

Welcome to the Patients Association's Weekly News

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 Forward

Patient partnership in action



NHS England and NHS Improvement have published guidance for Integrated Care Systems (ICSs) teams, including on how they should work with people and communities, which we played a role in developing.

Earlier this year we ran a focus group that gave NHS E/I practical ideas on how patients and communities should be involved in the work ICSs do. We made several suggestions and are really pleased to see many of them appear in the final guidance. They include:

- Start engagement early
- Provide clear and accessible public information
- Build relationships with excluded groups

- Co-produce and redesign services and tackle system priorities in partnership with people and communities.

As we champion patient partnership at all levels, we're really pleased to have played a role in the development of the guidance and to see that its first principle is:

- Put the voices of people and communities at the centre of decision-making and governance, at every level of the ICS.

[Read the guidance](#)

Our opinion on changes to social care funding



This week, the Government announced long-awaited plans for funding social care.

The announcement is a milestone, after decades of failure to reform the system, so this is welcome progress, although there are many details that are not yet clear, which makes it difficult to say how plans will affect individuals.

We also welcome the announcement of money for the NHS to tackle the waiting lists that have soared during the pandemic.

We've written two articles, which are on our website, to help you understand more about the announcement. One on the [general announcement](#) and one explaining [the cap and floor](#), which will be critical to how much anyone will have to pay before the state will step in and pay for your care.

We will be engaging with the Government about these plans, and working to ensure the new system works as well as possible for everyone who needs social care. We'll keep you up to date through Weekly News and on our website.

[Read more on our website](#)

Demographics: why we ask those questions Our Head of Patient Partnership explains



Several people have been in touch over the summer enquiring why we ask so many questions about who you are, when we invite you to take part in our surveys.

Some of you found the questions intrusive; several people couldn't see the relevance of their sexuality or ethnicity, in terms of their health or social care. So, I thought I'd explain why we ask these demographic questions and how they help us analyse our survey findings.

I'm Sarah Tilsed and I'm the Head of Patient Partnership, a new role for the Patients Association. My job is to get patients and health and care organisations to work in partnership. Partnership working applies to us here at the Patients Association, also.

Hearing from everyone

We want ALL patients' voices to be heard, in order that the health and social care system can better support the needs of the population. For everyone to be heard, that means we need to be representative of the population as a whole and, therefore, we would like the membership of the Patients Association to represent the views of patients from all backgrounds. I want to see our membership broadening to become much more diverse to ensure that we continue to ensure all voices are listened to.

By asking all those demographic questions, we get a better idea of what our membership looks like, as well as who reads Weekly News. By better understanding who you are, we know who isn't a member or reading Weekly News. This means we know who we need to approach to join us and partner with us, in order that we reflect the population and are better at voicing the views of a greater cohort of people, including our current members.

People from different backgrounds have very different health needs, due to stigma, lack of education, genetics, assumptions, culture, and deprivation – to name but a few. Often, we are not aware of the issues faced by many groups as their voices are not heard or even ignored. And we need to change this; we want to hear and learn from people from all walks of life to truly represent a range of experiences.

Different backgrounds

Bringing together people of various backgrounds with different life experiences can generate ideas or perspectives that others may not have considered or been aware of. And at the Patients Association we run focus groups, often on behalf of other organisations and, therefore, is imperative that we capture and value the experiences of all backgrounds. Additionally, why would organisations approach us if we cannot provide a wide cohort that does not represent the UK population?

Organisations working together that represent different backgrounds, can only result in better and more ambitious outcomes that empower more people. And we at the Patients Association want to collaborate with a wider range of organisations to ensure that empowerment, understanding, compassion and inclusiveness is at the heart of everything we do.

If you would like to speak to us about the contents of this article – or anything else – please contact Sarah at Sarah.Tilsed@Patients-Association.org.uk

Invitation to join NICE appeals panel



The National Institute for Health and Care Excellence is looking to appoint several people to join the Technology Appraisal and Highly Specialised Technologies Appeal Panels.

The panel is responsible for hearing appeals against final recommendations in technology appraisals of new drugs and technologies used in the NHS. When an appeal is submitted, an appeal panel comprising five members is drawn from those appointed to hear NICE appeals.

NICE is looking for people who could be a chair. It will consider patients or carers, or people who have experience representing patients or carers, for the role.

For further information on the role and how to apply, details are on the NICE website. Or you can write to Maria Pitan, Project Manager at maria.pitan@nice.org.uk for more information.

The deadline for applications is 5pm on Sunday 26 September.

[Find out more](#)

What you need to know about sepsis



Recently we've had a number calls about sepsis, so we thought we'd remind you about the resources we have on the subject.

Many of you will know sepsis by its other names of blood poisoning or septicaemia. It is a potentially life-threatening but as [our fact sheet points](#) out, if caught early can be treated.

If you would like to know more about sepsis you can visit our website and we also link from our website to the [UK Sepsis Trust](#), whose goal is to end preventable deaths from sepsis and improve outcomes for sepsis survivors.

From the helpline Making a complaint



Kirsty* from Paisley called our helpline on behalf of her husband, Bobby, who she felt had received poor care from their GP practice and also from one of Scotland's large acute hospitals.

She was so unhappy about the care Bobby had received that she also asked the adviser on our free phone helpline how they could get legal advice.

Our adviser sent them the link to Action against Medical Accidents' (AvMA) self-help guide about the complaints process in Scotland, together with information about how to seek legal advice.

* Name changed for privacy.

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

What our team is reading this week

An initial response to the Prime Minister's announcement on health, social care and National Insurance

Health and social care funding to 2024/25

Social care funding gap

COVID: Mandatory jobs for health staff being considered in consultation

Patients transferred from Wales to England were treated 'unjustly' by health board, says ombudsman

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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