

# **Integrated Care: The next steps to build strong and effective integrated care systems across England**

## **Carers UK response to NHS England consultation – January 2021**

### **Integrated Care: next steps to build strong and effective integrated care systems across England**

#### **About Carers UK**

---

Carers UK is the leading organisation of carers in the UK. Established in 1965, we have over 32,000 members, a network of 300 local Affiliates and have acted as the voice of carers for over 55 years. We provide information and advice to carers delivering the only national helpline dedicated to carers, informed by their needs. We provide carers with digital as well as peer support through a number of different mechanisms. Our knowledge and experience are also drawn from our colleagues in Carers Wales, Carers Scotland and Carers Northern Ireland. Carers UK also set up and runs an employers forum, Employers for Carers, with over 300 employers supporting unpaid carers within their workforce. We work in partnership with many organisations including health, social care and voluntary organisations. We regularly carry out research, engagement, and insight work with carers, ensuring they are able to shape their future. Our response is based on this work.

#### **Overall approach to consultation**

---

Carers UK agrees with putting the Integrated Care Systems on a statutory footing for many of the reasons set out.

However, our primary concern is that this proposal for legislation fails to include carers explicitly and that our points that we raised in response to the last consultation have not been taken on board. We repeat and build on those points in this response.

Our overall response:

- Carers must be explicitly included in all legislative structural mechanisms alongside any mentions of patients and people who use services. This is to ensure that the NHS delivers on its responsibilities and ensures that any integrated service delivers on local authorities' strong legal responsibilities to carers.
- There should be a duty to involve carers explicitly on the face of any legislation and a requirement to have a carer representative on any important decision-making boards

alongside a patient and a person who uses social care services, as well. This would aid integration and full understanding of a complex health and care system.

- The legislation needs to have explicit reference to wellbeing, namely Section 1 of the Care Act 2014, and to have regard to carers' wellbeing written into legislation.
- A legal reference to reducing health inequalities would be important to align NHS and LA responsibilities and support the delivery of the NHS Long Term Plan.
- Greater mechanisms need to be included which link with local authority and joint systems of accountability in order to deliver greater accountability and transparency overall.
- Greater explanation and detail of the proposals is needed to be able to make a decision about how this might impact on carers specifically as well as the people they care for. This includes any devolution of specialised commissioning.

## **Carers, health, and relationship with NHS**

---

During the pandemic, the number of carers rose dramatically at one point as many as 13.6 million carers across the UK or one in four of the population.<sup>1</sup> Outside of the pandemic, the value of their support, as the NHS has acknowledged, is £132 billion, roughly equivalent to the value of the NHS.<sup>2</sup> During the pandemic, the value of their support has been £530 million per day.<sup>3</sup>

Carers are twice as likely to suffer ill-health as a result of caring and the GP Patient Survey has established important health inequalities. Carers play an important role in the care of someone with medication, supporting daily activities of life such as eating, drinking, dressing, moving, supervision and cognitive support, through to more complex specialised nursing care. Carers often say if they stopped caring, health and social care would collapse.

## **NHS responsibilities towards carers – carers should be included in this legislation**

---

The NHS has a number of responsibilities towards carers. The NHS Plan published in January 2019 set out a strategic direction, recognising that carers have an important role (para 1.19) and need support:

Carers will benefit from greater recognition and support..... We will improve how we identify unpaid carers and strengthen support for them to address their individual health needs. We will do this through introducing best-practice Quality Markers for primary care that highlight best practice in carer identification and support.

---

<sup>1</sup> Carers Week 2020, [The rise in the number of carers during the coronavirus pandemic](#), Carers UK June 2020.

<sup>2</sup> Buckner, L and Yeandle, S, Calculating The Value of Unpaid Carers Support, Carers UK 2015

<sup>3</sup> [Unseen and Undervalued](#), the value of unpaid carers support during the COVID-19 pandemic, Carers UK November 2020.

There are several policy related documents that focus on NHS responsibilities to carers that promote joint working and integration namely the NHS Commitment to Carers, the NHS Carers Toolkit helping to promote locally integrated Memorandum of Understanding on Carers, a GP Quality Markers Toolkit and all the work relating to Universal Personalised Care, which incorporates carers within Personal Health Budgets, integrated and joint working.

Legally, the NHS has a duty to have regard to the NHS Constitution published in 2015, to which every NHS body in England must have regard (NHS Act 2006 section 14P). This commits the NHS to 'work in partnership with patients and carers' and to ensure that its services are 'coordinated around and tailored to, the needs and preferences of patients, their families and their carers'. It lists seven key principles to 'guide the NHS in all it does', of which Principle Four recognises that:

*"Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment".*

This consultation does not seem to be in line with the NHS Constitution.

The NHS has a duty to cooperate with local authorities in the discharge of its functions under the Care Act 2014, The NHS Act 2006 section 72 requires NHS bodies to co-operate with each other and section 82 requires that this also extend to working with local authorities 'in order to secure and advance the health and welfare of the people of England and Wales'. The duty is also highlighted by principle 5 of the NHS Constitution. Reciprocal duties on social services can be found in the Care Act 2014, section 6 and the Children Act 1989, section 27. In other words, the NHS has key responsibilities towards carers which it does not always put into practice. At times, carers are overlooked in key NHS documents and policies such as this consultation document.

Earlier this year, the NHS guidance regarding hospital discharge i.e. Discharge to Assess failed to include carers' rights to assessments, which is a legal part of the process alongside care assessments. We have some concerns that carers will continue to be overlooked, unless they are explicitly mentioned in legislation.

Whilst some Integrated Care Systems have good practice around carers e.g. West Yorkshire and Harrogate Partnership and Surrey Heartlands, this is not replicated everywhere. Carers should not have to rely on "good practice" but consistency across the whole system.

Given these legal provisions, policy and practice, it is disappointing that carers were not part of the overall ICS paper on legislation.

**Carers UK therefore recommends:** explicit references to carers in key sections of the legislation to ensure that they are visible, valued and an integral part of the NHS. This would help to deliver the vision for ICS's being fit for purpose over the next 10 years.

## Responses to the key questions:

---

**Question 4: Do you agree that giving ICSs a statutory footing from 2022, alongside other legislative proposals, provides the right foundation for the NHS over the next decade?**

We agree.

In principle, we agree with giving ICS's a statutory footing, but would need to see more detail to understand the precise impact on carers and the people for whom they provide unpaid care. Carers often say that caring would be made much easier if services were more joined up and integrated. We welcome the aspiration to work more closely with local health and care organisations, but more detail is needed about how the ICS would work with the Health and Wellbeing Boards locally and how the population based health planning would incorporate the Joint Strategic Needs Assessment (JSNA).

Most importantly to Carers UK and the carers we represent, is that the legislation establishing ICS must include a reference to carers in key areas, alongside key references to local authorities' duties. This is essential to ensure that carers' rights are included in the right way and that local authorities are correctly discharging their duties in an integrated system.

There are key elements mentioned in the paper that could potentially improve carers' lives such as data sharing. It is a great source of frustration for carers that they often have to repeat information, information goes missing or is delayed or opportunities for early intervention lost because data is not shared. However, with data sharing, it is vital that carers are recognised as a specific part in this journey, including in legal provisions.

There should be provisions requiring consultation, which should explicitly include carers in statute as well as involving patients and people who use social care services. This is critical since Integrated Care Systems (ICS) involve an element of integration with local authorities. Under the Care Act 2014 duties, carers have parity of esteem with people who need care and support.

Carers are part of the local authority duties under Section 1 of the Care Act 2014 relating to wellbeing. We believe that it is essential to include references to wellbeing and health inequalities in this legislation in order to provide greater alignment on shared goals and legal duties with local government.

An example of where this consultation falls short by not including carers is the proposal to "Develop or join a shared care record joining data safely across all health and social care settings, both to improve direct care for individual patients and service users, and to underpin population health and effective system management". By not explicitly including carers, it has ignored their specific rights to carers' assessments. This would also include young carers and their right to an assessment. Given that the shared care record involves local authorities, the lack of inclusion of carers would mean a failure of councils to meet their statutory obligations.

As mentioned above, the NHS document produced during the pandemic on "discharge to assess" failed to include any reference to carers' assessments and carers' rights to choice about providing care. This falls short of the legal requirements in the Care Act 2014 and is an example of why carers must be explicitly included in any work on integration.

The NHS has a duty to co-operate with local authorities in the delivery of its duties and this includes a duty to cooperate in the delivery of carers' rights and it would aid integration and alignment if carers were included in this legislation as we set out. Including carers would align with the aspirations of the Long Term Plan.

With a rising number of people providing unpaid care, the role and support that they provide would not make ICS fit for purpose for the next decade if carers were not explicitly included. In developing the Long Term Plan and providing advice to NHS England, Carers UK estimated at the time that over the next 10 years, over 20 million new carers would be providing care. The pandemic has shifted this dynamic and with 4.5 million becoming carers in one year alone.<sup>4</sup> Although we expect this number to decrease in time, it's clear that the NHS needs to take account of one of the biggest populations which provides support.

---

**Question 5: Do you agree that option 2 offers a model that provides greater incentive for collaboration alongside clarity of accountability across systems, to Parliament and most importantly, to patients?**

Neutral.

Carers UK's main concern is that accountability for carers will not be satisfied unless carers are explicitly mentioned in this legislation. As we set out the NHS Constitution requires the involvement of carers and this commitment by the NHS needs to be repeated in legislation.

Unless carers are clearly included in the legislation, it will not deliver any greater incentives for collaboration which delivers improvements for carers if they are not a visible and included part of the legislation. A lack of reference to carers would be at odds with local government legislation and the Care Act 2014 where carers have parity of esteem with people using services.

We would also like greater clarity about how accountability is reconciled with Health and Wellbeing Boards and other local accountability mechanisms.

---

**Question 6: Do you agree that, other than mandatory participation of NHS bodies and Local Authorities, membership should be sufficiently permissive to allow systems to shape their own governance arrangements to best suit their populations needs?**

Disagree.

We believe that it is essential to include a carer representative, alongside a patient representative and someone who uses social care services in order to fulfil the range of experience that would support governance arrangements for population needs in the area. This needs to be a statutory requirement and would specifically span the range of experience covering both health and social care from the point of view of lived experience.

The governance arrangements must also seek the view of carers as well as patients in making strategic and any commissioning decisions.

---

<sup>4</sup> Carers Week op cit.



**Question 7: Do you agree, subject to appropriate safeguards and where appropriate, that services currently commissioned by NHSE should be either transferred or delegated to ICS bodies?**

Neutral.

We do not feel able to comment on this until we have seen greater detail. Many carers are reliant on services which support the person they care for which are specialised commissioning e.g. services affecting people with MS. With so much disruption to services over the pandemic, including the loss of social care services, many will be rightly anxious about change might affect their services. With the NHS focussed on the pandemic and with a backlog of NHS treatment, the timetable for delivery needs to be very carefully considered.

**Additional comments:**

Carers are patients and citizens, part of “whole populations” and “communities in place”, and they would be included under all these terms. However, in reality, their specific knowledge, views and experience would be overlooked. The carers’ role is one which is completely different because of the provision of unpaid care which warrants explicit acknowledgement in legislation, guidance and policy. As already mentioned, carers’ support is over £108 billion a year in England and during the pandemic, £530 million a day is provided in support by unpaid carers. The NHS relies heavily on care provided by carers and needs to design a system that takes into account their views in providing care, not just the patient receiving care.

**Opportunities of including carers:**

By including carers explicitly in legislation, and by a reference to having regard to their wellbeing would provide the following positive outcomes:

- Greater insight for the system in the planning and delivery of services
- More responsive care
- Earlier prevention and appropriate intervention
- Improved health and wellbeing of carers
- Improvement in the health and wellbeing of the person being cared for

## **What are carers’ views about the lack of inclusion of carers in the consultation?**

---

Carers UK has consulted a number of carer advocates with years of caring experience who have been involved in NHS engagement work for many years. We are disappointed that this consultation was launched in the run up to and over Christmas meaning that we were not able to gather more views from carers.

However, the carers we were able to engage with have fed back that they have been shocked and disappointed to see that the proposals for ICS legislation did not include carers. They felt that this is a missed opportunity to recognise carers, as well as an oversight, particularly in the light of the pandemic when they have provided so much unpaid care. They hoped that this would be rectified when draft legislation is published.

## Contact us

---

For further information about this policy briefing, please contact: Emily Holzhausen OBE, Director of Policy and Public Affairs, Carers UK: [Emily.holzhausen@carersuk.org](mailto:Emily.holzhausen@carersuk.org)

20 Great Dover Street, London, SE1 4LX

Telephone: 020 73784 4999

Email: [info@carersuk.org](mailto:info@carersuk.org)

Web: [www.carersuk.org](http://www.carersuk.org)

Twitter: @CarersUK

© Carers UK, January 2021

Carers UK is a charity registered in England and Wales (246329) and in Scotland (SC039307) and a company limited by guarantee registered in England and Wales (864097). Registered office 20 Great Dover Street, London, SE1 4LX.

---