

## Welcome to the Patients Association's Weekly News

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### A message from Rachel Power

Dear members and supporters,

We are living through strange and difficult times, and will be for weeks and months to come. First and foremost, I hope you are coping with the lockdown and that you and your loved ones remain well. We know that this crisis is having a huge impact on our everyday life and lockdown measures can feel very lonely, but the most important thing we can do right now is to stay home and follow the Government's advice.

Remember our helpline is open for you if you need support, so please ring between 9:30 and 5 on weekdays, on **0800 3457115**, or email [helpline@patients-association.org.uk](mailto:helpline@patients-association.org.uk). We have also developed a range of advice articles to help support people during this difficult time.

Coronavirus seems certain to dominate the world of health and care throughout this time and as a result there will inevitably be less news about other health and care issues to share with you. However our work goes on, as we continue to support callers to our helpline, and some of our project work can also be continued despite the current restrictions. We are excited to be launching a project around shared decision making – there are more details below.

As a charity, we are also looking hard not just at what the current emergency might mean for us and how we might need to adapt our services to support those most in need, in line with our charitable objectives, but also at how we can continue to secure income to ensure that our work can continue. I want to thank those of you who have donations to our work in the past. If you are not currently a donor, [please consider supporting our work](#) if you are able to do so, whether regularly or through a one-off gift.

Lastly I want to thank you for some of the very kind words we have received and for your ongoing support, and send best wishes from the staff and trustees of the Patients Association that you stay safe and well during this period.

With all my very best,



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## Coronavirus advice and information



All our resources on coronavirus are now in one place on our website. They are:

- Coronavirus - advice, guidance and rules
- Coronavirus - what can you do?
- Your medicines during the coronavirus outbreak
- Self-care during self-isolation and social distancing
- Coronavirus – don't be caught out by fake news
- Patients Association work during coronavirus
- NHS complaints and PHSO during the coronavirus outbreak
- Highly vulnerable patients – what to do if you have not been contacted?

[Coronavirus resources](#)

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## ‘Highly vulnerable’ patients



We are still being contacted by patients who believe they should be in the ‘highly vulnerable’ group who are being contacted by the NHS, and advised to ‘shield’ themselves for 12 weeks.

[This article](#) outlines what you should do if you are in this situation. In short, your GP can arrange for you to be added to the list – we have heard of some GPs incorrectly advising patients that this is not possible, but instructions from NHS England and guidance from the Royal College of General Practitioners make clear that they can do this.

If your GP does not judge that you fall into the ‘highly’ vulnerable category, you can still voluntarily ‘shield’ yourself, although the official guidance is that it is sufficient for you to follow social distancing rules.

[Read more](#)

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## Shared decision-making



Shared decision making is when health professionals and patients arrive at decisions about care and treatment options together. This ensures that each individual gets the treatment that works best for them.

However, this can be easier said than done. Not all patients feel able to assert their preferences in conversations with clinicians, and not all professionals are receptive to it.

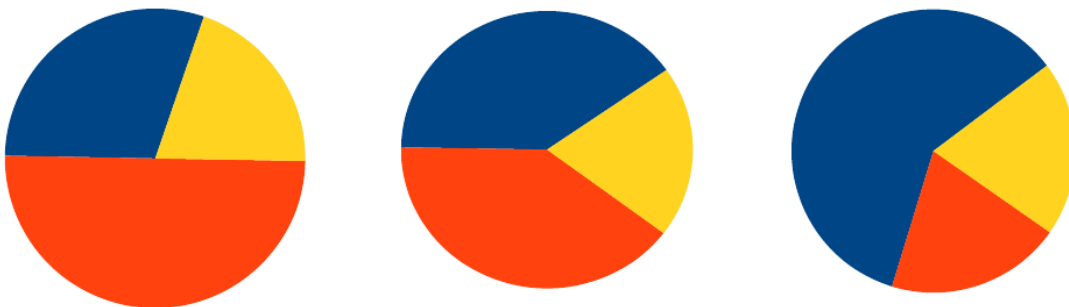
We will therefore be developing resources to support and empower patients in successful shared decision-making, and enable healthcare professionals to effectively support patients in the process.

There will be opportunities for you to get involved through a number of focus groups (possibly virtual) which we will update you on - keep an eye on future editions of Weekly News for this.

We hope to make these resources as robust as possible, so we will be piloting them to really understand the difference they make for patients. Following this, we hope to be able to roll them out nationally to support patients all over the country.

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## Health inequalities



The Patients Association hosted a roundtable discussion this Tuesday (7 April) on health inequalities. Due to the ongoing coronavirus outbreak, the discussion was held online by video conference. We were pleased to welcome a diverse range of organisations to take part.

The publication of Sir Michael Marmot's report on health inequalities, following up his report of a decade before, painted a shocking picture of reverses in life expectancy and deepening divisions along economic, geographic and ethnic lines. There is also emerging evidence that these inequalities are also evident in the impact that coronavirus is having on different groups.

The Patients Association intends to maintain a focus on health inequalities, and work constructively with other organisations to achieve meaningful improvements.

## [Our response to the Marmot report](#)

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## Get involved: Health Data Research UK

Health Data Research UK is the national institute for health data science, and is currently recruiting lay members to be part of two new advisory boards that will provide the patient and public perspective to its decision-making.

You can apply for either or both roles – read through the information on the Health Data Research UK website to see which you might be suited for.

- [Two Lay Members – Improving and Uniting the Data Delivery Group](#) (focusing on areas of work which support their aims to unite (i.e. bring together) and improve the health data (through various tools and methods))
- [Two Lay Members – Using the Data Delivery Group](#) (focusing more on the science and research that uses health data to ultimately make advances in healthcare).

Applications close on **Wednesday 15<sup>th</sup> April 2020**. To apply or ask any questions, email [enquiries@hdruk.ac.uk](mailto:enquiries@hdruk.ac.uk).

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# Calls to our helpline are now free of charge!

We've launched our new 0800 number, making it free for people to speak to our expert advisers:

**0800 345 7115**

## What our team is reading this week

[UK set for at least three more weeks of lockdown](#)

[Covid-19 hospital admissions 'flattening'](#)

[Are minorities being hit hardest by coronavirus?](#)

[Covid-19 antibody tests not ready until May at earliest](#)

[Cancer charities say coronavirus shortfall will set back research](#)

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## 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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