



Welcome to the Patients Association Weekly News

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'Listening to patients, speaking up for change'



As an independent organisation that seeks to represent and speak up for patients, we pride ourselves on hearing what you have to say. While the summer is a quieter time for most organisations, we're enjoying one of our busiest periods at the Patients Association, with preparation well underway for several events and focus groups in September, and an initial analysis due to begin from the results of our membership survey. The survey is open until the end of August and we've had a fantastic response so far – take part and share your views if you've not already done so [here](#).

None of this work is possible without you, our members and supporters, so please do consider joining us at one of the events outlined below. All of them are free to attend and we're offering to pay travel expenses for those in attendance. For the events where we're working in collaboration with partners and other organisations, we're also offering free high street vouchers for attendees, so do check your diaries and sign up to join us if you can. If you're not able to join us but think you know someone who would be interested, forward this email to them, or email membership@patients-association.com so we can follow up.

Your insight, experiences and views on the health and care system strengthen our work to improve patient care, so we hope to see you at one of the events below. All our latest events and focus groups can be found on the website [here](#).

[Have your say](#)

Leeds, 6 September: being switched to new medicines



Have you been switched from a 'biological' medication to a new 'biosimilar' drug? The Patients Association is hosting a workshop in Leeds on **Friday 6 September** to learn more

about how people who are taking these new medicines can be better supported and to understand how their experiences could be improved. This is an exciting and unique opportunity to shape and co-produce new guidance directly with healthcare professionals, and this work will help patients to be better equipped to make decisions and will allow them greater control over their own health and wellbeing.

Biologic medications are usually liquids given via a drip or injection pen. They are often used to treat long-term conditions including Crohn's disease, ulcerative colitis, psoriasis and rheumatoid arthritis, but patients with diabetes and people with some forms of cancer may also be taking biologics. Biosimilar drugs work in the same way and are newer versions of the original biological medications. If you've recently been switched onto a new biosimilar medicine and live in or near Leeds, we'd love for you to join our workshop on 6 September. The session will run from 10am to 2pm, and your feedback will help to shape our work. Places are limited so please contact anna.shears@patients-association.com to reserve your place. Lunch and light refreshments will be provided, and we're also offering high street vouchers to participants for giving their time.

[Join us in Leeds](#)

Oxford, Friday 6 September: patients with knee problems sought to help create new guidance



We've partnered with Oxford University to produce new patient information about the recommended treatment options for meniscal problems of the knee, and we'd like to hear from you if you currently have knee problems and are considering surgery, are waiting for a procedure or have recently had an operation. We want to recruit a diverse group of patients to pilot a new approach to creating guidance that will inform and empower patients.

Structured clinical guidance is central to the delivery of care in the NHS, and it is crucial that this guidance is developed with meaningful involvement from patients and the latest, best quality evidence.

As well as working with Oxford University, the project is also supported by the NHS Getting It Right First Time programme and the British Association for Surgery of the Knee. Participants will need to be able to attend a meeting in Oxford on Friday 6 September from 10.30am to 3pm. Travel expenses will be reimbursed. If you are interested in taking part please contact Heather Eardley on heather.eardley@patients-association.com.

[Join us in Oxford](#)

London, Thursday 5 September: private healthcare patients



Have you opted for private treatment over NHS care in the past? Has your treatment been as an inpatient in a private hospital - funded by yourself, medical insurance, or an employment benefits package? We're looking for people to join a focus group with in London on Thursday 5 September from 5.30 to 8.30pm to help develop a new resource for patients receiving private treatment.

If you have recently had private inpatient care or know someone who has, please get in touch by emailing Celia Turnbull at celia.turnbull@patients-association.com. Whether your experience was very good or one that could have been improved, we would like to hear from you. Light refreshments will be available on the day and reasonable travel expenses will be reimbursed. We're also offering a high street voucher to participants for giving their time. For more information, email Celia or call 020 8423 9111.

Join us in London

Manchester, 3 or 6 September: patient experience and our future policy work



If you recently completed our survey about your (or someone close to you) experience in hospital as a patient, many thanks. We'll soon be opening a more in-depth survey which will go into more detail, but we'd also like to hear from people in person and would like to [invite you to attend](#) one of our focus groups in Manchester next month. This event will also help us define the scope of our future policy work, so it's a great opportunity to shape what we'll be working on in future.

If you're free on either Tuesday 3 September or Friday 6 September, [join us](#) to play a part in shaping our future campaigning work, and to help us improve things for patients. We'll pay reasonable travel expenses and send more details about the focus groups closer to the time. [Complete the survey here](#) to register your interest. If you have any questions about this piece of work or would like more information, email policy@patients-association.com.

Join us in Manchester

'Urgent investment needed for GP premises'



The Patients Association this week joined senior GP leaders in writing to Prime Minister Boris Johnson urging him to prioritise investment for primary care premises in the next spending review.

The letter, signed by Rachel Power, Chief Executive of the Patients Association along with Dr Richard Vautrey, chair of the British Medical Association's GP Committee, Professor Helen Stokes-Lampard, chair of the Royal College of General Practitioners, Dr Peter Swinyard, national chairman of the Family Doctor Association, and Dr Minesh Patel, chair of the National Association of Primary Care, warned that the poor state of GP premises was putting patient safety at risk.

The letter stated that GP premises have been underfunded over a number of years and that the situation is compounded by an 'overall lack of infrastructure investment, policies of converting health capital budgets into revenue, and delays by NHS England in providing updated Premises Cost Directions'.

The Patients Association's [report into GP premises](#) in December 2018 found that patients highlighted several issues including poor confidentiality at reception desks, issues with access for disabled people and dated waiting rooms. You can read the full letter to the Prime Minister [here](#).

[Read more](#)

From the helpline: poor communication with GP reception staff



Earlier this week we heard from Roy*, who got in touch to find out more about the complaints process. Roy has been registered at his GP practice for more than four years and wished to report an 'unfriendly atmosphere' whenever he communicates with receptionist staff. Roy reported that he felt rushed with his enquiries to reception, and that he was being blamed for not knowing information. Roy also reported being spoken to with sarcasm, and a lack of empathy from staff. Roy said that on occasion he overheard reception staff arguing with a patient on the phone and that after the call had been cut off, the member of staff said aloud to her colleague that "you just can't win with them!". This upset Roy, who has an anxiety disorder, and who already finds it challenging to contact his practice to request repeat prescriptions.

Roy wanted to complain and to change practice, and asked our helpline for advice with these matters.

We advised Roy that in the first instance he may wish to contact the Practice Manager to raise his concerns, and that he could do so in writing by email or by letter. We also checked online and found that Roy could request repeat prescriptions online directly via his practice website, and suggested that he might consider doing this to minimise interaction with reception staff.

We also provided contact details for NHS England in the event Roy wanted to formally complain. We affirmed that, while the NHS is under pressure with patients across the country experiencing waits for appointments, under no circumstance should a receptionist speak in a rude manner or be disrespectful in any way to any patient. Finally, we directed Roy to the [complaints resources](#) on our website and recommended that he report his experience with the [Care Quality Commission](#). We gave Roy information about the other practices in his local area should he wish to register with them, and advice on how to change practice. We also provided contact details for his local out of hours service, should he need medical attention.

If you need health or care advice, call 0208 423 8999 between 9.30 and 5pm on weekdays, or email helpline@patients-association.com. You can also visit our website to find out more

about our helpline, and visit our advice and information leaflets [here](#).
*Name has been changed

[Contact our helpline](#)

What our team is reading this week

[Asthma deaths in England and Wales 'highest in a decade'](#)

[Women in labour given virtual reality to ease pain of childbirth](#)

[NHS to set up national artificial intelligence lab](#)

[Drug overdose eclipses suicide as biggest killer of middle-aged men, ONS figures reveal](#)

[Dame Barbara Windsor urges Johnson to 'sort out' dementia care](#)

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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