

JOINT CARERS STRATEGY REFRESH 2022-2025

Recognising, valuing and supporting carers in
Leicester, Leicestershire and Rutland



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1. Foreword

The COVID-19 pandemic has been a challenging time for everyone. While many people have played an important role enabling others to cope with those challenges, it is especially important to recognise all those people who look after someone who couldn't manage without their support. 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. We would like to express our thanks to carers across Leicester, Leicestershire & Rutland and publicly recognise the outstanding contribution they make to our communities.

We have heard carers tell us how they can feel isolated, that they may experience higher levels of strain on their own physical health and wellbeing, and that they often feel worried about what the future holds since the pandemic. We have been mindful of this when setting the priorities detailed in the refreshed strategy. Central to this is that carers have told us that they want to have opportunities to live their own life alongside their caring role. We have listened to what they have said to us. We want to make sure that carers across Leicester, Leicestershire & Rutland have access to services that support their physical and mental health and promote their wellbeing. One important element of this is identifying carers early and ensuring that the right support is accessible in the right places and at the right time for all carers.

We recognise that in order to achieve this vision and the best possible outcomes for carers, NHS and local authority partners need to work collaboratively. We therefore publish our strategy jointly as a sign of how we intend to work together. With our minds now set firmly on 'recovery' and living with COVID, this refreshed strategy reflects our ongoing commitment to carers. We look forward to seeing the implementation of the plans within the strategy over the next five years and being part of a system that ensures carers are not only recognised but are valued and supported to live healthy and fulfilled lives.

2. Carers' foreword

Young carers

'For us the strategy means that someone recognises what we do, how we feel and how we struggle.

It's a start in being supported as a young carer and being given time out to think about my emotional wellbeing as I suffer, as I'm isolated more than my friends.

It's important that everyone who is involved with young carers sees the strategy, especially schools. We spend so much time in school it would be great if this strategy brings change. We'd like to see every school having a named person who is the link person for the young carers, someone who understand us more, who understands the reasons we miss deadlines or are late to school. The strategy will hopefully affect the things that matter to us and allow us to talk about our worries and our good parts of life.'

Adult carers

'I'm delighted to have been asked to write this foreword. Cards on the table. I don't think carers were particularly well served in the past and I'm not sure they are now. I could go on about that but I won't. Why? Because I think it's changing, in fact I know it is, and I know the desire to improve is coming from providers as well as carers. A glimpse of this is a carer's voice being heard here right at the beginning.

What is a carer and why do they need a strategy? With one in four adults becoming a carer during the pandemic (and already we're ignoring the vast number of young carers) the idea that there will be a simple definition is wishful thinking. What connects me (a working carer) with a young carer, with a parent carer, with a young adult carer? Well, there is someone who couldn't cope with their everyday life without my help, without our help. Doesn't much matter who or how, there is someone who we have a commitment to support. We are part of the team (us, medical, domiciliary care, social work) that works together to help someone live their life.

And that's where this strategy could, and should, and will if we follow it, take us. A team. Working together. Agencies communicating with each other, carers in that loop. Carers being treated the same way as professionals, informed, included, supported. Good employment practice extended to include **all** the care team members, to include carers.

As well as treating carers as part of the team there's another job for you professionals. You need to tell us that what we're doing has a name. Carers rarely define themselves as 'a carer' we're sons, daughters, parents, friends, and that's how we see ourselves.

'Carer' is a label not an identity. The thing is, if I don't think to call what I do 'caring' then I'm unlikely to know there's an Act that grants me rights; that there's a dedicated support service for me; that there are people who will help me. 'Carers' don't know this. We really don't. If you tip us the nod you can make our lives so much better and that's got to be worth your effort.

Sounds like a plan? We all want the same thing. The best possible life for the person we're supporting without burning ourselves out. Here's how we do it...'

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3. Who is the strategy for?

‘We would describe 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.’

One of the biggest challenges in developing a strategy for carers, is that there are many definitions that apply, including within various national policy and legislation documents. Comments provided to us by carers across Leicester, Leicestershire & Rutland have suggested that the following factors are important to acknowledge explicitly:

- That a carer does not always live with the person they care for
- That a caring role should not be defined by the number of hours they provide care
- That the carer could be caring for their son, daughter, husband, wife, mother, or father, but that this list is not exhaustive, and the relationship between the carer and the person may also extend beyond traditional family roles
- Sometimes a carer can be caring for more than one person, across differing generations
- Carers may also receive support from a carer themselves
- Receipt of a carers allowance does not mean that they are in a paid carer role
- Carers can be any age – adult carers over age 18, young carers under age 18 and young adult carers aged between 18 and 25.

It is recognised that some people do not relate to the term ‘carer’ however, for the purpose of this strategy this will be the term used to encapsulate the diverse nature of the caring role.

4. Profile of carers in Leicester, Leicestershire and Rutland

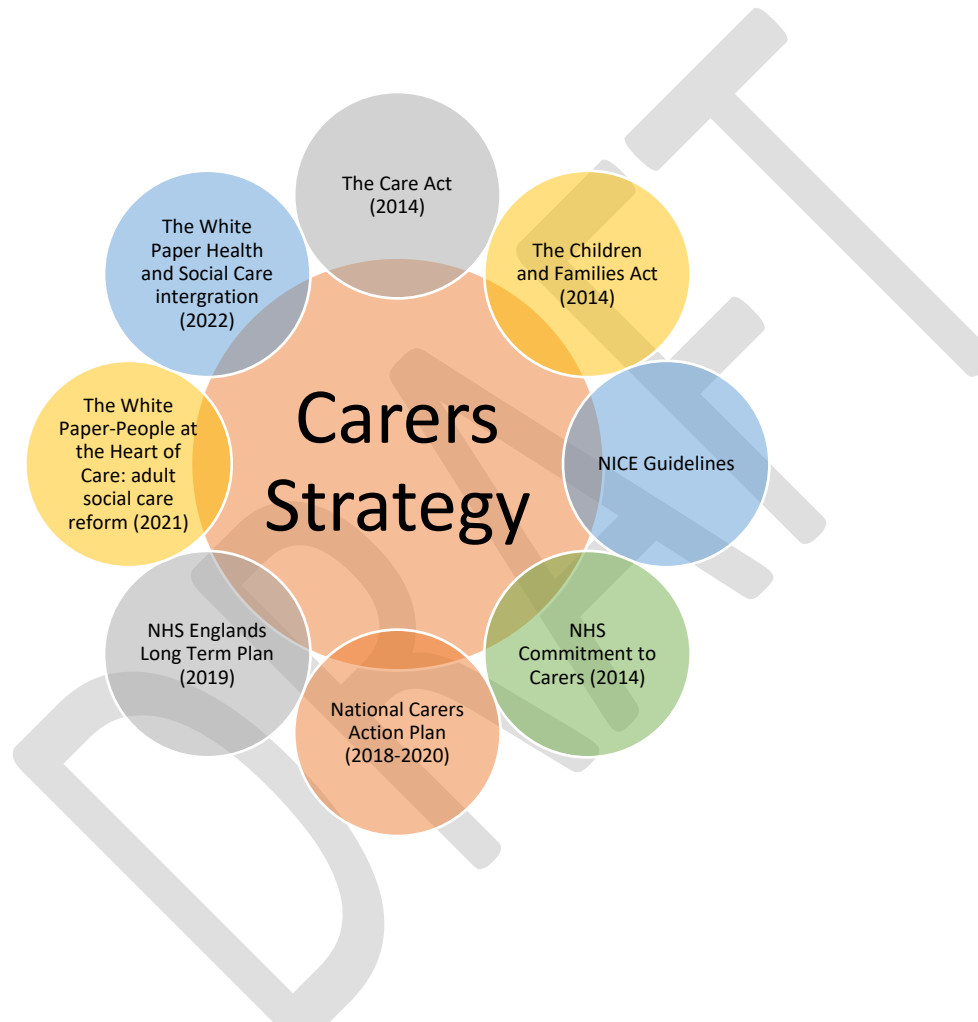
NEED CENSUS DATA – not due until Summer 2022

Census data to be included

- Carers' gender
- Ethnicity
- Age
- Number of hours spent caring

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5. National Policy and Legislation



This carers strategy works to support the aims of the Government as highlighted within these national policy and legislative documents.

6. Our local vision for carers

‘Carers, of all ages across Leicester, Leicestershire and Rutland will be identified early, 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’.

This strategy has been refreshed to reflect the accomplishments of the previous strategy such as:

- Launching a Leicester, Leicestershire and Rutland carers passport
- The incorporation of quality markers in GP surgeries
- Staff training around carer awareness within a number of health and social care organisations
- A review of the information and advice available to carers with necessary updates
- Larger numbers of carers registering with their GP’s
- A new regional carer co-production group.

It builds on existing actions and represents the voice of local carers across Leicester, Leicestershire and Rutland, particularly following the COVID-19 pandemic. It also sits alongside other local plans, such as the Health and Wellbeing Strategies for Leicester, Leicestershire & Rutland 2022-2032 and Social Care Strategies for Adults and Children’s Services across Leicester City & Leicestershire and Rutland County Councils. Ongoing challenges such as continuing to raise awareness of carer issues, promoting the early identification of carers, and continuing to keep information up to date remain embedded within the priorities of the refreshed strategy.

The organisations signed up to this strategy have committed to work together to deliver our local vision for carers. These include Leicester City Council, Leicestershire, and Rutland County Councils (responsible for social care), Leicester, Leicestershire & Rutland Clinical Commissioning Groups who work alongside GP surgeries, Leicestershire Partnership NHS Trust, University Hospitals of Leicester, voluntary and community sector organisations (notably organisations delivering carer support services and speaking on behalf of carers), and Healthwatch Leicestershire. This means the strategy is a guiding document for both health and social care support.

7. The impact of the COVID-19 pandemic

No one could have anticipated that during the life of the 2018-2021 strategy, there would be a pandemic that would have such a monumental impact on carers' lives. As a nation we are moving to recovery and living safely with Covid but for carers there are lasting effects on many areas of their lives: their mental and physical health, employment and finances, their emotional wellbeing, with many taking on a new role as a carer.

Increase in carer numbers

Carers UK estimate 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 would be around 220,000 adult carers.

We acknowledge this increase and prioritise carer identification

Loneliness

Carers had already told us they experience feelings of loneliness; and Carers UK research shows that the number of carers feeling isolated 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 well-being 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.

We acknowledge and prioritise the need for carers to have a life alongside caring

Providing more care

According to Carers Trust, 58% of young carers are caring for longer since Covid-19 and are spending on average ten hours a week more on their caring responsibilities. Among young adult carers the proportion is even higher at 63.6%.

A Carers UK report released in October 2020 states 81% of carers reported that 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 have increased.
- That local services reduced their offer or closed altogether
- Someone they rely 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 have not had any breaks throughout the pandemic.

We acknowledge the need for carers to have a break from caring and prioritise actions to support this

Financial Impact

Carer's UK State of Caring report 2021, stated that 36% of carers said their financial situation had got worse 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 have 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.

We acknowledge and prioritise the need for carers to have appropriate advice around their financial circumstances

Sortified The East Midlands' Unpaid Key Workers: Supporting Unpaid Carers by adapting services and responding to need during the COVID-19 crisis

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 are now learning to live with COVID-19 some of the immediate

concerns presented in the report are now resolved, however those that remain, have been built into our priorities within this strategy. The full report can be found at: <https://www.sortified.com/eastmidlandscarers>

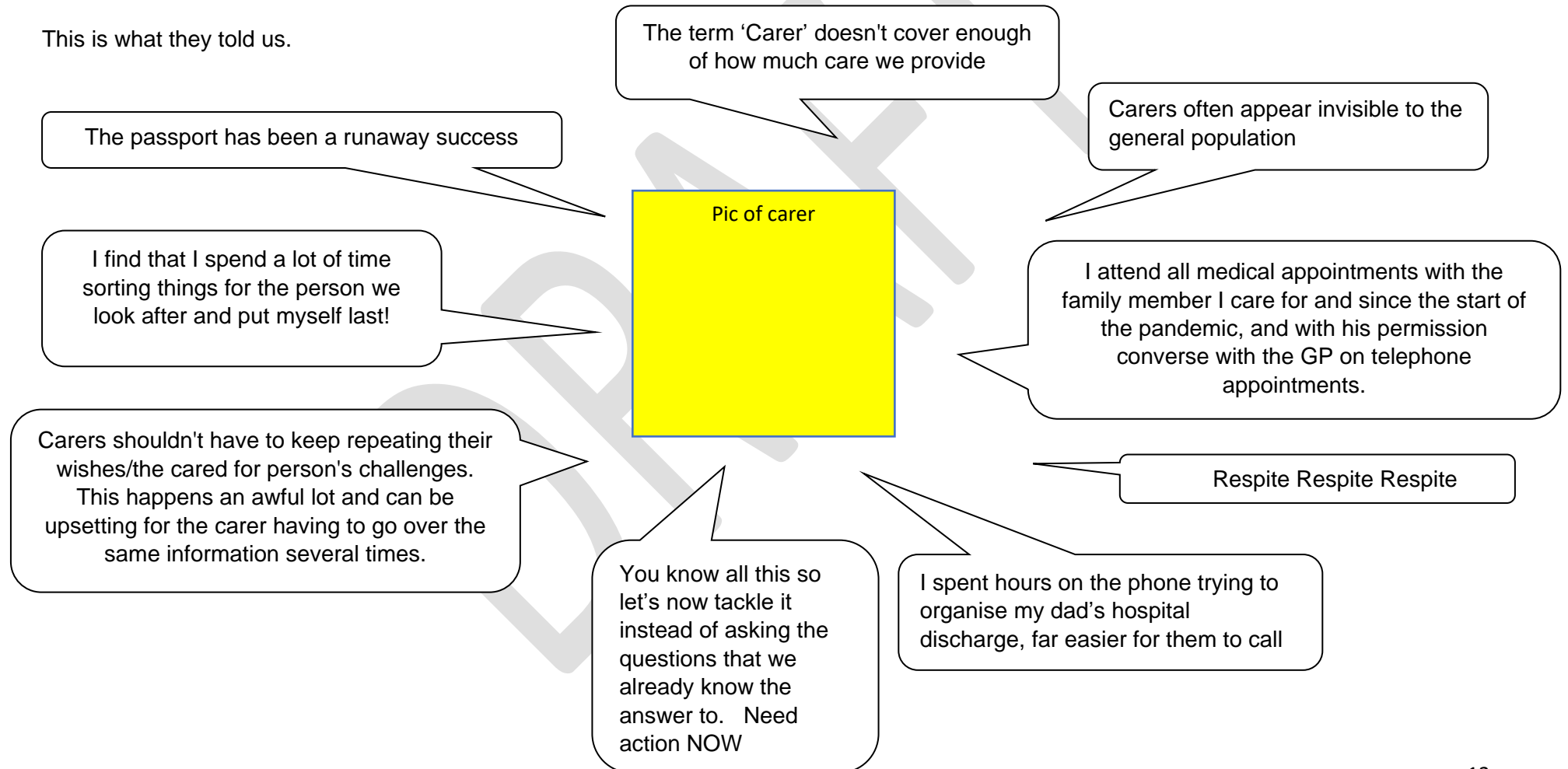
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8. What Leicester, Leicestershire and Rutland carers say

During the summer of 2021 we tried to speak to as many local carers as we could about the 2018-2021 Carers Strategy and their caring situations.

The carers were from a range of backgrounds: including parent carers, carers of different ethnic origins, young carers, older carers and working carers.

This is what they told us.



9. Guiding principles



The strategy continues to be underpinned by the guiding principles that reflect both the national and local requirements of carers.

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

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

10. Key priorities and associated actions

1. Carers are identified early and recognised - Building awareness of caring and its diversity		
<p>What the engagement told us</p> <p>Identification is still an issue for carers linked to lack of understanding of what caring is.</p> <p>Engagement recognised the need for GP surgeries to improve identification of carers.</p> <p>Lack of recognition was cited as a barrier to being kept informed; this was mentioned as a particular issue in hospital settings.</p> <p>Carers not receiving Carers Allowance feel they aren't recognised like those who receive it.</p>	<p>What will we carry forward?</p> <p>Ongoing staff training development to aid awareness and identification</p> <p>Ongoing review of information and use of pages to aid carers to identify themselves</p> <p>Continued promotion of Digital Resource for Carers & Employers for Carers resources</p>	<p>What are our new actions?</p> <p>Continued promotion and growth of the carers passport scheme.</p> <p>Improving access to primary care and health checks for carers as a means of supporting carers to maintain their own physical and mental health and wellbeing.</p> <p>A social seeding programme to provide ongoing relationships and alliances through the ICS and ensure it is reaching out to carers across cultures.</p> <p>Ensure better carer identification and consideration of their needs on admission to and discharge from hospital.</p> <p>Use of social media, to raise carer awareness, particularly around young carers.</p>
<p>How will we know this has worked?</p>		
<ul style="list-style-type: none"> • Increase in identified carers – GP registers, council systems, carers recorded to be accessing commissioned services • An increase in the number of carers registered for a carers passport 		

2. Carers are valued and involved - Caring today and in the future

What the engagement told us	What will we carry forward?	What are our new actions?
<p>Carers told us they would like simple acknowledgement of the role they play in supporting the person they care for.</p> <p>Carers still do not feel valued, they report feeling forgotten about during the pandemic and isolated.</p> <p>Those carers that are identified, report not being recognised as experts by experience in the health and wellbeing of the cared for.</p> <p>Carers reported lack of feeling valued, and comment this is often linked to not being recognised as a carer.</p>	<p>Further staff training – to ensure carers are recognised as experts by experience.</p> <p>Move towards a more co-productive approach to the planning and delivery of services.</p> <p>Ongoing work with hospital teams regarding discharge</p>	<p>Create an agreed approach for communicating with carers across Leicester Leicestershire and Rutland.</p> <p>The Carers Delivery Group will seek to influence the information provided to carers around the differing care pathways across the system.</p> <p>Development of ‘You Said We Did’ approach – showing that carer voice influences and shapes the design and delivery of our services.</p> <p>Utilise an ‘integration index’ to be co-produced to measure the extent to which the local health service and its partners are genuinely providing joined up, personalised and anticipatory care.</p> <p>Ensure that adult services are aware of and include young carers that may be involved in supporting the person receiving care.</p>
<p>How will we know this has worked?</p>		
<ul style="list-style-type: none"> • Increased satisfaction level from carers within the next national carers survey • Positive outcomes feedback from commissioned services 		

3. Carers are informed - Carers receive easily accessible, appropriate information, advice and signposting

What the engagement told us	What will we carry forward?	What are our new actions?
<p>Knowing where to look for required information was noted as a barrier for carers.</p> <p>Carers told us that when they were identified as the main contact for the person they care for they were kept informed in some instances.</p> <p>Carers like to use their GP for information and support</p> <p>Lack of recognition was cited as a barrier to being kept informed, carers feel they aren't offered the information as the person dealing with them doesn't view them as a carer.</p>	<p>Further sessions planned for key staff to ensure all teams have access to knowledgeable staff member for support around working with carers.</p> <p>Consider best communication pathways particularly in light of the COVID-19 pandemic.</p>	<p>Ensuring carers can access the information they need; in the formats they require.</p> <p>Refresh of the internet pages to ensure information is clear, pages are easy to navigate and language used isn't "too corporate". Including information for young carers.</p> <p>Including information on advocacy and getting carers voices heard.</p> <p>Development of relationships with schools and colleges to improve young carers awareness.</p>
<p>How will we know this has worked?</p>		
<ul style="list-style-type: none"> • Increase in the proportion of carers who say they find it easy to find information about services • Increase in carers identified • Increase in numbers of carers accessing carer support 		

4. Carer friendly communities

What the engagement told us	What will we carry forward?	What are our new actions?
<p>Carers told us they would like to see the use of volunteers to support carers.</p> <p>Carers told us that by raising awareness of caring in communities, community venues, and local businesses may become more accommodating.</p>	<p>Continue to take the views of carers into account in future commissioning exercises, including consideration of updated geographic and demographic data from the updated census 2021.</p> <p>Continue to work with communities to support carers through awareness raising within existing community groups.</p>	<p>We will ensure that the priorities within the carers strategy are aligned with The Integrated Care Board People and Communities Strategy 2022/2023</p> <p>Continued promotion and growth of the carers passport scheme. Specifically targeting community schemes and groups within neighbourhoods.</p> <p>Development of relationships with schools and colleges to improve young carers awareness.</p>
How will we know this has worked?		
<ul style="list-style-type: none">• Carers report greater satisfaction in the accessibility of services• Increase in the proportion of carers who say they find it easy to find information		

5. Carers have a life alongside caring – Health, employment and financial wellbeing

What the engagement told us?	What will we carry forward?	What are our new actions?
<p>Loneliness, isolation and not having time for themselves were key themes fed back by carers, all having the potential to affect their mental wellbeing negatively.</p> <p>The financial impact of caring for someone was of real concern to carers.</p> <p>Carers are neglecting their own physical health and wellbeing, putting off routine appointments and in some cases elective surgeries because they are unable to find appropriate support for the person they care for.</p> <p>Carers do not get enough time for themselves.</p> <p>Although we received limited feedback from working carers, we know that flexibility is a key factor in the ability to continue working.</p>	<p>Ongoing review of information and use of web pages – to ensure carers know where they can go for financial advice or support</p> <p>CareFree promotion ensuring all workers are aware and are utilising the offer.</p> <p>Carers breaks provision still under review</p> <p>CCG's will continue to encourage carers to take up screening invitations, NHS health checks and vaccinations, where relevant.</p>	<p>Ensuring carers have the information they need to keep themselves well.</p> <p>Forging robust links with the Mental Health programme of work across the integrated care system to ensure carers needs are recognised.</p> <p>Work to improve transition planning with young carers, to consider their future aspirations in terms of college, university, leaving home.</p> <p>Continue work with Leicestershire Partnership Trust to develop a Lived Experience Framework. This alongside trust-wide systems and processes will allow for the creation of paid opportunities for those with lived experience whilst developing skills and experience.</p>
How will we know this has worked?		
<ul style="list-style-type: none"> • Increase in number of carers accessing carefree breaks • Increased satisfaction level from carers within the next national carers survey • Increase in the numbers of carers receiving information and advice regarding finance and benefits • Increase in number of young carers receiving transition assessments 		

6. Care with confidence – Technology and skills supporting you to care effectively

What the engagement told us	What will we carry forward?	What are our new actions?
<p>Local carers didn't identify with the previous title of priority 6 - <i>Carers and the impact of Technology Products and the living space</i>. However, what did come through was that carers have been reliant on technology or gadgets during the pandemic.</p> <p>There was acknowledgement that housing needs still exist, where properties aren't always suitable particularly for carers supporting someone who has severe needs.</p>	<p>We will continue to work with professionals from housing, equipment and adaptations to improve the carers' pathway and embed carer awareness.</p>	<p>Ensure carers are informed of technology solutions that can support them.</p> <p>Work to enable carers to be confident using technology/gadgets.</p> <p>Introduce mechanisms to better support patients, carers and volunteers to enhance 'supported self-management' particularly of long-term health conditions</p>
<p>How will we know this has worked?</p>		
<ul style="list-style-type: none"> • Increase in the proportion of carers who say they find it easy to find information 		

7. Carers can access the right support at the right time - Services and systems that work for carers

What the engagement told us?

Carers tell us they want to receive support that recognises their individual circumstances, and they sometimes needed support to navigate through the health and social care system.

Carers want to be able to help themselves too and are looking for access to carer courses, to support them in their caring role.

Carers want support with health and wellbeing particularly mental health support for carers, both for their own health and with support managing caring for somebody with a mental health condition.

Carers require support with hospital discharge, starting right at the point of admission ensuring they are kept informed and involved.

What will we carry forward?

Ongoing use of Carers Delivery Group (CDG) to ensure that all organisations work together to improve support for carers.

People will be signposted to sources of support post-caring.

What are our new actions?

Forging robust links with the Mental Health programme of work across the integrated care system to ensure carers needs are recognised.

The Carers Delivery Group will seek to influence the information provided to carers around the differing care pathways across the system.

Targeted work to raise the profile of the carers passports within Hospital and GP services.

To ensure that carers are supported to plan for emergencies.

Work alongside LOROS and the Carers Matters Stakeholder group to understand what matters to carers supporting a loved one at the end of life.

Roll out of Young Carers passport across Leicester, Leicestershire, and Rutland.

How will we know this has worked?

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

8. Supporting young carers

What the engagement told us	What will we carry forward?	What are our new actions?
<p>A number of Leicestershire young carers wanted to remove priority 8 and have actions for supporting young carers embedded within the actions for the other priorities.</p> <p>Young carers identified the need to be 'young people' and want time for themselves.</p> <p>Young carers want to be able to find the information they need.</p> <p>Young carers need support to identify as young carers, which is mindful of the needs of the whole family, particularly within schools, and colleges.</p> <p>Young carers say they often miss education due to their caring responsibilities which can impact their life choices.</p>	<p>Embed the whole family approach</p> <p>Working with educational establishments</p>	<p>Develop young carer support that acknowledges young carers miss out on childhood and other key activities as well as providing appropriate mental health support where required.</p> <p>Work with young carers to improve the way that the health system including GP's supports young carers.</p> <p>Local authorities will work with young carers to ensure that their aspirations of going to college, university, leaving home, are considered as part of their work with young carer services.</p> <p>Under 11 years support for young carers.</p>
<p>How will we know this has worked?</p>		
<ul style="list-style-type: none"> • Increased number of young carers known to services will be reported • Young carers report feeling listened to and respected • Organisations can evidence a more robust approach to working with young carers and their families • The impact of caring on young carers is taken into account in assessments and transition planning across social care • Young carers report improved outcomes at home, school or in employment 		

11. Monitoring progress

The Carers Delivery Group have led on the development of this strategy and recognise the impact that positive carer support can have across all workstreams. The group will oversee delivery of the strategies priorities, and report progress to the respective partner organisations governance arrangements and health and wellbeing boards.

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