

## Welcome to the Patients Association's Weekly News

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### Opportunity to join surgeons' patient and public group



The Royal College of Surgeons of England (RCS England) is recruiting patient members to its Patient and Public Group (PPG). First established in April 1999, the PPG provides a direct patient and public voice across the everyday business of the RCS England.

As a brief summary, the RCS England PPG works to:

- Ensure an effective patient voice in RCS England's work
- Influence RCS England's standards and policies
- Proactively raise areas of patient concern to RCS England
- Advise RCS England about the best way to engage with patients
- Act as a critical friend to RCS England.

More information about the Patient and Public Group can be found [here](#). The job advertisement and description can be found on our website [here](#)

The deadline for applications is 11th March.

[Read the job description](#)

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## Influencing the Health and Care Bill



The Health and Care Bill currently in the House of Lords proposes a major shake-up of how health and care services are organised in England, by introducing [Integrated Care Systems](#) (ICSs).

The Continuing Healthcare Alliance, which we're a member of, has been campaigning to ensure ICSs deliver NHS continuing healthcare (CHC) in a way that meets patients' needs. CHC is a package of care arranged and funded by the NHS, and people may be eligible if they have substantial and ongoing care needs related to their health.

Changes the Alliance wants to see include:

- ICSs to report on the quality of services they deliver to both NHS England, the national body who is responsible for the quality of NHS services, and also the care regulator, the Care Quality Commission

- NHS England to have the right powers to take action if an ICS fails to do its job properly.

In the House of Lords, Lady Finlay and Lady Greengross have [proposed several amendments to the bill](#), which were debated, signalling that the way in which a person applies for CHC, and the way in which it is delivered, might become easier.

Laura Cockram, coordinator of the Continuing Healthcare Alliance said: "Alliance members have heard numerous and terrible stories about people not being able to easily access CHC, which can be hugely distressing.

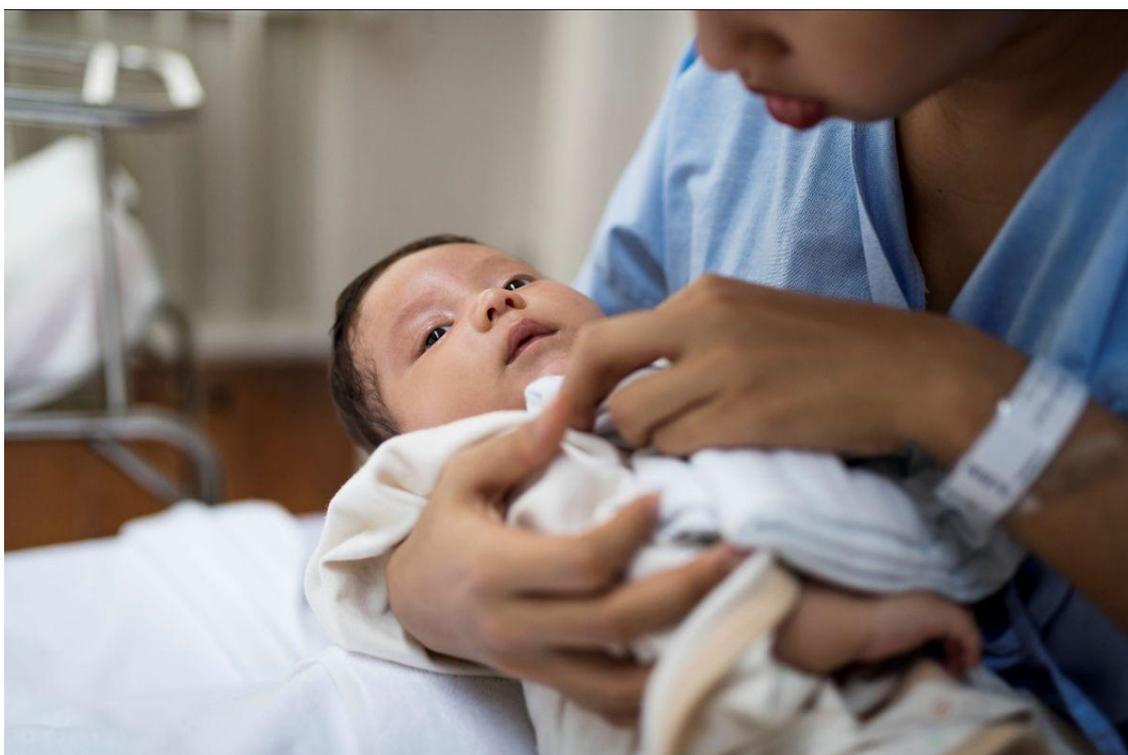
"For too long our supporters have faced numerous issues with CHC, including poor quality decisions and a postcode lottery when it comes to accessing support. This cannot continue.

"We want to see annual reports on how each ICS is performing on CHC and that NHS England has the right powers to take action if an ICS isn't delivering what it should."

[Read the debate](#)

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## Scottish consultation on mother and baby units



The Scottish government is consulting on whether more mother and baby beds are needed to support mums with mental health needs. The consultation is open until 31st May.

Currently, there are two regional mother and baby units in Scotland to support women with mental health conditions.

The two units are unable to take all the women who need care and many health boards admit mums and babies to non-specific units if they require inpatient mental health treatment.

The Perinatal and Infant Mental Health Programme Board, established in April 2019, says Scotland could benefit from an additional four mother and baby unit beds. These additional beds could be created by expanding one or other of the existing units or through creating a new, third unit in the north of Scotland.

People are invited to respond to the consultation. Follow the link in the button below which leads to more information, including an Easy Read version of the consultation paper.

[Respond to the consultation](#)

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## From the helpline Inadequate end of life care



A recent call to our helpline raised a number of issues that can arise when a loved one is dying: issues that can be difficult to deal with when family and friends are dealing with the imminent loss of a loved one.

Tony\* called to get our advice following the death of his mother, Celia\*. She had died at home. Tony believed the care she had received from nurses visiting her was inadequate and had left her in pain.

He told our adviser that a family member living with Celia, who was named as her next of kin, repeatedly prevented nurses from administering pain relief, even refusing them entrance to the home. Tony said this meant his mum died in a lot of pain and the nurses should have used their clinical judgement rather than listen to this relative.

Tony said Celia's carers and the district nurses had been arranged by the hospital, but that neither the carers nor the nurses had reported any of these incidents to the hospital. Now, Tony wanted to take the issue further.

Our adviser explained the complaint process to Tony and told him where to find our information on making a complaint. She also gave him the contact details for the Care Quality Commission, so that he could feedback on his mum's care.

Tony had only contacted us after Celia's death because he had wanted to avoid causing a family dispute while she was dying, but he could have raised the issue at the time if he had wanted.

Healthcare professionals can override a decision made by next of kin if the patient is in a confused state or lacks capacity. There was evidence to suggest Tony's mum was confused. Someone who is down as next of kin does not have any right to make decisions about treatments if the patient lacks capacity, unless they have a power of attorney for health and welfare, which they didn't in this case. This means, the nurses caring for Celia could have provided pain relief if they felt it was in her best interest, even if the next of kin objected.

We have several information sources on our website that may be useful to other people who may be in Tony's situation.

- [How to make a complaint](#)
- [Who is next of kin and what is their role](#)
- [Planning your care if you lose capacity](#)

\*Names changed to protect privacy

To contact our helpline team, call 0800 3457115 between 9.30am and 5pm on weekdays or email [helpline@patients-association.org.uk](mailto:helpline@patients-association.org.uk). See [our website](#) for more ways to get in touch.

And remember, we have a [range of information](#) on our website from our very popular nutrition checklist right through to understanding your medicines.

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## What our team is reading this week

[CVDPREVENT: Next steps for patients](#)

[England Rare Diseases Action Plan 2022](#)

[The state of health and care 2022](#)

[Private healthcare boom adds to fears of two-tier system in UK](#)

[Mental health problems cost UK economy at least £118 billion a year - new research](#)

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### About Us

Our purpose is to ensure that everybody can access and benefit from the health and care they need to live well, by ensuring that services are designed and delivered through equal partnership with patients.

Our strategic focus for 2021-25 is patient partnership in the design and delivery of health and care services.

We are a registered charity raising all our own funds. If you'd like to support our work for all patients and make a difference, please [donate or consider making a regular donation](#). Thank you.

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