



## Welcome to the Patients Association's Weekly News



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### Improving transparency in health data sharing



Recently, we invited you to take part in a survey looking into why patients opted out of sharing their GP health data.

The researchers behind that survey at the University of Manchester would like to explore further the views of patients who opted out and those who chose to

permit sharing of their data. They want to understand how people might be given the control they want over their data, and to help them to feel more confident in sharing their data.

If you have strong views on data sharing and would like to contribute to this work, then you could be part of our focus groups, which we are running on behalf of the University of Manchester.

The focus groups will take place over Zoom and will be two hours long on the following dates:

**24th November** 10:00 – 12:00

**29th November** 18:00 – 20:00

If you would like to join one of the focus groups, please let us know by filling in this [simple form](#) by 11th November.

If you've already completed the survey, you can still join the focus groups, but if you have been interviewed as part of the University's work, then the researchers already have your views, thank you.

We are offering a voucher to the value of £80 as a one-off token of appreciation for your time.

If you have any further questions about the focus groups, please contact [Suzanne.meenan@patients-association.org.uk](mailto:Suzanne.meenan@patients-association.org.uk)

And if you haven't completed the survey, it's still open. You can complete it whether or not you opted out of sharing your data. There are two surveys: a [Patient Survey](#) and a [GP Survey](#).

If you don't remember if you did or didn't opt out and you have the NHS App, start at the home screen. Select 'Your Health' at the bottom. Select 'Choose if data from your health records is shared for research and planning'. Select 'Make your Choice'. At the bottom of the screen is a 'Start' button. Click 'Start' and it will tell you what your status is and allow you to change it if you wish.

**Register your interest in the focus groups**

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**Booking opens for third patient partnership week  
event**



Places are now available on the, Partnering with patients and communities – what's happening in ICSs, webinar, part of our patient partnership week.

Our speakers are:

- Helen Hassell, carer and member of the NHS Assembly, and Sophie Randall, Director at the Patient Information Forum (PIF), will talk about the work the Patients Association, PIF, and Nottingham and Nottinghamshire Integrated Care System (ICS) are doing to improve patients' experience of treatment for muscle and bone problems.
- Dr Debbie Freake, GP and member of the National Centre for Rural Health and Care.
- Heather Aylward, Public Engagement Manager, and Lauren Oldershaw, Senior Communications Officer, from NHS Hertfordshire and West Essex Integrated Care Board, who will talk about our joint project to support patient participation groups in 155 of the Board's GP practices.

This webinar is on Wednesday 30th November, 12.30pm – 2:00pm.

And we're delighted to announce that Dr Sal Peterson, a GP in Perth, and GP clinical lead for Scotland's [Realistic Medicine](#), will join the Monday webinar, Shared decision making – examples of great practice. She'll be talking about a project in Tayside to design shared decision making resources for patients.

Follow the link in the button below to read more about the events in patient partnership week and to book your place on the webinars. All the events will be held on Zoom and are free.

Read the week's programme and book your place

## How should we remember COVID-19?



Photo credit: Kelly Foster

People across the UK have the opportunity to say how they think the COVID-19 pandemic should be remembered.

Possible ways could include the adoption of a Remembrance Sunday-style symbol, dedicated memorials and reflective spaces.

The UK Commission on Covid Commemoration is running the consultation. It was established to secure a broad consensus from across the UK on how we, as a nation, commemorate the COVID-19 pandemic, and mark this period at a national and community level.

The Commission is also seeking suggestions on suitable dates to hold a national day of remembrance and views on how future generations should be educated about the pandemic.



The consultation is open until 5th December and available in various formats. The Commission will report its recommendations to the Prime Minister by the end of March 2023.

To learn more and respond to the consultation, follow the link in the button below.

[Take part in the consultation](#)

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## New patient story on our website



Matt Eagles

Member Matt Eagles was only 7 when he was diagnosed with Parkinson's disease.

Now, as an adult, he uses his experiences of healthcare to support other patients to improve their relationship with healthcare professionals.

Follow the link in the button below to read his blog.

[Read Matt's blog](#)

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## Sky News looking for patients affected by delays in care



Broadcaster Sky News wants to interview patients whose care has been delayed as part of its coverage of the NHS crisis.

Each month, the NHS publishes statistics about its performance. Over the last few months, the statistics have shown rising numbers of patients on waiting lists, delays in A&E departments, and more and more patients waiting for diagnostic tests.

The Sky News health team would like show what the impact the delays have on individuals by filming patients talking about their experiences.

If you'd like to find out more and be featured in the coverage, follow the link in the button below to email the health producer, Mark. Filming would take place between 7th - 9th November.

[Contact Sky News](#)

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## Invitation to patient safety talk



Readers of Weekly News are invited to an interactive event exploring what makes us safe in hospital, part of the Festival of Social Sciences taking place in Leicester next month.

Research into what patients understand about patient safety, and how their knowledge affects their involvement in their hospital care, will be presented. The meeting will then be open for discussions. The Head of Patient Safety at University Hospitals of Leicester NHS Trust will also take part.

The event will be held twice, on the afternoon of 8th November and the evening of 9th November at the Attenborough Arts Centre, Leicester.

To book your free place, follow the link in the button below.

[Book your place](#)

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## From the helpline Data shared without permission



Teodor\* called our helpline to find out what he could do about a GP who shared information about him without his permission.

Teodor had consulted the GP privately.

The first thing our adviser suggested is that Teodor find out if the GP was a member of the Independent Doctors Federation (IDF). He could do that online if he knew the doctor's full name.

Knowing if the GP is a member of the IDF is important because IDF members agree to abide by the Independent Sector Complaints Adjudication Service (ISCAS) three-step complaints process. ISCAS provides independent adjudication on complaints that arise in the private health sector. But it can only consider complaints once the first two steps of the local complaints procedure have been concluded without resolution.

The first step of the process is for Teodor to make a complaint to the doctor. Our adviser directed Teodor to the IDF and ISCAS website, where he could read more information about the complaints process. Earlier this year we worked with ISCAS to update [its guide](#) on making complaints about private or independent healthcare.

Our adviser also suggested Teodor read our information about medical records and how to make a complaint, both of which are on our website.



\* 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](mailto:helpline@patients-association.org.uk). See [our website](#) for more ways to get in touch.

And remember, we have a [range of information](#) on our website from our very popular nutrition checklist right through to understanding your medicines.

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## What our team is reading this week

**Further raids on the NHS budget will plunge it into its deepest crisis in decades and is now a direct threat to patient safety**

**Health of nation study calls on millions to sign up**

**Reducing waiting times in Wales**

**Public health underspend starves England's most deprived areas of vital services**

**Good mental health linked to a reduction in productivity losses to the economy**

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## 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](#). If you use Amazon, you can help raise funds by nominating us to receive funds via AmazonSmile - for more information on how to do this visit our [website](#). Thank you.



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