



Welcome to the Patients Association's Weekly News

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Join our panel and help improve wound care



We're looking for patients with experience of managing their own wounds who would like to use their personal experience to help improve wound care.

We're putting together a panel of patients to take part in three online events this June. Together, we'll develop messages aimed at decision-makers in healthcare about how improved wound care can be delivered.

If you would like to take part in these small groups please get in touch with our project manager, Daniel, at daniel.phelps@patients-association.org.uk to express your interest and to find out more.

Panel members will receive a £80 Amazon gift voucher per event to thank them for their time.

Updated PPG kit now available

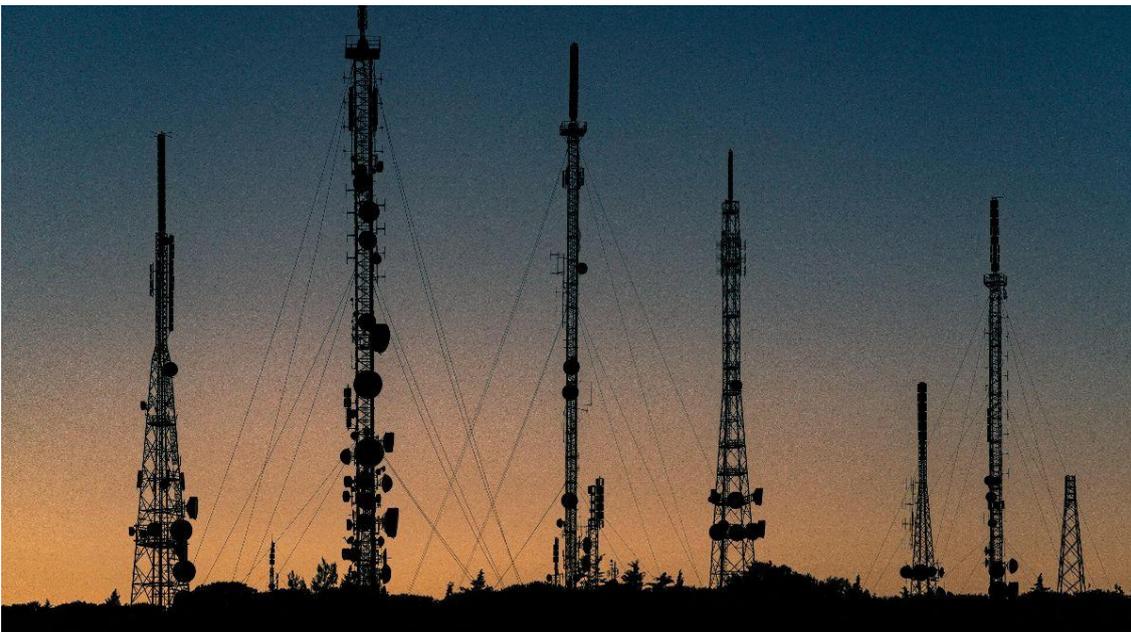


We have updated our Guide to setting up and developing your own Patient Participation Group, based on feedback from PPG members and GP practices.

Every English GP practice is required to have a PPG and to make reasonable efforts for this to be representative of the practice population. A PPG is a group of patients, carers and GP practice staff who meet to discuss practice issues and patient experience to help improve the service.

Our guide is designed to provide you with information and templates to help you set up, establish and maintain a well-run, effective PPG. You'll find the pack [here](#).

NHS England guidance on communications



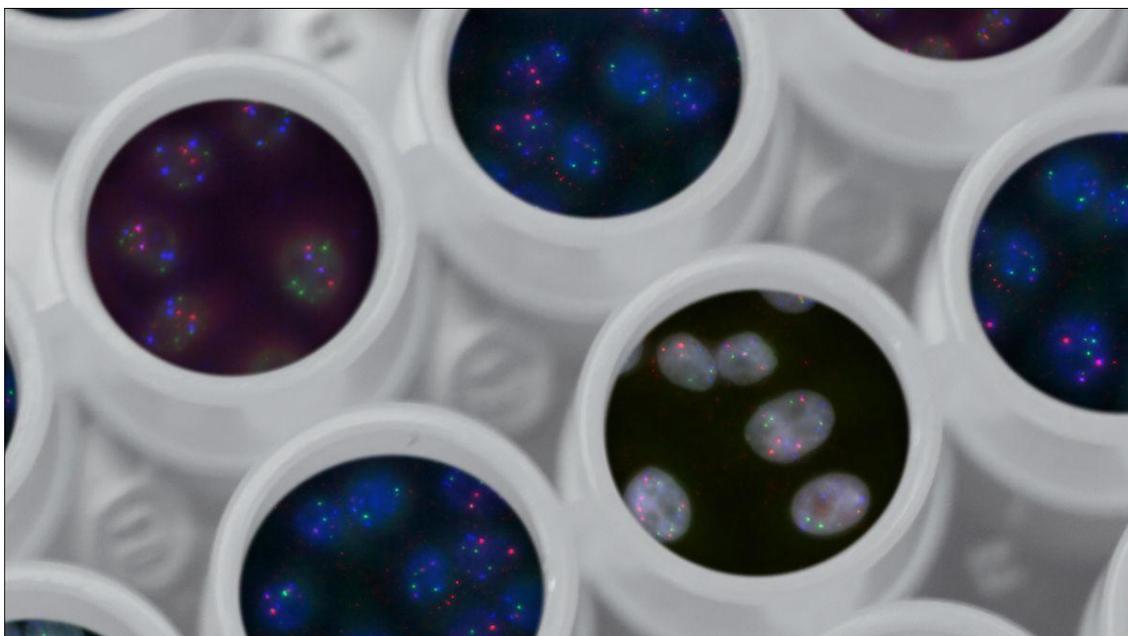
It is important to maintain frequent and honest contact with patients who are waiting for care. In support of this, we've worked with NHS England and NHS Improvement to produce guidance for healthcare providers on how to deliver personalised, patient-centred communications.

The guidance provides a set of core communication principles to help improve the experience of patients who are waiting for care.

Other organisations that helped NHS England develop this guidance were Healthwatch, National Voices, The Richmond Group of Charities and Versus Arthritis.

The guidance and principles are available here. [Coronavirus » Good communications with patients waiting for care \(england.nhs.uk\)](#)

Opportunity to influence rare disease policy



The Department of Health and Social Care is seeking patient representatives to join the UK Rare Diseases Framework Board and the UK Rare Diseases Delivery Group for England.

The Board will provide oversight and coordination of rare disease policy across the four nations and the Delivery Group will develop and monitor implementation of the England Action Plan.

Applications are open for both oversight boards until 2 June 2021 and details of the opportunities and how to apply are here.

UK Rare Diseases Framework Board - [application pack](#), [application form](#)

UK Rare Diseases Delivery Group for England – [application pack](#), [application form](#)

Carbon footprint of surgical procedures – survey



Did you know that healthcare is responsible for around 5% of the UK's carbon footprint?

Whether you're a healthcare professional involved in peri-operative care, a member of the public, a patient or carer with experience of having surgery, spare 15 minutes to complete a survey about how to make operations greener.

Operations are among the most resource-intensive healthcare interventions; each operating theatre creates around 2 tonnes of waste per year, and a single operation can generate a carbon footprint equivalent to driving over 2,000 miles.

The link to the survey, which is being run by the Greener Operations Priority Setting Partnership, is [here](#).

Feedback sought on our Nutrition Checklist



We'd like feedback from people who have either used our Nutrition Checklist, or have been concerned about being underweight, or losing weight unintentionally, to see how and in what way the checklist has been useful. Your feedback will help us consider whether there are ways to refresh or improve it.

If you would like to give feedback via a virtual focus group or a short survey, please let us know by contacting our project manager, Gloria, via her email gloria.clark@patients-association.org.uk.

GMC updates guidance for patients on raising concerns



The General Medical Council has developed a new online guide to support patients who wish to raise a concern about a doctor.

It's a step-by-step tool that explains what concerns the GMC can help with, how to raise a concern, and who else can help if a patient's concern is more appropriately dealt with by another organisation.

You can access the tool here <https://www.gmc-uk.org/concerns/supporting-you-with-your-concern>.

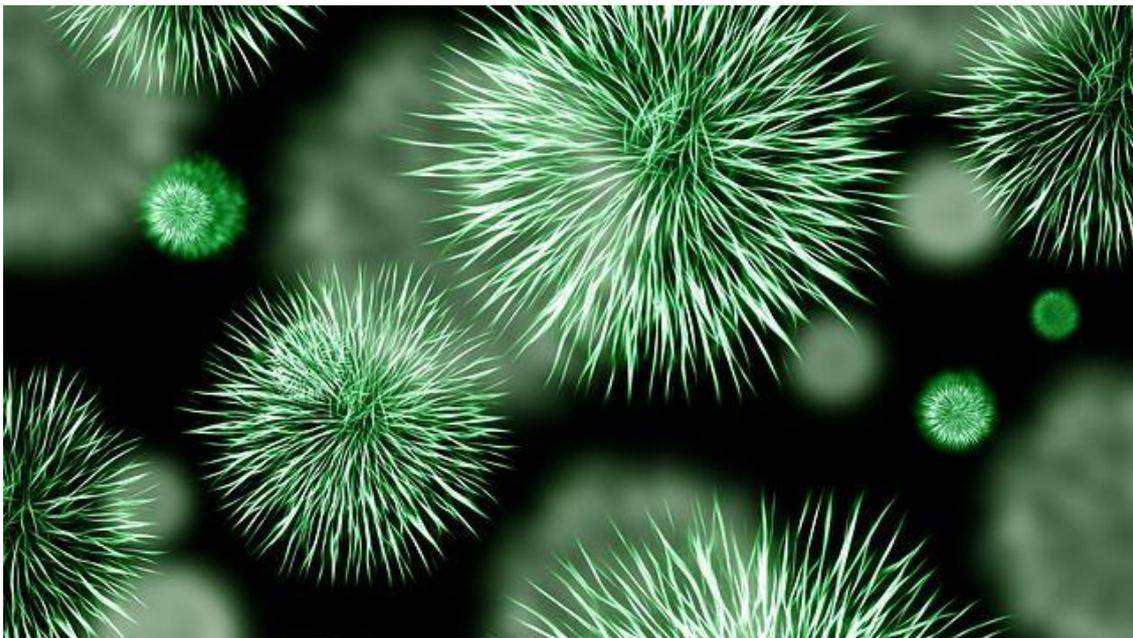
Still open for your opinions



Our shared decision-making survey is an important part of our ongoing work to empower and enable patients to have a greater say in decisions about their care and treatment. It asks you a few questions about the role you play in your own health, and how you feel about this.

[Take the survey](#)

Seeking participants for a virtual patient advisory group on tackling antibiotic resistance



Antibiotics play a crucial role in treating infections. Antimicrobial resistance (or antibiotic resistance) occurs when a microorganism (bacteria, virus, fungi, parasite) no longer responds to an antibiotic. These 'superbugs' make infections harder to treat, which can increase the risk of the infection/disease spreading, severe illness and death.

The rising rates of antibiotic resistant 'superbugs' is of great concern for everyone, especially in patients whose care has been affected by infection. Patients can play a key role in safeguarding against antibiotic resistance by actively engaging and participating in their care and to be stewards of appropriate use of antibiotics.

Pfizer will be hosting a Patient Advisory Group to learn more about the experiences and insights of patients who have had to deal with severe infections due to antibiotic resistance, with the goal of elevating the patient voice in the fight against 'superbugs' and the rising challenge of antibiotic resistance. Pfizer has engaged the Patients Association to help convene and co-chair the Patient Advisory Group.

The Patient Advisory Group will help Pfizer to:

- Understand patient perspectives regarding antibiotic resistance and identify meaningful initiatives to involve patients in safeguarding the appropriate use of antibiotics
- Empower patients to see themselves as owners of their medical history and partners in determining the best treatment plans for them

- Raise awareness about antibiotic resistance among patients and communities
- Shape its future work to address the rising rates of antibiotic resistance

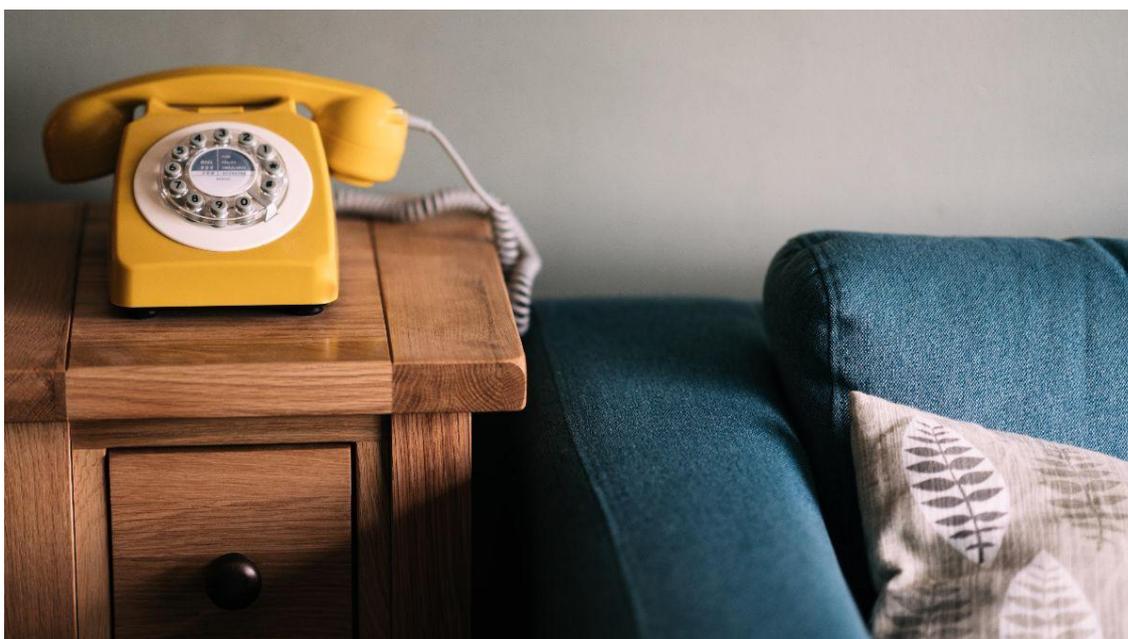
Pfizer is seeking patients who meet the following criteria:

- Adult UK residents only
- Experience with bacterial infections* that have required recurrent and/or prolonged courses of intravenous antibiotics in a hospital setting only (e.g., hospital medical or surgical ward, ambulatory care, clinic environments).

**bacterial infections, such as (but not limited to) urine infection, chest infections, pneumonia, skin infections, etc.*

The Patient Advisory Group will be convened in early June for a 3 hour virtual meeting. Pfizer will reimburse participants £81 per hour. If you meet these criteria and would like to be considered for the Patient Advisory Group, please contact Sharrie McIntosh, sharrie.mcintosh@patients-association.org.uk.

From the helpline



Carl* was told by his GP practice to call at 8am to get an appointment. When he called he was offered an appointment that day but couldn't accept it because he works full time and wasn't able to take it up at such short notice. The surgery doesn't offer advance bookings.

Carl called our free helpline to get advice on what to do as he'd found a lump and cannot see properly from his left eye. He told the adviser that he'd been trying for two months to make an appointment.

Our adviser suggested Carl speak to his employer about taking time off for a GP's appointment, explaining the GP's booking practice. Our adviser also explained how out-of-hour services work. And we also suggested Carl speaks to the Practice Manager regarding booking appointments in advance.

* 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

[Call for 'surgery hubs' amid 'colossal backlog' of cancelled operations during pandemic](#)

[Hancock faces calls to explain Covid test failings at care homes](#)

[How rising patient numbers threaten to overwhelm GPs](#)

[NI hospital waiting lists 'undermining' free health service](#)

[Interactive map: check how much pressure your GP practice is under](#)

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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The Patients Association
PO BOX 935
London, England HA1 3YJ
United Kingdom