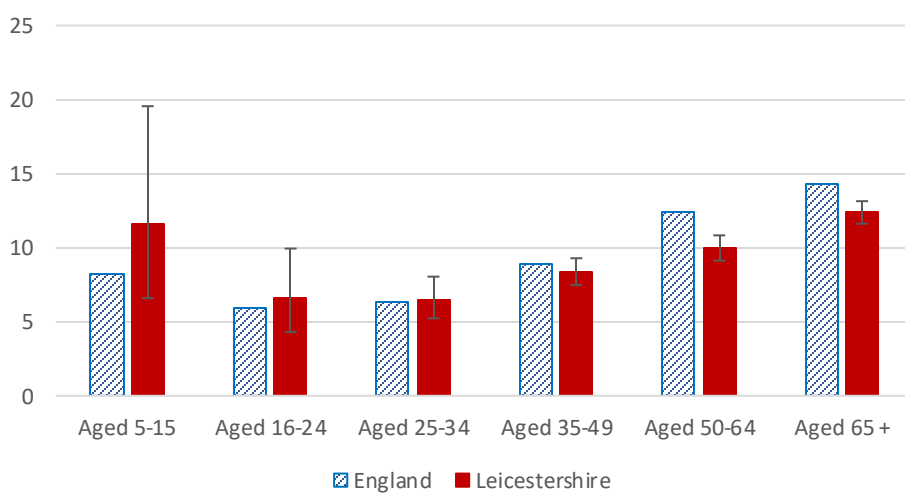
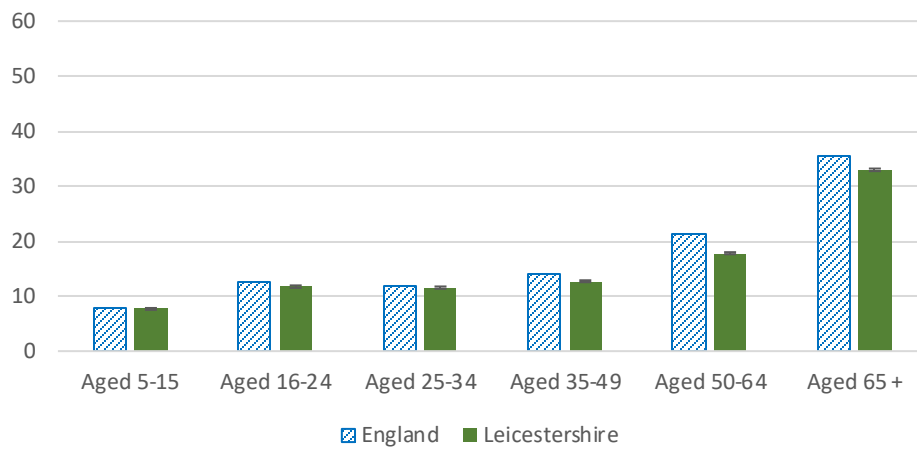
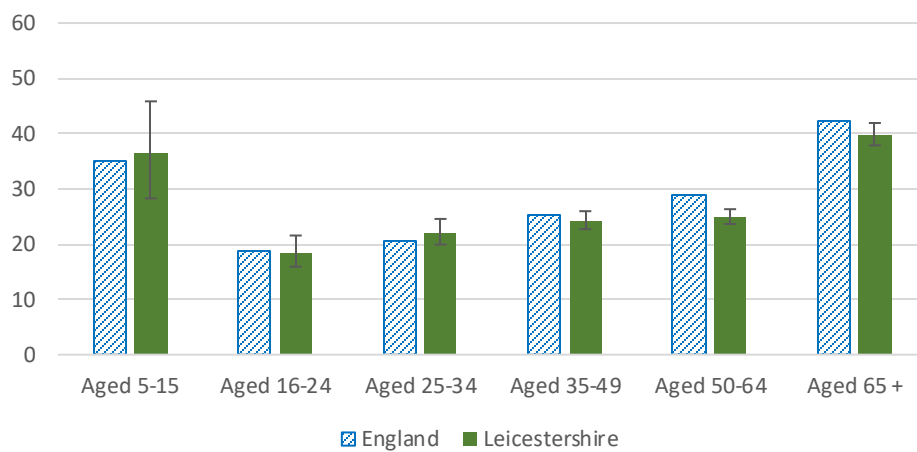


Figure 33 Rates of disability among people providing unpaid care (Census 2021)

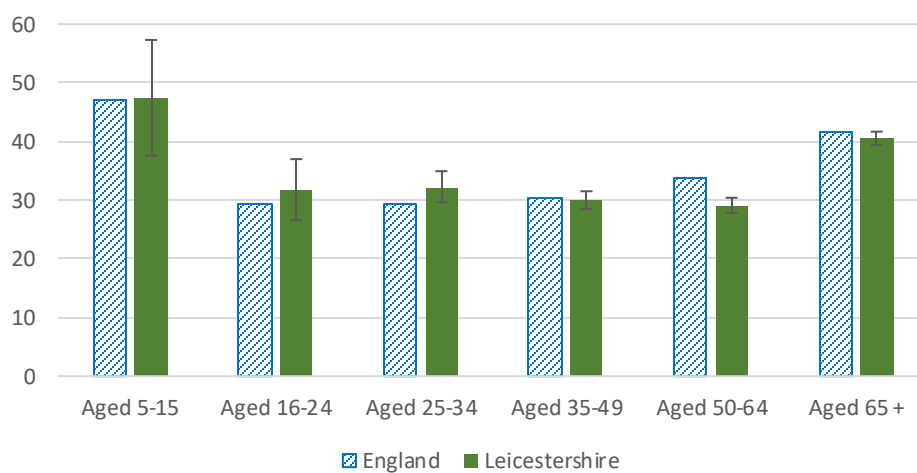
A. Population disability rate (%)



B. Disability of carers providing 20-49 hours of care per week (%)



C. Disability of carers providing 50+ hours of care per week (%)



#### 4.5. Impact of the COVID-19 pandemic

COVID pandemic had a significant impact on carers' lives, in many cases resulting in lasting effects on many areas, including their mental and physical health, employment and finances, their emotional wellbeing, with many taking on a new role as a carer.

Carers UK estimated that an additional 4.5 million people became carers overnight, in March 2020 which equates to 1 in 4 UK adults providing care to an older, disabled or ill relative or friend at the height of the pandemic. If we apply this across Leicester, Leicestershire and Rutland this suggests there was around 220,000 adult carers.

The Health Foundation report published in May 2021 found that wider health impacts including social isolation and the increased burden on carers were harder to measure<sup>40</sup>. There were gaps in the national covid policy response including support for people providing unpaid care. The lack of publicly available data means we only know so much about the impacts of the pandemic on social care. Data on care provided outside care homes is limited and hard to interpret.

Additional government support for unpaid carers came late in the pandemic. In the first wave support and respite services that enabled unpaid carers to take breaks from caring often closed, but government provided minimal support to reopen them. In September 2020 of carers surveyed 64% said they had not taken a break during the pandemic. The taskforce recommended increasing its respite offer for carers. In December guidance exempted carer breaks from restrictions on gathering and the need to stay at home. In November 2020 policy changes to allow people to continue receiving their Carer's Allowance when self-isolating was extended to May 2021.

The burden on unpaid carers appeared to increase, with negative effects. In a survey in October 2020, four out of five unpaid carers reported that they provided more care since the start of the pandemic. Fifty-eight percent reported feeling more stressed and many reported other negative impacts on their mental health and capacity to care safely.

Carers UK research showed that, nationally, the number of carers feeling isolated had doubled from 2020-2021 from 9% to 18%. This was also echoed by carers locally. Those feelings increased because of physical distancing and shielding, the closure of community services, unemployment, and the loss of loved ones which subsequently affected the mental wellbeing and resilience of the caring community. Prior to the pandemic, young carers were already an under-identified and under-recognised group. The closure of schools, universities and other educational settings during the pandemic meant that many young carers lost regular forms of contact, increasing the invisibility of young carers.

The broader health impacts of the pandemic on people using and providing social care are

also likely to be significant, including the effects of social isolation, and increased burden on people providing care. However, data on self-funders, unpaid carers and unmet need are lacking and limit analysis.

#### 4.5.1. Financial impact

The Carer's UK State of Caring report in 2021, stated that 36% of carers said their financial situation had worsened since the start of the pandemic, largely due to people being at home more, using more energy, being unable to work either due to being furloughed or as a result of the increase in care they were providing. Locally, carers also highlighted these challenges, and this remains an area of concern as they also tackle the cost of living and fuel crises. Caring households are significantly more likely to have had difficulty paying for at least one type of living expense since the beginning of the pandemic compared to non-caring households<sup>41</sup>.

#### 4.5.2. Providing more care

According to the Carers Trust, 58% of young carers had cared for longer since Coronavirus and were spending on average ten hours a week more on their caring responsibilities. Among young adult carers the proportion was even higher at 63.6%. A Carers UK report released in October 2020 stated that 81% of carers reported they were providing more care since the start of the outbreak for one or more of the following reasons: -

- The needs of the person they care for had increased.
- That local services reduced their offer or closed altogether.
- Someone they relied on for breaks was no longer available.
- They were worried about paid health and social care staff having contact with the person they care for.

As a result of this, 72% of carers did not have any breaks throughout the pandemic.

#### 4.5.3. ADASS Unpaid Carers Report

The East Midlands Association of Directors of Social Services (EM ADASS) recognised the impact of the pandemic on carers and commissioned a community interest company called Sortified to work with local carers to establish a simple list of recommendations for councils, based on their experiences of the pandemic. The subsequent report outlined areas where carers required support both on an immediate and long-term basis. As we live with COVID-19 some of the concerns presented in the report are now resolved, however those that remain, have been built into priorities within the Carers Strategy.

#### 4.5.4. Impact of NHS Pressures/Waiting Lists on Carers

The increases in NHS waiting lists following the pandemic is likely to have exacerbated the pressure on and number of carers as people have been waiting longer for treatment.

## 5. Policy and Guidance

The publication of Carers Strategy: Carers at the Heart of 21st-Century Families and Communities in 2008, was followed by a number of national programs - the full timeline of the relevant initiatives is provided in the Appendix.

The recent national policy and guidelines for carers include:

### 5.1. The Care Act 2014

The Care Act 2014<sup>42</sup>, a significant piece of legislation in England, reformed the law relating to adult social care. A key aspect of the Act is its provisions for carers, including:

- **Carers' Assessments:** The Act places a duty on local authorities to carry out a carer's assessment where it appears that a carer may have needs for support. This is regardless of the level of support they are providing, and whether or not the person they care for is receiving care services. The assessment must consider the carer's ability to provide care, the impact on their wellbeing, and what they want to achieve in their day-to-day life.
- **Eligibility Criteria:** carers are entitled to support if they meet the national eligibility criteria. This is based on the impact their caring responsibilities have on their wellbeing, their ability to achieve outcomes, and their needs.
- **Support Plans:** if a carer is assessed as having eligible needs, the local authority must create a support plan, detailing how these needs will be met. This may include services such as respite care, help with household tasks, or direct payments to arrange their own support.
- **Wellbeing Principle:** The Act introduces a general duty to promote an individual's wellbeing, which includes physical, mental, and emotional wellbeing. This applies to both the person needing care and the carer.
- **Information and Advice:** local authorities must provide information and advice relating to care and support for adults and carers. This includes helping them understand their rights and navigate the care system.
- **Prevention:** The Act emphasizes the importance of preventing or delaying the



development of needs for care and support and reducing the needs of carers. This includes providing services or information to help carers maintain their wellbeing and continue caring.

The Care Act 2014 represents a shift towards recognizing and supporting carers, rather than just as adjuncts to the person they care for. It acknowledges the critical role that carers play and ensures they receive the necessary support to sustain their own health and wellbeing.

The Care Act helps to improve people's independence and wellbeing. It makes clear that local authorities must provide or arrange services that help prevent people developing needs for care and support or delay people deteriorating such that they would need ongoing care and support. The Care Act relates mostly to adult carers – people over 18 who are caring for another adult. This is because young carers (aged under 18) and adults who care for disabled children can be assessed and supported under children's law. The Care Act does not deal with assessment of people under the age of 18 who care for others. The Children and Families Act gives young carers (and parent carers) similar rights to assessment as other carers have under the Care Act.

These provisions collectively ensure that carers receive a comprehensive assessment of their needs, support for their wellbeing, and access to necessary resources and information, highlighting a more inclusive approach to social care.

The Health and Care Act 2022 revoked Schedule 3 and amended Section 74 of the Care Act 2014 on 1 July 2022<sup>43</sup>. Section 91 of the Health and Care Act 2022 replaces section 74 of the Care Act 2014 with a new duty on National Health Service trusts and foundation trusts to consider how to involve an adult patient and their carer, including young carers, in discharge planning, in circumstances where the patient is likely to require care and support following discharge from hospital.

## 5.2. The Children and Families Act 2014

Section 96 requires local authorities to assess whether young carers within their area have support needs and, if so, what those needs are. The right to an assessment of need for support extends to all young carers under the age of 18, regardless of who they care for, what type of care they provide and how often they provide it. Local authorities must take reasonable steps to identify the extent to which there are young carers within their area who have needs for support.

Section 97 requires local authorities to assess whether parent carers within their area have support needs and, if so, what those needs are. The local authority should take reasonable steps to identify the extent to which there are parent carers within their area who have support needs. The requirement that carers provide a substantial amount of care on a regular

basis in order to be assessed was removed.

### 5.3. National Carers Action Plan 2018-20

The plan set out the cross-government programme of work to support carers over the next 2 years. It was structured around the following themes:

- services and systems that work for carers
- employment and financial wellbeing
- supporting young carers
- recognising and supporting carers in the wider community and society
- building research and evidence to improve outcomes for carers

### 5.4. NHS England's Long-Term Plan 2019

The NHS Long-Term Plan<sup>44</sup> Chapter Five sets out a wide-ranging and funded programme to upgrade technology and digitally enabled care across the NHS so that patients and their carers can better manage their health and condition.

The Plan aimed to boost 'out-of-hospital' care, dissolving the historic divide between primary and community health services, carers to benefit from greater recognition and support. Many carers are themselves older people living with complex and multiple long-term conditions; the programme aimed to improve identifying unpaid carers and strengthen support for them to address their individual health needs, through best-practice Quality Markers for primary care that highlight best practice in carer identification and support.

### 5.5. White Paper 2021 – People at the Heart of Care: Adult Social Care Reform

The white paper, People at the Heart of Care, set out a 10-year vision for transforming support and care in England, revolving around three objectives:

- To ensure people have choice, control and support to live independent lives,
- people can access outstanding quality and tailored care and support, and
- people find adult social care fair and accessible.

The white paper acknowledged the significant role of unpaid care and the diversity in their needs, including young or older carers, carers of people with dementia or for people who have had a stroke, employed carers providing a high volume of care per week and economically inactive carers.

Building on the foundations of the carers action plan the approach of the white paper concentrated on three strands:

- Working with the sector to kick-start a change in the services provided to support unpaid carers,
- identifying, recognising and involving unpaid carers, and
- supporting the economic and social participation of unpaid carers.

Additional funding was identified to kick start projects to enhance provision for respite and breaks, peer group and wellbeing support, and new ways to combine these to maximise their impact.

The white paper focuses also on:

- Identifying, recognising and involving unpaid carers, for example, increasing the voluntary use of unpaid carer markers in NHS and other services,
- supporting the social and economic participation of unpaid carers, helping them to access and stay in work whatever their personal circumstances, reducing feelings of loneliness, and
- supporting young carers – ensuring their visibility, ensuring their education, training or health doesn't suffer as result of their caring responsibilities.

## 5.6. Health and Care Act 2022

The Health and Care Act 2022 is a comprehensive piece of legislation aimed at improving health and social care integration in England <sup>45</sup>. Its key provisions for carers include:

- **Integration of Health and Social Care:** the Act promotes better integration between health and social care services. For carers, this means more coordinated support and services, which can help reduce the burden of navigating complex systems and ensure more seamless care for the individuals they support.
- **Enhanced Support for Carers:** the Act acknowledges the essential role of carers and emphasizes the need for enhanced support. This includes ensuring carers have access to appropriate information, advice, and services to help them in their caring role.
- **Local Authorities and Integrated Care Boards (ICBs):** the Act introduces Integrated Care Boards (ICBs) and Integrated Care Partnerships (ICPs) to plan and commission health and care services in a more integrated manner. These bodies are required to consider the needs of carers in their planning and delivery of services, ensuring that carers' perspectives and requirements are integrated into health and care strategies.
- **Workforce Planning:** the Act emphasizes the importance of workforce planning to ensure that there are sufficient health and social care staff to meet the needs of carers and those they care for. This includes training and supporting staff to better

understand and address the needs of carers.

- **Digital and Data Sharing:** the Act supports improved data sharing between health and social care services. For carers, better data sharing can lead to more coordinated care and quicker access to support services, reducing the administrative burden on carers.
- **Care Quality Commission (CQC) Oversight:** the Act expands the role of the Care Quality Commission (CQC) to include oversight of local authority performance in adult social care, including how well they support carers. This provides a mechanism for ensuring that carers receive the support and services they need.
- **Carer Involvement in Decision Making:** the Act stresses the importance of involving carers in the decision-making process regarding the care of the individuals they support. This includes ensuring that carers' views are considered in care planning and delivery.

In summary, the Health and Care Act 2022 seeks to create a more integrated and supportive environment for carers. By promoting better coordination between health and social care services, enhancing support, and ensuring that carers are involved in decision-making processes, the Act aims to improve the overall experience and wellbeing of carers.

### 5.7. Carer's Leave Act 2023

The Carer's Leave Act gained Royal Assent and became the Carer's Leave Act in May 2023. The Act was approved by Parliament and became into force in April 2024. The Act provides all carers in employment, a new statutory right to take five days of unpaid leave from work, each year to fulfil their caring responsibilities. This means carers will have workplace support and flexibility to support their loved ones and take time off work when required.

### 5.8. NICE Guidance

The National Institute for Care Excellence (NICE) issued the following guidance documents relevant to carers:

#### 5.8.1. Supporting adult carers (NG150)

Published in January 2020, covers support for adults (aged 18 and over) who provide unpaid care for anyone aged 16 or over with health or social care needs. It aims to improve the lives of carers by helping health and social care practitioners identify people who are caring for someone and give them the right information and support. It covers carers' assessments, practical, emotional and social support and training, and support for carers providing end of life care. It provides recommendations on information and support for carers, identifying

carers, carers' assessments, helping carers stay in, enter or return to work, education and training, social and community support for carers, training to provide care and support, psychological and emotional support for carers and support during changes to the caring role and during end-of-life care.

#### 5.8.2. [Dementia: assessment, management and support for people living with dementia and their carers \(NG97\)](#)

Published in June 2018, covers diagnosing and managing dementia (including Alzheimer's disease). It aims to improve care by making recommendations on training staff and helping carers to support people living with dementia, such as involving people living with dementia in decisions about their care, assessment and diagnosis, interventions to promote cognition, independence and wellbeing, pharmacological interventions, managing non-cognitive symptoms, supporting carers, staff training and education.

#### 5.8.3. [People's experience in adult social care services: improving the experience of care and support for people using adult social care services \(NG86\)](#)

Published in February 2018, covers the care and support of adults receiving social care in their own homes, residential care and community settings. It aims to help people understand what care they can expect and to improve their experience by supporting them to make decisions about their care. It addresses issues such as providing information, assessing care and support needs and care planning, providing care and support, staff skills and experience and involving people who use services in service design and improvement.

#### 5.8.4. [Children's attachment: attachment in children and young people who are adopted from care, in care or at high risk of going into care \(NG26\)](#)

Published in November 2015, covers the identification, assessment and treatment of attachment difficulties in children and young people up to age 18 who are adopted from care, in special guardianship, looked after by local authorities in foster homes (including kinship foster care), residential settings and other accommodation, or on the edge of care. It aims to address the many emotional and psychological needs of children and young people in these situations, including those resulting from maltreatment.

#### 5.8.5. [Older people with social care needs and multiple long-term conditions \(NG22\)](#)

Published in November 2015, covers planning and delivering social care and support for older people who have multiple long-term conditions. It promotes an integrated and person-centred approach to delivering effective health and social care services and covers such areas as identifying and assessing social care needs, care planning, supporting carers, integrating

health and social care planning, delivering care, preventing social isolation and training health and social care practitioners.

#### 5.8.6. Home care: delivering personal care and practical support to older people living in their own homes (NG21)

Published in September 2015, covers the planning and delivery of person-centred care for older people living in their own homes. It aims to promote older people's independence and to ensure safe and consistently high quality home care services.

### 5.9. NICE Quality Standards

In addition to guidelines covering general principles that apply to all carers, recommendations about supporting carers of people with specific health needs can be found in NICE guidance on those conditions. The most relevant general principal quality standards relating to carers are listed below. As with the published guidance documents above, standards relating to specific health needs can be found in NICE quality standards on those conditions.

#### 5.9.1. Supporting Adult Carers (QS200)

Published in March 2021, covers the provision of support for adults aged 18 or over who provide unpaid care for 1 or more people aged 16 or over with health and social care needs. It describes high-quality care in priority areas for improvement and includes following five quality statements:

- Identifying carers: Carers are identified by health and social care organisations and encouraged to recognise their role and rights.
- Working with carers: Carers are supported to actively participate in decision making and care planning for the person they care for.
- Assessing carers' needs: Carers having a carer's assessment are given the opportunity to discuss what matters most to them, including their own health, wellbeing and social care needs, and work, education, or training.
- Carers' breaks: Carers are regularly given the opportunity to discuss with health and social care practitioners the value of having a break from caring and the options available to them.
- Helping carers stay in work: Carers are offered supportive working arrangements by workplaces.

### 5.9.2. People's Experience Using Adult Social Care Services (QS182)

Published in February 2019, covers the experience of adults using social care services. It applies to all settings where people use social care services, including people's own homes, residential care and community settings. Its aim is to help people understand what care they can expect and to improve their experience by supporting them to make decisions about their care. It describes high-quality care in priority areas for improvement through the following four quality statements:

- Care and support needs assessment: people's personal strengths, preferences, aspirations and needs are discussed when they have a care and support needs assessment.
- Empowering people to manage their personal budget: people using adult social care services have as much control as they would like over their personal budget.
- Continuity of care and support: people using adult social care services have continuity of care and support.
- Using people's views to improve services: people using adult social care services have their views used to inform service improvement.

### 5.9.3. Children's Attachment (QS133)

Published in October 2016, covers identifying, assessing and treating attachment difficulties in children and young people (under 18). It focuses on children and young people at high risk of going into care, looked after by local authorities in foster homes, in special guardianship, adopted from care, and those in residential settings and other accommodation. It describes high-quality care in priority areas for improvement through the following quality statements:

- Comprehensive assessment: children and young people who may have attachment difficulties, and their parents or carers, have a comprehensive assessment before any intervention programme.
- Education plan: children and young people with attachment difficulties have an up-to-date education plan setting out how they will be supported in school.
- Video feedback programmes: parents and carers of preschool-age children with or at risk of attachment difficulties are offered a video feedback programme.
- Training and support for carers: health and social care provider organisations provide training, education and support programmes for carers of school aged children and young people with attachment difficulties.

## 5.10. NICE Clinical Knowledge Summaries

NICE also publishes accessible clinical knowledge summaries (CKS) of the current evidence

base and advice on best practice across clinical areas (full list at <https://cks.nice.org.uk/>), including a number of general support documents relevant to carers or specific scenarios, for example:

- Support for adult carers: How can I identify carers?
- Support for adult carers: Management
- Autism in adults: Scenario: Managing confirmed autism
- Dementia: Scenario: Management of end-stage dementia
- Autism in children
- Conduct disorders in children and young people: Scenario: Managing suspected conduct disorders
- Dementia: Scenario: Follow up of confirmed dementia in primary care
- Palliative care - general issues: Scenario: Communication

The above is only a selected list of topics.

## 5.11. Local Priorities

### 5.11.1. LLR Joint Carers Strategy Refresh 2022-25

The LLR Carers Strategy 2022-2025 is a joint Strategy which has been developed by the County Council, Leicester City Council, Rutland Council and the Integrated Care Board (ICB) across the LLR area. The Strategy seeks to ensure for that 'Carers of all ages across LLR will be identified early and feel valued and respected. They will be offered appropriate support wherever possible to enable them to continue their caring role and maintain their own health and wellbeing.' The LLR Joint Carers Strategy 2022–2025 sets out eight strategic priorities, relating to unpaid carers of all ages:

- Carer identification - building awareness of caring and its diversity; continuing promotion and growth of Carers Passport scheme; improving access to primary and health checks for carers; social seeding programme; better hospital admission and discharge from hospital; raising awareness through social media.
- Carers are valued and involved – through agreed approach to communicating effectively with carers, improving information on care pathways, development of 'you said we did' approach, improving awareness of young carers within adult services.
- Carers are informed – carers to receive easily accessible, appropriate information, advice and signposting; developing relationships with schools and colleges to improve young carer awareness.
- Carer friendly communities – work with communities to support carers through



awareness raising with community groups.

- Carers have a life alongside caring - ensuring that carers' health, education, employment and financial wellbeing needs are met; robust links with mental health services, improving move from children's to adult services; developing a Lived Experience Framework; considering the cost-of-living crisis in future planning.
- Care with confidence – ensuring carers are informed of technology solutions and other skills to care effectively.
- Carers can access the right support at the right time – developing robust links across integrated care system to ensure carers needs are recognised; raising the profile of the Carers Passports within primary and secondary health care; rolling out Young Carers Passports.
- Supporting young carers.

This Strategy has been refreshed to reflect the accomplishments of the previous strategy. The refreshed strategy builds on existing actions and represents the voice of local carers across LLR area, particularly following the COVID-19 pandemic.

<https://www.leicester.gov.uk/media/umxo4c5q/joint-carers-strategy-2022-25.pdf>

#### 5.11.2. Leicestershire County Council - Strategic Plan 2022-26

The LCC Strategic Plan for 2022-26 set out the vision for the four years. Although formulated for Leicestershire adults, the aspirational strategic outcomes particularly relevant to wellbeing of carers include:

- Great Communities: Leicestershire to have active and inclusive communities in which people support each other and participate in service design and delivery.
- Safe and Well: ensuring that people are safe and protected from harm, live in a healthy environment and have the opportunities and support they need to live active, independent and fulfilling lives.

<https://www.leicestershire.gov.uk/sites/default/files/field/pdf/faq/2022/4/12/Appendix-B-LCC-Strategic-Plan-2022-26.pdf>

#### 5.11.3. Delivering Good Health and Prevention Services 2022-2027 – Public Health Strategy

The Public Health Department within Leicestershire County Council have a service mission and aim to protect and improve the health and quality of life of the residents of Leicestershire<sup>46</sup>. This will be achieved through a commitment to the Authorities core values

and behaviours. The Public Health Strategy has a number of strategic priorities that are linked to ensuring better health and services for carers:

- Ensure that people have appropriate access to services and information that they need to improve their health.
- Pay special attention to the health of children and young people and other vulnerable groups. Work in a way that empowers communities.
- Building a network of partners to develop asset-based, community-centred approaches to increasing well-being.
- Working with communities and partners to maximise resources (including financial resources, skills and social and natural resources).

#### 5.11.4. Leicestershire Health and Wellbeing Board (HWB)

The Leicestershire Health and Wellbeing Strategy<sup>47</sup> sets out the key priorities and actions of the Health and Wellbeing Board for 2022-2032. The Strategy acknowledges the needs of carers, including the following outcomes as a marker of success:

- Improved quality of life for carers.

The Leicestershire HWB commitments include:

- Improving the quality and coverage of joined up care planning for the most vulnerable including strengthening care planning links across primary and secondary care to achieve 95% of the vulnerable population having a care plan in place.
- Continuing to implement the LLR Carers strategy for Leicestershire and strengthen links with the LLR Carers Board.

#### 5.11.5. LLR Joint Living Well with Dementia Strategy 2024-28

The outlines the local strategy to support people to live well with dementia highlights the importance of awareness of person-centred support for individuals living with dementia and their carers, especially seldom heard groups (e.g., prison population, ethnic minorities).  
Improving end of life pathways

#### 5.11.6. Community Health and Wellbeing Plans

Community Health and Wellbeing Plans (CHWP) are strategic frameworks designed by local authorities and health organisations to address and improve the health and wellbeing of local populations. They are developed in collaboration with a range of stakeholders, including public health, local government, voluntary, community and social enterprises, and healthcare providers.

They are developed in response to the DHSC 2021 Integration and Innovation White Paper<sup>48</sup> inherent to the establishment of Integrated Care Systems (ICS) in 2022. The ICS for Leicester, Leicestershire and Rutland (LLR) was established in July 2022. Partnership working has been established across the system (LLR collectively), place (Leicester, Leicestershire, and Rutland separately) and neighbourhood (at locality level). While the Leicestershire Joint Health and Wellbeing Strategy sets out the strategic vision and priorities for health and wellbeing at place level, across the County of Leicestershire, it is recognised that some needs are better identified and tackled at a neighbourhood level. Therefore, Community Health and Wellbeing Plans are also being developed to identify local needs and actions that, alongside the County and system (LLR) wide work, will help to improve people's overall health and wellbeing, to achieve local integration, prevention and improvement.

Across all seven Leicestershire CHWPs, there is recognition of informal carers as a vulnerable group and their specific needs, highlighting the need to address inequalities, focus on young carers, supporting carers in their workplace, and developing effective planning and support for the end stage of life both for patients and their carers. CHWPs fully support all relevant Place based strategies and the LLR Joint Carers Strategy.

## 6. Current Services

Anyone who supports and cares, unpaid, for a family member or friend with disability, long-term illness, substance misuse or a mental health need, who would not manage without their help, is described as a carer. This is independent of whether the carer lives with, or has a family relationship to, the person they care for, number of hours of care provided, receipt of a carers allowance, or the age of the carer. It is also recognised that in some cases the need of the person cared for may not be visible<sup>49</sup>.

Following is a brief description of services available for Leicestershire carers.

### 6.1. Support for Carers Leicestershire (SFC)

This service is commissioned by the Adult Social care department of Leicestershire County council and available to any carer at any point and can be accessed by carers or a referral from a professional. It is provided by an independent charity Voluntary Action South Leicestershire, VASL (Torch House, Torch Way, Market Harborough, LE16 9HL).

The service provides a dedicated telephone advice and support line, assistance in completing the carers assessment, information on carers' support groups around the county, advice on any aspect of the caring role, including financial and legal assistance as well as a website and self-help videos. The advice and help with issues such as dealing with GP appointments, getting medication from pharmacies, completing Carer's Assessments, arranging domiciliary care through Adult Social Care or private agencies, guidance on options for respite care, obtaining appropriate aids and adaptations, emergency plans, help with disability and carer benefits, as well as other financial or legal issues carers may face in their caring role.

SFC runs monthly support groups across the County, in Blaby, Oadby & Wigston, Harborough, Hinkley & Bosworth, Charnwood, North West Leicestershire and Melton.

The service is currently also running an energy advice support for carers and dementia friendly scheme.

In 2023 and 2024, SFC also supported two short-term schemes - hospital discharge grant for carers (HDGfC) - one from 23 January to 31 March 2023 and second from 1 August to 31 March 2024. This included administering the scheme on behalf of LCC, support the carers with completing the HDGfC application, identify how the HDGfC can support the carer, obtaining evidence of the cared for discharge and bank account details and paying the carers. HDGfC identified 77% (324/421) new carers over 2 periods.

## 6.2. Adult Social Care

Under the Care Act 2014, carers can get support from their local authority. If the carer has needs for support and they meet the national eligible criteria, carers are entitled to a Carers Assessment. In Leicestershire, Carers Assessment can be completed through customer service portal<sup>+++</sup> or by calling the Adult Social Care Customer Service Centre or VASL Support for Carers for help and support to complete their carer's assessment. The outcome of the Carers Assessment will establish whether a carer is entitled to a personal budget to support their health and wellbeing and provide respite from their caring responsibilities.

There are many ways which carers can get help and support across Leicestershire. Wide ranging information and advice is available via the adult social care website<sup>+++</sup>. The website aims to help with identifying carers, defining a carer role and specific types of carers (e.g., young, parent or sandwich carer), advice on self-care for carers, help with carer's assessment, available benefits, financial/legal assistance or planning for emergencies. The website also signposts to other sources of help and advice, including national charities such as Carers UK and Carers Trust, or First Contact Plus.

Carers who care for someone who lives within Leicestershire County Council area, have access to VASL Support for Carers (VASL:SFC). This is a free service commissioned by Leicestershire County Council. Support for Carers offers carers a variety of different services to support unpaid carers including issuing a Carers Passport, providing information and advice, financial and emotional support, befriending service, and local support groups to give carers the opportunity to connect with other carers. Carers Passports were launched across Leicester, Leicestershire and Rutland in 2020. This is an ID card for carers aged 18 years and above and is recognised across Leicester, Leicestershire and Rutland<sup>555</sup>. It aids easy recognition of carers in a variety of settings and enable access to services and support, such as Leicestershire Support for Carers coffee shops, cafes and Sports Centres. On production, carers can receive anything from a free hot drink, swim, gym class to a discount on food.

Carers can receive a Direct Payment from ASC to support in their caring role. This may be in the form of a one-off Direct Payment of up to £250, which can be applied for on an annual basis, or a weekly Direct Payment. Direct Payments can be used to support the carer, whether

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<sup>+++</sup> <https://customerportal.leics.gov.uk/web/portal/pages/home>

<sup>+++</sup> <https://www.leicestershire.gov.uk/adult-social-care-and-health/looking-after-someone/are-you-a-carer>

<sup>555</sup> Includes a carers passport scheme for adult carers and young carers passport for Leicester, Leicestershire and Rutland. This needs to be distinguished from parent carers passport scheme for Leicester and Rutland (does not apply in the County). Also, University Hospitals of Leicester have a separate carers passport scheme.

this is in the form of a sitting service or services such as cleaning and gardening. There are a small number of carers still in receipt of a commissioned carers sitting service, which is no longer commissioned to new carers.

As part of the SALT (Short and Long Term Return) carers can also be acknowledged as receiving services if they have been given 'Info & Advice' or 'No Direct Support' (support provided to the person cared for, for the benefit of the carer). 'Info & Advice' can be given when a carer contacts ASC or receives an assessment. 'No Direct Support' can be services such as residential respite, whereby the person cared for accesses respite to provide the carer a break.

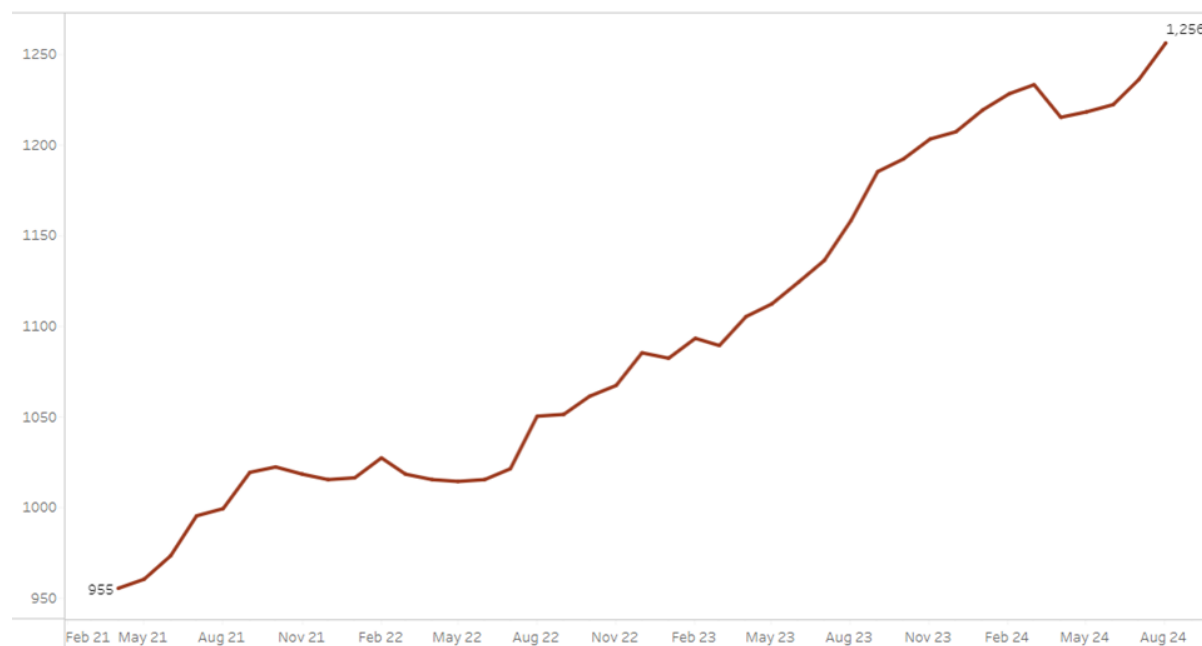
The numbers of carers in receipt of these services over the past three years is presented in Figure 34. While there has been a rise in Direct Payments, there has been a fall in 'Info & Advice' and 'No Direct Support'.

Figure 34. The number of carers in receipt of services over the last three financial years.

Period	Direct Payment Only	Part Direct Payment	Managed Personal Budget	Info And Advice	No Direct Support	Grand Total
2023/24	2,717	1	6	643	407	3,774
2022/23	2,597	1	8	716	473	3,795
2021/22	2,251	4	10	912	498	3,670

The number of carers in receipt of a weekly Direct Payment on any given day has been increasing over the last 3 years. On 1<sup>st</sup> April 2021 there were 955 carers in receipt of a weekly Direct Payment, with a 32% increase there are now 1,256 carers in receipt as of the latest snapshot 1<sup>st</sup> August 2024 (Figure 35).

Figure 35. The number of carers in receipt of a weekly Direct Payment on a 1st of the month snapshot (Apr 21 – Aug 24)



A **parent carer assessment** can be requested for those families where the parent or carer is the main carer for a child or young person up to the age of 18 that has either a physical or learning disability and/or has a mental disorder.

A parent carer assessment can be carried out either through the Family Help service or by a Children's Social Worker. A range of questions are asked, and if the LA agree support can consist of:

- A short break for the child or young person
- Family support including support around routines, behaviour, etc.
- Support to access services in the local community such as play schemes, leisure activities
- Help with caring for the child or young person, for example help with bathing
- Adaptations to the home

### 6.3. Young Carer Service

The principal goal of these services is to ensure that young carers can balance their caring responsibilities with their own wellbeing, education and social development. Local authorities are required to assess the needs of young carers including the impact of caring on those aspects of their own lives. Based on the assessment, authorities may offer support to reduce

the young carer's responsibilities or provide additional services for the family. These may include respite or short breaks, holiday programs, after-school clubs or day trips, one-on-one or group counselling, educational support, such as help with schoolwork, extra time for assignments, tutoring, or additional learning support. Services may offer life skills training, such as first aid or financial management, to improve both their caregiving skills and their future independence. Other help includes advocacy and information, as well as social activities and peer support.

Under the Children and Families Act of 2014 and Health and Care Act of 2022, Leicestershire County Council has a statutory responsibility to identify the number of young carers across the county and to the right to an assessment. The Local Authority has dedicated Young Carers Team which comprises of one Young Carers Co-ordinator and one Young Carers Youth Worker (two full-time equivalent).

Where a young carer is not known to the Local Authority, a Young Carers Assessment will be undertaken by the Young Carers Team who will then formulate a plan, which could be for on-going support if required. Where a young carer is identified but already has an assessment open within the Department, such as a Child in Need Plan or a Child Protection Plan, then the plan in place around the child will address the needs of the child relating to their caring capacity and support with the focus on their caring responsibilities not hindering their childhood and aspirations.

The Youth and Justice Service run a number of referral-only young carers groups across the county, some of which are in person and some digital. The purpose of these groups is to provide respite from caring activities and to encourage fun and friendships.

The Young Carers Team have recently introduced the Young Carers Passport to support children in working with their schools, GP's and other professionals to ensure that they are recognised as young carers. It is planned to link this in the future to the Adult Carers Card, which is incentivised by saving money at attractions, coffee shops or other.

Since 2023, the Department for Education have requested that schools identify young carers on an annual basis. In 2023, 255 young carers were identified within secondary schools in Leicestershire and in 2024, this slightly increased to 288 young carers. (0.5% and 0.6% respectively of the secondary school population). It is estimated that there are many more young carers, not yet identified or who are not willing to be identified. Seventy-two percent of schools reported having no young carers which is a concern. The current capacity of two full-time workers, may not be enough to fully support the further identification of young carers across the county.

As a result of the small size of the team, there is a waiting time before a Young Carers Worker



can be allocated. On average this is just under 23 days, with a peak in September of 49 days. Additional resource is pulled upon from Youth Workers when required, which provides a faster response but can mean that the specialist knowledge of young carers is not present, and this additional capacity is not an option when youth work referrals peak.

#### 6.4. Carer Support at University Hospitals of Leicester

NHS University Hospitals of Leicester (UHL) introduced a Carers Strategy, which replaced the Carers Charter. The three focus points of the Strategy include:

- Identifying carers - recognising carers early, from first outpatient appointment or early on in admission, through implementing the Carers Passport scheme and ensuring questions are asked in outpatient and admission departments.
- Involving carers in the care of persons they care for, through meetings about the patient, consultation within the outpatient setting, discharge planning and feedback via the Family, Carers and Friends Survey.
- Keeping the carer informed throughout the admission of person cared for, ensuring your they receive daily updates on care at UHL, providing up to date leaflets and other relevant information.

Following the COVID pandemic, in response to feedback from carers, UHL introduced a Carers Passport, initially piloted on a ward and now being rolled out to the rest of the Trust. The Passport aims to support carers whilst the person they care for is in hospital, enabling carers to visit outside of normal visiting hours, helping with personal care, meals and drinking (if carer wishes to do so), being actively involved in discussions about the person they care for, and being involved in discussions and planning for discharge from hospital.

UHL is also in the process of reviewing the Family, Carers and Friends Feedback Form. Furthermore, additional carer resources are being developed.

#### 6.5. Carer Support at Leicestershire Partnership Trust

Following staff and carer engagement in September 2023 Leicestershire Partnership NHS Trust (LPT) signed up to the National Carers Trust Triangle of Care (TOC) programme. This supports the improvement in a three-way partnership between service users, their carer and their health and care professionals. The Triangle of Care is a therapeutic alliance between carers, service users and health professionals. It aims to promote safety and recovery and to sustain wellbeing in mental health by including and supporting carers and is based on six principles that health and care providers can use to include and support unpaid carers, staff and those receiving care. The principles are as follows:

- Carers and the essential role they play are identified at first contact or as soon as possible thereafter.
- Staff are 'carer aware' and trained in carer engagement strategies.
- Policy and practice protocols re: confidentiality and sharing information, are in place.
- Defined post(s) responsible for carers are in place.
- A carer introduction to the service is available, with a relevant range of information across the care pathway.
- A range of carer support services is available.

LPT confirmed that the TOC would be one of the Trust 4 quality account priorities for 2024/5 promoting and supporting the priority and value of this work.

In response to the standards and supporting services to achieve TOC status the following pieces of work have been completed during 2023-4 and are ongoing:

- development of a Carers Pack\*\*\*\*
- Systmone Carers dashboard (on patient records in order to keep carer information updated, refer for carer assessments and support)
- development of Carer awareness training to date 288 staff have received this training since June 2024
- employment of two Carer lived experience partners to support the Carers work and feed this work into other co-production groups across the Trust
- engagement with carers from the LPT carers network to involve, inform and share ongoing work around TOC
- network of 30 TOC leads across the Trust leading the self-assessment work and becoming champions in their own areas.
- establishment of over seven additional carer groups aligned to mental health services in adult and children's services, to support carers of patients receiving care and treatment.

Over the next two years LPT will continue to deliver the TOC framework across all community and LD services, so that the whole Trust is working towards a set of standards whereby carers who reach service will receive the same support and involvement.

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\*\*\*\* <https://www.leicspart.nhs.uk/wp-content/uploads/2024/03/Carers-Pack-V10-APRIL-2024.pdf>

## 6.6. Carer Support in Primary Care

Primary care services may offer several forms of assistance to unpaid carers, including:

- Identification and registration of carers – this helps practices tailor care and services to the specific needs of the carer, for example prioritizing appointments.
- Health and wellbeing support including annual health checks and mental health support.
- Signposting to local support services, including local support groups, social services, and charities.
- Flexible GP services include priority appointments to accommodate the time constraints of carers, home visits if necessary.
- Support for carers of patients with specific conditions, including specialist information and advice on conditions, such as dementia or cancer, and medication management of the cared-for person.
- Referrals for Carer's Assessments.
- Vaccination prioritization for flu or other conditions that could pose threat to them or people they care for.

From April 2023, a non-recurrent hospital discharge grant monies were used to roll out a project (Mobilise) across County and Rutland to identify carers on a large scale using digital marketing techniques.

Other recent actions to enhance early recognition and awareness of caring, improving information and advice to carers, include:

- GP Carer Registration Form has been updated and shared widely to encourage carers to register with their GP practice.
- LLR GP Carer Registration Dataset was established. The national figures (Census 2021) suggest that 10% of registered population are caring, however the current, unvalidated, register accounts for just 1-2%. Work is ongoing to try and reduce this gap. It is important to note that carer identification is not mandated.
- Other actions to improve carer identifications include:
  - Publication and sharing of the relevant SNOMED codes with GP practices (their use and recording are not mandated).
  - Completed development of the GP support pack.
  - Promotion of key messages around the importance of carer identification through

the GP newsletter.

- Delivering carer awareness training for primary care staff was delivered (there was low attendance but good feedback).
- Work through Integrated neighbourhood teams - many areas have chosen to target unpaid carers as part of the personalised social prescribing work (in Charnwood this has had a notable positive impact on carer register figures). Hinckley and Bosworth, and Charnwood have been prioritising carer identification and support.
- Continuing general internal Think Carer awareness raising with ICB staff involved in service transformation.
- A prompt introduced on the Electronic Staff Record for ICB staff to record their carer status.

#### 6.7. Voluntary, Community and Social Enterprise (VCSE)

There are many independent charities, such as Age UK or Carers UK, providing a variety of help, information and advice to carers. The support may include home respite, benefits checks and advice, support with domestic tasks and personal care, domestic help, friendship and support and dementia and memory services.

## 7. Main Findings

### 7.1. Low proportion of carers identified

Not limited to Leicestershire, but it is highly likely that a large proportion of carers in the county remain unidentified. Census 2021 responses accounted for just over 61.3 thousand carers in the county, while it is broadly estimated that as much as 156 thousand of adults could be providing unpaid care.

### 7.2. Demographic trends indicating increasing need

With proportionately more older people (65 and above) in Leicestershire, significant past and projected growth in this demographic group, there are significant implications for the future need for care in the county. The numbers of people with more than three long-term conditions are likely to increase by twenty thousand in the next decade.

### 7.3. Additional risk factors for Leicestershire carers

Although general measures of socio-economic deprivation indicate that Leicestershire population is at a relative advantage, indices linked to rural deprivation such as access to housing and services show significant disadvantage locally. Rural deprivation, strongly linked to social isolation, poor access to transport and services, is an added dimension to risks faced by Leicestershire carers. While average measures of social isolation don't seem to be high, areas of rural deprivation should be acknowledged in future planning of services.

### 7.4. Burden of care

In 2021 (Census 21) there were over 22.7 thousand Leicestershire residents providing 35 or more hour of care per week, equivalent to a full time job. There is strong correlation between the However, weekly rates are overall lower when compared to the national average.

### 7.5. Service satisfaction

One in twenty of carers surveyed recently in Leicestershire were dissatisfied with services, but this rate much lower than national average (4.8% vs 8%).

### 7.6. Carers survey – long term carers

The proportion of carers caring for someone long-term (over 20 years) have been increasing. One in ten local carers report having financial difficulties linked their caring role; this rate has been increasing recently.

### 7.7. Services

The demand for financial support has increased in the past three years – the number of Leicestershire carers receiving weekly direct payments has increased by almost a third between 2021 and 2024 (to 1,256).

## 8. Recommendations

To be completed once the Carers Strategy working group has agreed the strategy recommendations.

DRAFT

## Appendix

Table 12 National policy timeline

<b>2008</b>	Carers Strategy: <i>Carers at the Heart of 21st-Century Families and Communities: 'A caring system on your side. A life of your own'</i>
<b>2009</b>	
<b>2010</b>	<i>Recognised, Valued and Supported: Next steps for the Carers Strategy</i> - national strategy for carers is reviewed
<b>2011</b>	
<b>2012</b>	<i>Caring for Our Future: Reforming Care and Support</i> (White Paper)
<b>2013</b>	
<b>2014</b>	<ul style="list-style-type: none"> <li>• <i>Carers Strategy: Second national action plan 2014–2016</i></li> <li>• Care Act</li> <li>• Children and Families Act</li> <li>• <i>NHS Five Year Forward View</i></li> <li>• Commitment to Carers programme launched (NHS England)</li> <li>• <i>Commissioning for Carers: Principles and resources to support effective commissioning for adult and young carers</i></li> </ul>
<b>2015</b>	
<b>2016</b>	<ul style="list-style-type: none"> <li>• <i>An Integrated Approach to Identifying and Assessing Carer Health and Wellbeing</i></li> <li>• Young Carers Health Champion programme, established by NHS England;</li> <li>• Consultation on the proposed updated Carers Strategy and forthcoming social care Green Paper.</li> </ul>
<b>2017</b>	<i>Next Steps on the NHS Five Year Forward View</i>
<b>2018</b>	<ul style="list-style-type: none"> <li>• The government confirmed that it would not now publish a revised Carers Strategy</li> <li>• <i>Carers Action Plan 2018–2020: Supporting carers today</i></li> </ul>
<b>2019</b>	<ul style="list-style-type: none"> <li>• <i>Carers Action Plan 2018–2020: One-year on progress review</i></li> <li>• <i>The NHS Long Term Plan 2019</i></li> <li>• <i>Supporting Carers in General Practice: A framework of quality markers</i></li> </ul>
<b>2020</b>	Guidelines for supporting unpaid adult carers, from the National Institute for Health and Clinical Excellence (NICE)
<b>2021</b>	<i>People at the Heart of Care: Adult social care reform White Paper</i>
<b>2022</b>	Health and Care Act

Source: Adapted from Nuffield Trust (2022) - *Falling short: How far have we come in improving support for unpaid carers in England?*

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