

Welcome to the Patients Association Weekly News

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Possible general election - opportunities to get involved



With a general election a near-certainty before the end of the year, there will be opportunities for you to campaign and make your voice heard.

We are currently making plans to ensure that patients are not forgotten in the hurly-burly of the election campaign. People waiting for a GP appointment, those receiving care as an inpatient or hospital outpatient, and everyone receiving some form of health treatment or social care – we represent you, and want to enable you to make sure your health interests are not forgotten during the upcoming election campaign.

In particular, we will be asking politicians to put people's health and wellbeing above partisan point-scoring – and this is where we need you to get involved.

Politicians need to hear from patients directly. It's vital for you to tell them why it's important that they prioritise

patient care over party political bickering.

We are developing a range of ways for you to get involved – if you'd like to be the first to hear about our plans, you can [register your interest here](#).

In the first instance, we're looking for people who are willing to film a short video clip saying why they want patients' needs to be put first in this election. It's easy to do – you can film it on your smartphone, and we'll provide a simple guide showing you how to do it.

We'd also like to hear what else you'd be interested in doing during the campaign – we have some suggestions, and would be delighted to hear further ideas from you. To register your interest, please [complete the short survey here](#).

If you have any questions on the campaign, email policy@patients-association.com

Get involved

Thank you to our focus group participants



We'd like to say a big thank you to everyone who attended our workshops in Leeds and London last week.

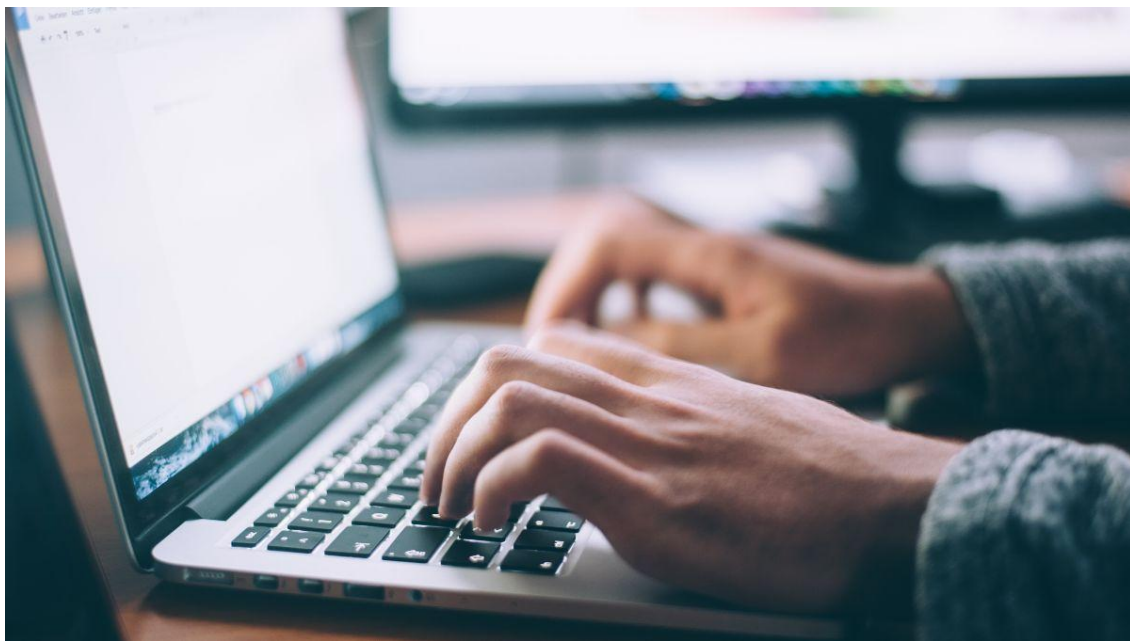
The Leeds workshop was intended for people who had recently switched their medication from biologics to biosimilars, and we were pleased to have a room full of patients and clinicians on the day, including people from Manchester, Chesterfield and across Yorkshire. We discussed a range of topics, from looking at the positive experiences of people who had changed medication to exploring how the switch to new medicines can be improved in future. The group looked at existing patient resources and suggested changes to content and design, making recommendations for how new material can better support shared decision making. Over the autumn, the Patients Association will be using this feedback to develop new resources and will share these drafts with the members who attended the workshop. We'll then discuss the new resources at another workshop with the group, with a view to publishing new material later in the year.

At our focus group in London, a group of patients discussed their recent experiences of private treatment, and shared their thoughts about what makes good quality care, and whether they received accurate and relevant information from their healthcare provider ahead of their procedure or treatment. The group reviewed a draft patient resource developed by the Independent Healthcare Providers Network, the 'Medical Practitioner Assurance Framework', which outlines standards for private hospitals and medical practitioners. Over the next few weeks we will be reviewing people's feedback on private healthcare and this document, and we'll arrange a further workshop with people to explore the key issues that emerged in more detail.

If you want to get involved and have your say, see the opportunities below or [visit our website](#).

Take part

Find it hard to access health information online? Join our workshop



It can sometimes be difficult to find the right health information, advice or guidance online when you or a family member are unwell. With so many different sources available and no concrete way of knowing that any of the web pages online are accurate and trustworthy, looking for advice and guidance on the Internet can feel like a bit of a maze.

We're exploring whether the needs of people aged 60 and over are being met online and would like to invite you to join our focus group in Birmingham on **Monday 30 September from 9.30am to 2pm**. If you've ever found looking for information online overwhelming, or asked how you know information is accurate, up to date and from a trusted source, then you'll want to join our discussion. Your contribution will make a difference in shaping the way information is presented in future. Places are limited so contact anna.shears@patients-association.org.uk to reserve your seat. Reasonable travel expenses will be reimbursed and we're also offering a high street shopping voucher to participants for their time.

Take part

Last few days to apply: NHS England recruiting for patient representatives



NHS England is recruiting four patient representatives for the Clinical Priorities Advisory Group (CPAG). This is the body that makes formal recommendations about how NHS England should decide its priorities for specialised services. The post is being advertised for a length of one year in the first instance, which will then be renewable for a period of up to three years.

The role of patient public members of the CPAG is to:

- Bring independent judgement and experience from a patient perspective
- Act as an ambassador for patient and public participation
- Provide strategic advice and assurance that the views of patients and the public have been sought and considered in the delivery of the commissioning products presented for consideration by CPAG.

The deadline for applications is 15 September 2019. Find out more about the vacancies [here](#).

Read more

From the helpline: poor communication with hospital staff



This week we heard from Angelo*, who got in touch after a poor experience with a member of staff in his local A&E. Angelo's elderly mother was admitted to A&E with a chest infection at around 3pm. After staying with his mother for a few hours while she received treatment, Angelo was told by a staff nurse to get some rest at home and that the nurse would call Angelo to update him on his mother's condition later.

A few hours elapsed and at around 7pm, as Angelo had not received a call, he decided to call to check on his mother's condition. Angelo reported to us that the staff nurse leading on his mother's condition was rude, uninformative and condescending on the phone, and that despite Angelo being his mother's next of kin, getting information about her health was 'like pulling teeth'. Angelo told the staff nurse that he was concerned about his mother's wellbeing and prognosis, but reported to us that the nurse displayed no empathy about his situation. Angelo reported that the nurse hung up on him, and asked our helpline adviser for advice on how to obtain an apology from the staff member.

We advised Angelo that he should contact the Patient Advice and Liaison Service (PALS) at the hospital in the first instance, and we provided their telephone number and email address. We informed Angelo that he would have 12 months from the date of the incident to make this complaint, and we also pointed him in the direction of the [complaints resources](#) on our website. We asked Angelo to get in touch if there was anything we could do for him or his mother in future, and shared the contact details for the health regulator, the Care Quality Commission, if he wished to report his experiences to them.

*Name changed

[Contact our helpline](#)



What our team is reading this week

Cancer survival in the UK improving, but lagging behind other countries – study

Hospitals need way out of 'toxic' NHS mortgages

NHS agrees to fund drug for children with incurable Batten disease after High Court threat

NHS to open specialist FGM support clinics across England

Social media linked to increased risk of mental health problems

About Us

Our vision is that health and social care will be delivered in a way that meets every person's health and social care needs.

Our mission is to give effect to the patient voice, to improve patient experience and support people to engage fully in their own care. Find out more about our values on our [website](#).



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