

Welcome to the Patients Association's Weekly News



Patient involvement has been too easily swept aside



In an opinion piece in the influential Health Service Journal, our Chief Executive Rachel Power has argued that the NHS found it too easy to discard patient involvement when it made radical changes to its services in response to coronavirus.

In the article, Rachel argues that the discussion about what the NHS should look like after the emergency has passed should not draw the wrong lessons from recent events.

The emergency changes to what services are available to patients, and how they can access them, were almost certainly necessary in the circumstances. But the NHS must not develop a taste for making bold change without patient input. Instead, any 'reset' of the NHS must bake a meaningful patient partnership into new systems and processes, and fix the problems the NHS has had with this in the past.

Readers with an HSJ login can click through to the article. If you don't have a login, you can register for free.

[Read the article](#)

Changes to lockdown, but it's not over



Pictures in the news make it look like lockdown is over across the UK, but it isn't.

Rules have changed and diverged between the four home nations, but we should still be staying at home unless we have a clear reason for venturing out.

We've full details of the current regulations for each country [on our website](#), but here's a handy overview of what you everyone in the UK can and can't do at the moment.

Stay at home unless you are:

- Shopping for basic necessities, for example food and medicine
- Seeking medical need, or providing care or to help a vulnerable person
- Travelling to and from work, if you cannot work from home, or
- Undertaking exercise or other outdoors activity, which may now be done in small groups in certain circumstances.

You should still be keeping two metres away from people you don't live with whenever possible, and practising good hand hygiene. Patients classed as 'vulnerable' are advised to follow this guidance particularly stringently, while '[clinically extremely vulnerable](#)' patients should still 'shield' themselves.

If you've not already done so, please tell us about your experiences during the coronavirus pandemic by taking our online survey.

[Take the survey](#)

Webinars: patient generated data



Listening to the patient's gut

RSM  LIVE

Explore the future of personalised medicine made possible by listening to a patient's gut bacteria

**Wednesday 10 June 2020
12:00pm to 1:00 pm BST
Royal Society of Medicine**

[Click here for more details ►](#)

The Royal Society of Medicine is running a series of webinars throughout June and July on The Power of Patient Generated Data, which explores digital health technologies used to collect data directly from patients - particularly those aimed at preventing or shortening hospital episodes and for use by patients in their homes and in the community.

The webinars are suitable for patients, healthcare professionals and trainees alike. The RSM has made available ten free tickets per webinar to readers of the Patients Association's Weekly News.

On Wednesday 10th June at 12:00-13:00 a webinar titled 'Listening to the patient's gut' by Dr James Kinross, Consultant Colorectal Surgeon at St Mary's Hospital, will appeal to patients interested in understanding the importance of gut bacteria to various aspects of one's health and our individual response to treatment. Further details can be found here: <https://rsm.ac/36r6SOW>. The first ten readers to email digitalhealth@rsm.ac.uk with the subject TEN55 will each receive a free ticket for the webinar.

[Read more](#)

Recognising carers during Carers Week 8-14 June



This Carers Week we're coming together to help Make Caring Visible.

carersweek.org

We support carers all year round but next week, during Carers Week 2020, we're going to make a little more noise on our social media channels, and we hope you'll also show your support.

Carers Week is the largest annual carers awareness campaign in the UK, led by Carers UK. This year, it is supported by Age UK, Carers Trust, the Motor Neurone Disease Association, Oxfam GB, and Rethink Mental Illness.

The theme this year is make caring visible. Early in the pandemic, Carers UK surveyed members and found many were close to burnout, with 70% having no choice but to take on more care responsibility during the crisis.

You can very easily show your support for carers by adding your name to Carers UK wall of support.

[Add your voice](#)

Review of data confirms higher COVID-19 toll among BAME populations



Public Health England's review has found that outcomes of COVID-19 are worse among people from the black, Asian and minority ethnic communities (BAME) than in white ethnic groups.

People of Bangladeshi origin were at most risk, with around twice the risk of death of white people. People of Chinese, Indian, Pakistani, other Asian, Caribbean and other black ethnicity had between 10% and 50% higher risk of death.

Diagnosis of COVID-19 among BAME people was also more common. The highest diagnosis rates of COVID-19 were in black ethnic groups, and the lowest were in people of white ethnic groups.

[Read the report](#)

Premature discharge



Thank you to everyone who responded to our survey on unsafe, premature discharge from hospital.

We have now published the report, which shows how serious the consequences can be of discharging someone from hospital who is not ready to go home. Particular themes emerge around pressures on beds, and how premature discharge of people from mental health settings can quickly lead them to harm.

The findings are particularly timely, in light of the large scale discharge of many patients from hospital, to free up capacity in the early stages of the coronavirus pandemic. Our report shows that even in normal times, badly managed discharges can expose patients to risk.

[Read the report](#)

From the helpline



Dorothy* rang us, concerned that tablets she had recently been dispensed, although supposedly the same type as she regularly takes, could be counterfeit.

Dorothy's GP has prescribed her diazepam, popularly known as Valium, for a long time. But she called our free helpline because she was concerned that her most recent tablets did not taste the same and it seemed to have a different effect on her. She was worried that this might mean they were fake and wanted our advice on what she could do about this.

We advised her to talk to the pharmacist who had dispensed them and contact the manufacturers of the medication to tell them of her concerns. Every medicine prescribed in the UK comes with a patient information leaflet that has the details of the medicine's manufacturer and how to contact them.

We also advised Dorothy that if the medication were counterfeit, she could report it to the Medicines and Healthcare products Regulatory Agency (MHRA), which regulates drugs in the UK. We told her how to do this via the MHRA website.

*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.com. See our website for more ways to get in touch.

What our team is reading this week

Government censored BAME COVID risk review

ECT depression therapy should be suspended, study suggests

Doctor quits NHS over Dominic Cummings' refusal to resign

The NHS is not returning to normal any time soon

Dementia deaths up during pandemic

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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