

Welcome to the Patients Association's Weekly News

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Patient Voices Matter is a community



Sarah Tilsed, Head of Patient Partnership, is also a member of our lived experience advisory panel, now called Patient Voices Matter.

In a new blog on our website, Sarah reflects on what a privilege it is to work with the group and what the members' concerns are. While members are all from very different backgrounds, they share many of the same concerns about their healthcare.

You can learn more about those concerns in Sarah's blog.

[Read Sarah's blog](#)

Have your medicines been stopped in the last year?



Researchers from the School of Pharmacy at the University of East Anglia are recruiting patients for a research project into stopping medicines (or deprescribing).

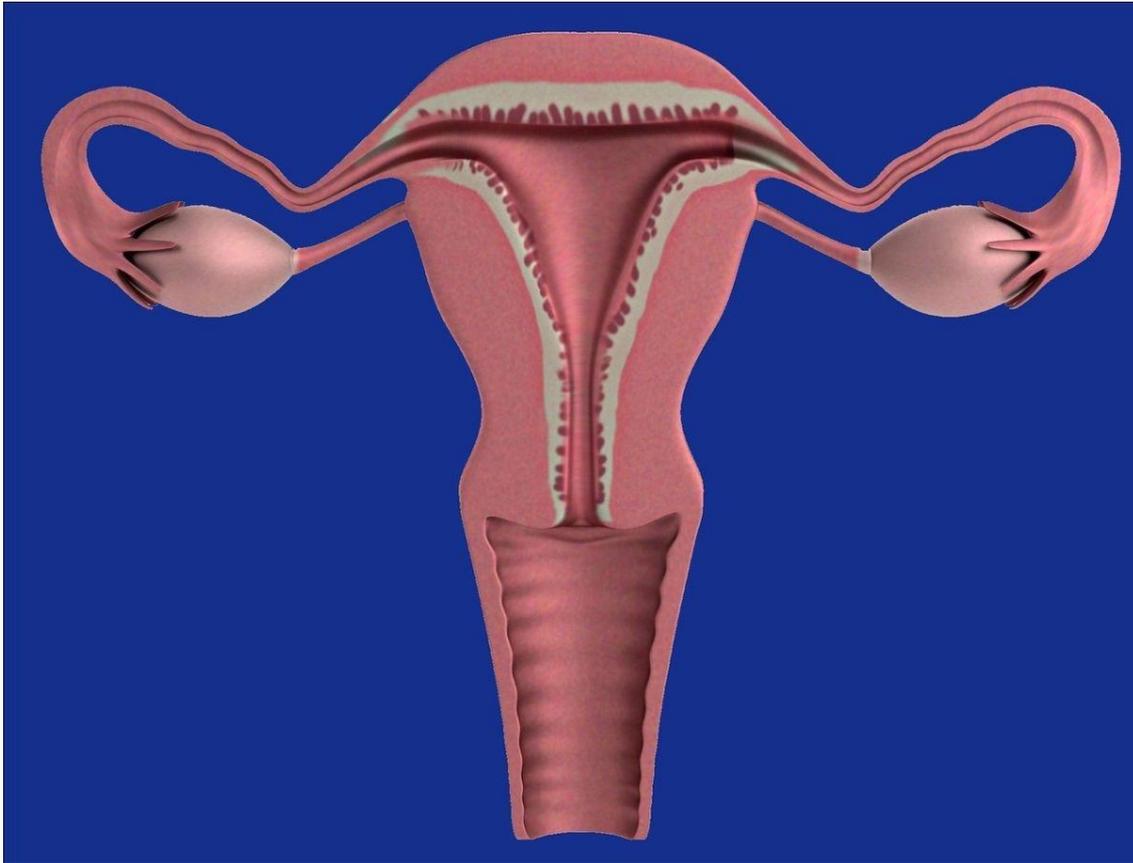
If you are aged 18 or over, living in England and have had a prescription medicine stopped in the last year, then you could qualify to take part. Please use this link below to express an interest in taking part in the study.

If selected, the researchers will ask you to review a questionnaire they have developed that asks patients about their experience of having a medicine stopped by their doctor. The questionnaire will help doctors and researchers to spot things that could be done differently when medicines are stopped to improve the patient experience.

You will be offered a £50 voucher for participating

[Register your interest](#)

How has the pandemic affected your gynaecological care?



The Royal College of Obstetricians and Gynaecologists (RCOG) is undertaking a project to look at the impact of the pandemic on gynaecology waiting lists.

The work will look at the size and scale of waiting lists and at the impact this is having on those who are waiting longer for diagnosis and treatment, and on the wider health service.

The College would like to hear from people whose gynaecology care has been affected by the pandemic. This might mean you have struggled to get an appointment with or a referral from your GP to see a gynaecologist, waited longer for tests or a scan to receive a diagnosis of a gynaecological condition, or waited longer for treatment or surgery.

The College wants to understand your experiences of having a suspected or diagnosed gynaecological condition that isn't cancer, as 'benign' gynaecological conditions are managed differently in the NHS. This could be for conditions such as endometriosis or fibroids, heavy periods, incontinence or recurrent urinary infections – anything you'd be referred to a gynaecologist for.

You can access the survey through the link below and the College would love if you could share it with any friends, family or networks you have to help it get as clear a picture as possible about the true impact of the pandemic on gynaecology.

[Take the survey](#)

Event: Shared decision making - a reality for everyone?



There's still time to book your place on our shared decision making event next Thursday. We've speakers from the National Institute for Health and Care Excellence (NICE), NHS England & NHS Improvement, the Winton Centre for Risk & Evidence Communication, as well as patient/carers.

You can register to join the event below.

[Register for Shared decision making: a reality for everyone?](#)

Health advice for refugees



The Refugee Council works with refugees and people seeking asylum in the UK.

An important element of its work centres on people's health needs. This month it has launched a series of resources aimed at reducing the inequality many refugees face when accessing healthcare in the UK.

The Refugee Council has identified cases of refugees wrongly refused access to primary care, denied translation services, and refused care in hospitals or asked to pay upfront for assistance, even though they have a right to healthcare. The Council has evidence of pregnant women choosing not to access antenatal care because they fear they will be charged or even detained and deported if they use health services.

To counteract these perceptions and improve access, the Council has developed resources for refugees and health professionals such as a card with useful vocabulary and phrases with translations in five languages, that can be used to speed up and clarify communication about health problems with the doctor, nurse, or reception staff.

Click the link below to access the communication card and the other resources.

[Refugee Council healthcare resources](#)

Medical device public consultation ending soon



The Medicines and Healthcare products Regulatory Agency (MHRA) is conducting a consultation that will shape the future regulation of medical devices in the UK and would like your opinions.

From contact lenses and plasters, to thermometers and walking sticks, for many of us, medical devices are an essential part of our everyday lives. Chapter 17 of the consultation was written with the general public in mind. If you have limited time to spare, you may prefer to complete this chapter only.

But don't delay, the consultation **closes on 25 November at 11:55pm.**

World Antibiotic Awareness Week



Yesterday was the start of World Antibiotic Awareness Week, the annual global campaign to focus attention on the rising problem of antimicrobial resistance (AMR).

AMR occurs when microbes, such as bacteria, no longer respond to medicines, making common infections harder to treat and increasing the risk of disease spread, severe illness and death. Misuse and overuse of antimicrobials in humans, animals and plants are the main drivers in the development of drug-resistant infections. Poor diagnostic and prescribing practices and patients not following their treatment also contribute, as do lack of clean water and sanitation in health care facilities, farms and community settings and inadequate infection prevention and control.

As an organisation, we have explored best practices in managing antibiotic prescribing. We have been following how well local clinical commissioning groups (CCGs) are implementing government policy and guidance on antimicrobial stewardship, and how much progress they had made in recent years.

Click below to read our latest report.

[Read our report](#)

From the helpline

Missing underwear



Malcolm* called our free helpline to talk to one of trained advisers about incontinence supplies.

Malcolm, who lives in Greater London, had originally been provided with incontinence pants by the teaching hospital where he had been treated, but the hospital had transferred that responsibility to his GP. The GP made a referral to the local bladder and bowel team about six weeks ago for a specific type of incontinence underwear.

Malcolm has received no supplies despite ringing and leaving messages on the team's answering machine since the referral six weeks ago. Our adviser suggested Malcolm call his local clinical commissioning group and gave him the telephone number. But Malcolm called the helpline again to say he'd had to leave a message with the CCG, and was now really worried about what he was going to do without his special underwear.

Because Malcolm's need was so urgent, our helpline adviser emailed the CCG who responded quickly asking us to complain to the bladder and bowel team, which our adviser did. The bladder and bowel team replied saying there was a six to ten week wait for new patients to be assessed.

Our adviser pointed out that Malcolm had already been waiting six weeks and had not received any information from the team at all. He said that if Malcolm had at least been told about the waiting time he'd have understood the priority his referral had been given. Our adviser asked the bladder and bowel team to at least send Malcolm information about its procedures, which the team agreed to do.

And we're pleased to report that the day after our adviser had spoken to the bladder and bowel team, someone from the team got in touch with Malcolm and asked him to come for his assessment on 3rd December.

*Name 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. See [our website](#) for more ways to get in touch.

What our team is reading this week

[NHS Wales: A&E and ambulance performance worst ever - again](#)

[A&E overcrowding in UK 'killing thousands a year', say doctors](#)

[COVID: Proportion of adults with depression has almost doubled since before pandemic, says Sajid Javid](#)

[Scotland becomes first UK nation to give vaccine booster to half of over-50s](#)

[COVID-19: Tougher restrictions for NI 'may be needed before Christmas'](#)

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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