

A guide for unpaid carers: engaging with Integrated Care Systems

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The purpose of this document

This resource has been developed to support unpaid carers' understanding of Integrated Care Systems (ICSs). It covers:

- What ICSs and ICBs are:
 - How they were formed
 - What they are and the services they provide
 - Where to find your local ICS
- ICS legal responsibilities toward unpaid carers
- How engagement works, and how to get involved
- Potential challenges and solutions when engaging with an ICS
- The challenges you may face
- How to communicate with health and care structures
- Ten reasons why involving carers matters
- Good practice in involving carers
- Key questions you can ask your local ICB/ICS

What is an Integrated Care System (ICS)?

How ICBs and ICSs were formed

Integrated Care Systems (ICSs) were legally established in July 2022 in order to improve outcomes for patients by putting decision-making into the hands of local structures and aiming to increase efficiency in service delivery and decision making. There are 42 in total.

Integrated Care Boards (ICBs) were formed at the same time and are an NHS organisation. They replaced clinical commissioning groups (CCGs). The ICB has board members representing different elements of health and care systems within the ICS. In Surrey Heartlands ICB, the Independent Carers Lead sits on the Board.

There is a single ICB within each ICS and they share the same geography. They are responsible for meeting the health needs of a population, managing the NHS budget, and arranging provision of services within the ICS area on behalf of NHS structures.

What are they? And what kind of services do they provide?

Integrated Care Systems are partnerships made up of NHS organisations, local authority health and care bodies, and also bring in VCSE (voluntary, community and social enterprise) sector organisations and social care providers. The structures that make up the ICS are responsible for the provision of all health and care services in that area – the ICS lays out the infrastructure that connects them together. Each ICS has a VCSE Alliance (or equivalent) to represent the sector, sometimes with board membership (including, in some cases, unpaid carer representation).

Each ICS has a published Integrated Care Strategy that will state their aims for health outcomes, policies they will be implementing, and how they will tackle inequalities in health outcomes for different backgrounds. We would expect an Integrated Care Strategy to have provisions relating to unpaid carers.

The Integrated Care Strategy is developed by the Integrated Care Partnership (ICP). An ICP is a statutory committee made up of key partners, including the ICB and local authorities, and others (including social care providers and the VCSE sector) to work jointly on the strategy.

Where is my ICS?

ICS areas run along boundaries which were created upon their implementation and some cut across local authority boundaries. You can find your ICS using this tool, developed by the [National Care Forum](#).

Where can I find more information about my ICS and the wider system?

A good place to start is the [NHS website](#), which explains what ICSs are and why they have been formed.

In our research, we found that each ICS is different in the way it operates due to the varying demands and priorities that are found in each region. As a result, it may be better to learn about your specific ICS and what their aims are.

By law, ICSs had to publish a **Joint Forward Plan (JFP)** by June 2023, which set out their intentions over a certain number of years; more specifically how they aimed to tackle certain local issues with regards to the population's health. Many included their plans of how they intend to support carers. By using the [National Care Forum tool](#) to find your local ICS, you should also be able to find their JFP, which gives you a better idea of what to expect over the coming years from your ICS. Here's one example: [Nottingham and Nottinghamshire Joint Forward Plan](#).

Another way you can find out more about your local ICS is by reading their **Integrated Care Strategy**. These strategies provide more detail as to how the ICS intends to meet the goals laid out in the JFPs, using further data and evidence gathered both before and after the introduction of ICSs. [Look at this example from Sussex ICS](#);

In some areas, the ICS relies on a local Carers Strategy which underpins their work and delivers on their goals, such as in Somerset which is about to publish a new Carers Strategy.

Some local carers' services have services that are commissioned through an ICS and will be able to inform you about local engagement thanks to their links. ICSs sometimes also run carers' engagement through a local Healthwatch or another community-based organisation or may have established a Carers Partnership Board.

What legal responsibilities do ICSs have to involve carers?

Integrated Care Boards have two key legal responsibilities under the [Health and Care Act 2022](#) to involve carers:

- Involving unpaid carers when decisions are made about changing or developing a service
- To involve unpaid carers when it comes to decision-making around a patient's care that is provided by commissioned services, such as prevention, treatment, diagnosis and care.

ICSs and ICBs must also use the [NHS constitution](#). Every health body has a duty to promote the constitution and it applies to all NHS staff. This means that they need to promote it as a document, and work to make sure the principles are adopted in practice.

The constitution sets out that carers must be involved in a patient's care and in the planning and delivery of services. It also states that carers should be respected in decision-making. This means that ICSs and ICBs have a duty to ensure that carers' opinions are considered in relation to services you or the person you care for receive directly, or when there are planned changes to services provision.

The [Equality Act 2010](#) also sets out some of the legal responsibilities of ICSs, with the Act making clear that all services provided by the public sector must promote equality of opportunity for people, with specific regard towards those who have a protected characteristic, which carers come under due to association with a disabled or elderly person.

Local authorities have a duty to involve carers strategically as well as having key responsibilities towards carers to promote wellbeing. These are very well established in the [Care Act 2014](#).

How does engagement with carers work in my area? How can I get involved?

Depending on your ICS, there can be several different ways of engaging, examples of which include:

- Policies around hospital discharge e.g. Hertfordshire and West Essex.
- Wider engagement to develop a particular policy or process e.g. Carer Passports in Norfolk and Waveney.
- A major consultation looking for responses and experiences to help gather insight such as in Cornwall and Scilly Isles.
- There may also be questionnaires or QR codes in your GP practices or in acute hospitals, which will link to surveys and engagement opportunities.

Most ICS websites have a link to get involved – you can see this example on the home page for [NHS South East London ICS](#). The ICS also includes unpaid carers within their Equality Impact Assessment and Statement, as well as the nine protected characteristics. Carers UK really welcomes this approach. Does your local area include carers in their Equality Impact Assessment, too?

All ICS will have Patient and Carer Experience teams and leads and they often provide toolkits for engagement for staff or a plan around engagement – like [Joined Up Derbyshire](#).

Local carers' organisations may work alongside the local ICS to run engagement programmes or let carers know about services on offer. Northamptonshire carers, alongside Northamptonshire Integrated Care, ran a [set of events](#) in support of Carers Rights Day, providing information for carers as well as means of engaging with services. In other areas, this might be undertaken by a local HealthWatch, with [guidance stating](#) that there will be expectations that Healthwatch along with other place-based partners will be involved in the development and implementation of ICS strategies.

In some areas, the main way to engage is through local authority structures which often have pre-existing relationships with unpaid carers and carer organisations. An example of this is the Nottingham and Nottinghamshire ICS, where engagement is led by Nottinghamshire County Council. Thanks to their previous experience and connections established over many years, they are better able to engage with unpaid carers and carer organisations to make sure carers' voices are considered in the ICSs strategy.

Some ICSs have developed specific structures and roles to bring in carer experience and voice e.g. Carers Partnership Boards. These often exist in local authority areas, but some ICSs are using these to provide carer input and collective decision-making.

Surrey ICS has created the role of an Independent Carers Lead (ICL). This role has a clear job description and is involved in key areas of work such as hospital discharge and carer engagement. Sue Tresman has long-term experience as a carer herself, ensuring that carers are directly represented within the ICS. In [this video](#), Sue discusses the importance of carers being identified by the ICS and other support services, as well as the avenues through which carers can identify themselves with and more easily access ICS services, such as by registering as a carer with your GP and filling out a Carers' Assessment, or registering with local carer organisations.

By identifying yourself as a carer with the ICS it's also more likely you'll be offered opportunities to engage when there are consultations, or insight from carers is needed.

Potential challenges and solutions when engaging with your ICS

Often, engagement with your ICB or ICS can come with challenges, which is understandable due to the scale of ICSs, and the fact that there are many different structures that work within them. Some challenges include:

- They can feel remote as they cover big geographical areas which at times cross over more traditional local authority/county areas, but also often have more local structures in place, depending on the ICS. Some engagement does take place at 'place' level, as this is closer to where people use local services.
- The structures can be difficult to understand, but they often provide diagrams to explain them
- It can be hard to find out who is responsible for what in terms of carers.

Some of the topics they discuss might be very strategic and far removed from how it feels for day-to-day caring. However, strategic decisions also impact on and involve carers. Is your time better spent engaging with your local HealthWatch (on a local authority area) or with your local GP practice patient, carer and public group (it is normally called a PPG – but Carers UK would like them to change this to Patient, Carer and Public Group (PCPG) to recognise carers)? It is worth noting that some ICSs have HealthWatch members on their Boards, so can be an effective way to influence an ICS.





Although there are documents, such as the JFPs and Integrated Care Strategies that you can read to find out more about your local ICS, these can at times be complicated and quite vague. Due to how unique each ICS is and how recently they have come into being, it can be difficult to find information online. This is why we would encourage you to contact local authority services you may already have communicated with or accessed in the past, or local carer organisations who may run consultations on behalf of the ICS.

How to communicate with health and care systems

Carers UK has produced a resource – our [Being Heard](#) self-advocacy guide – that provides advice on how you can find more effective methods to communicate with local health and care systems that sit within the ICS. Here is some of the advice contained within it:

Effective methods to communicate with local health and care systems that sit within the ICS



-  **Ask for clarification if you do not understand what is being said**, especially as much of the language and terms used are not things that we would hear in day-to-day conversation.
-  **Do not be afraid of silence.** It is important to make sure you fully understand what is being said, and silence provides you with a chance to calmly reflect on what is being said, so you can best direct the conversation where it needs to go.
-  **Repeat what you have said if you feel you are not being listened to.** Many of the health and care systems within the ICS have a legal responsibility to your wellbeing as an unpaid carer, make sure that you feel listened to and understood.
-  **Be assertive.** Being direct and standing up for yourself, in a way that still maintains a level of respect towards the people you are dealing with, will help to make sure you are listened to. As noted above, ICB's have specific legal duties with regard to unpaid carers, so should be able to demonstrate how they are involving and listening to carers.

Why does involving carers matter? Here's 10 reasons.

- 1** The value of unpaid care provided by unpaid carers is £154 billion – the same value as the NHS. That means your care matters.
- 2** You outnumber health and social care workers 3:1. The NHS would collapse without your support. It makes sense to see you as part of the team.
- 3** You know the person you care for very well, or even best, and are therefore the real experts in care. That means health and care systems need your insight to provide effective services.
- 4** Carers say, “we can improve people’s outcomes if we are well supported and involved.” This is better for the person needing care, staff and the whole NHS!
- 5** Being an unpaid carer is a social determinant of health. This means that providing a lot of care can impact negatively on your physical and mental health. In turn, carers need to be involved to give their views about how health inequalities impact people in their day-to-day lives.
- 6** Being a carer can also have an impact on your ability to work, your relationships and your finances. Getting it right can mean helping to stay in paid employment, maintaining important relationships, and keeping your finances positive.
- 7** One in three NHS staff is an unpaid carer – this will affect the local workforce as much as it does other working carers in the community. A staggering 600 people a day give up work to care.
- 8** Any one of us can become a carer at any time – 12,000 people become carers every day.
- 9** Supporting carers helps deliver person-centred care and promotes equality and inclusion for everyone.
- 10** There is some evidence that supporting carers can reduce readmissions or emergency admissions to hospital.

What is good practice when supporting carers' engagement?

It is important that engagement takes different forms – there is no ‘one size fits all’ approach. The systems and structures that engage with carers need to be conscious of the different needs and experiences of carers. You may be engaging with your ICS through a number of different ways, such as through your local carers’ organisation or local authority.

Information about the purpose of the engagement should be provided in advance with sufficient time to consider it. This can be especially important for carers who are often time poor. Good engagement also includes a response and follow up. Ideally it should include how the insights will be used and next steps.

For carers, and especially those who are engaged over longer-periods of time or more frequently, it is important to consider whether alternative care has been provided or offered, or if costs such as travel expenses have been covered. Some areas are able to offer payments and additional support, such as alternative care, for certain types of engagement. You can find guidance from the [Social Care Institute for Excellence \(SCIE\)](#) which details how expenses being covered can affect benefit claims.

Key questions you can ask your local ICB/ICS



- ✍ Who is the lead for unpaid carers in the ICB?
- ✍ What is your strategy to support unpaid carers?
- ✍ What measures and plans have you got to reduce unpaid carers’ health inequalities and promote their health, wellbeing and employment?
- ✍ How do you ensure that the NHS Constitution is followed for unpaid carers strategically and in practice?
- ✍ How do you engage unpaid carers in relation to services?
- ✍ How is the ICB delivering on the duty to promote carers in the prevention, diagnosis, care and treatment of the patient?
- ✍ How are you fulfilling your legal duties to unpaid carers?

Contact

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