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| |  |  | | --- | --- | | |  | | --- | | https://gallery.mailchimp.com/9dd6577cf3f36af3c2f6682ed/images/570163e5-2b4c-498d-9798-6a605474ae76.jpg | |  |  |  |  | | --- | --- | --- | | |  |  | | --- | --- | | |  | | --- | | **Welcome to the Patients Association's Weekly News** | | |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | | |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | | |  |  |  |  |  |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | | |  |  |  |  |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | | |  |  |  |  | | --- | --- | --- | --- | | |  |  |  | | --- | --- | --- | | |  |  | | --- | --- | | [Share](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=7b86295cf8&e=b00dac9705) | [Share](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=f66fc9b7ff&e=b00dac9705) | | |  |  |  |  |  | | --- | --- | --- | --- | | |  |  |  | | --- | --- | --- | | |  |  | | --- | --- | | [Tweet](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=ddde87bcb5&e=b00dac9705) | [Tweet](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=7935b9c84a&e=b00dac9705) | | |  |  |  |  |  | | --- | --- | --- | --- | | |  |  |  | | --- | --- | --- | | |  |  | | --- | --- | | [Forward](http://us5.forward-to-friend.com/forward?u=9dd6577cf3f36af3c2f6682ed&id=cb2cb5394d&e=b00dac9705) | [Forward](http://us5.forward-to-friend.com/forward?u=9dd6577cf3f36af3c2f6682ed&id=cb2cb5394d&e=b00dac9705) | | | | | | |  |  |  | | --- | --- | | |  | | --- | | **It’s time to change how we think about patient experience** | | |
| |  |  | | --- | --- | | |  | | --- | | https://mcusercontent.com/9dd6577cf3f36af3c2f6682ed/images/cf1d6d7b-5103-4da2-950f-99309b55989f.jpg | |  |  |  | | --- | --- | | |  | | --- | | Research conducted for our patient experience programme finds that traditional methods of capturing patient experience miss much and do not drive change in healthcare systems.   Although a breakthrough when the notion of collecting patient experiences was introduced 30 years ago, current approaches do not actually appear to improve patients' experience of care.   Our new report Being a Patient, launched this week, suggests that a more patient-focused understanding of patient experience can best be achieved by framing health and care issues from patients’ perspectives, rather than focusing on an analysis of the services provided to patients.   Our conclusion is provisional and we hope to work with partners to investigate how patient experience can be captured to produce results that are capable of improving services.     The report also details how bleak being a patient can be.  When patients were asked to describe their experience in three words, there were no clearly positive words in the top ten most popular choices, with the top three being 'frustrating', 'frightened', and 'vulnerable'. When we asked about how their illness had affected their lives, patients’ top three answers were tiredness, discomfort and worry.  Our patient experience programme is an important stream of work and one that we’ll be working on until at least the end of this year. | |  |  |  | | --- | --- | | |  | | --- | | [**Read more**](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=4413b0de1d&e=b00dac9705) | |  |  |  | | --- | --- | | |  | | --- | |  | |  |  |  | | --- | --- | | |  | | --- | | **First Do No Harm – the Cumberlege Report** | |  |  |  | | --- | --- | | |  | | --- | | https://mcusercontent.com/9dd6577cf3f36af3c2f6682ed/images/56faae11-7d86-4696-9884-264fd7b9c0fb.jpg | |  |  |  | | --- | --- | | |  | | --- | | In the week we launched Being a Patient, we were appalled to read the contents of the Independent Medicines and Medical Devices Safety Review, First Do No Harm, which Baroness Cumberlege chaired.   The level of suffering, the failure by the NHS to act, and the evidence of so many, mainly women patients, was deeply shocking. In response, our Chief Executive, Rachel Power, issued a statement arguing that fixing what is clearly a systemic problem for the NHS will require every clinician, professional and manager in the NHS to face up to uncomfortable truths and examine their own behaviour honestly. | |  |  |  | | --- | --- | | |  | | --- | | [**Read the statement**](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=70fb62a71f&e=b00dac9705) | |  |  |  | | --- | --- | | |  | | --- | |  | |  |  |  | | --- | --- | | |  | | --- | | **Personalise dying, says the National Audit of Care at the End of Life** | |  |  |  | | --- | --- | | |  | | --- | | https://mcusercontent.com/9dd6577cf3f36af3c2f6682ed/images/cc421946-9852-499c-a50d-1e987c87beef.jpg | |  |  |  | | --- | --- | | |  | | --- | | The second report of the National Audit for Care at the End of Life, to which the Patients Association was a contributor, was published this week. It includes recommendations on how care for the dying may be improved, including:   * Ensuring that care is personalised to the needs and preferences of the person who is dying * Ensuring that all care settings are capable of providing appropriate care to the person who is dying, and support to people who are experiencing bereavement * Ensuring access to specialist palliative care in hospitals * Create an action panel to ensure that the review’s findings are implemented throughout the system * Ensure systems for anticipatory prescribing, for when people move from hospital to their home or a care home to die, are aligned across the whole system.   The Patients Association was a key partner in this work. In addition to providing the patient perspective, we assisted with the survey – people completing the survey were given our helpline number and invited to call if they needed help in filling it in. | |  |  |  | | --- | --- | | |  | | --- | | [**Read more**](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=7cac90eaf9&e=b00dac9705) | |  |  |  | | --- | --- | | |  | | --- | |  | |  |  |  | | --- | --- | | |  | | --- | | **#BecauseWeAllCare campaign launched** | |  |  |  | | --- | --- | | |  | | --- | | https://mcusercontent.com/9dd6577cf3f36af3c2f6682ed/images/e2a38172-5f8b-46f1-af5d-6bda5d8f3fd5.jpeg | |  |  |  | | --- | --- | | |  | | --- | | The Care Quality Commission and Healthwatch England launched the #BecauseWeAllCare campaign this week to encourage people to provide feedback on care they receive.  The Patients Association is among the many organisations supporting this campaign.   #BecauseWeAllCare is based on research that shows since the start of the COVID-19 pandemic close to two thirds of people are more willing to support NHS and social care services by actively providing feedback on their care. People also said they are more grateful for the healthcare services they receive – particularly GP and hospital services – since the outbreak. This sentiment was strongest among young people (aged 18-34).   Our President, Sir Robert Francis QC, who also chairs Healthwatch England, said: “As the UK looks to the future after COVID-19, it's never been more important for people to share their experiences of care. Services won’t bounce back overnight. There'll be problems to tackle but also opportunities to make care better.”  If you'd like to provide feedback to the CQC,  the Patients Association is a partner in its Tell Us About Your Care programme, so we can collect your feedback and pass it to the CQC. Simple call our helpline on 0800 345 7115, or email [helpline@patients-association.org.uk](mailto:helpline@patients-association.org.uk). | |  |  |  | | --- | --- | | |  | | --- | | [**Read more**](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=e1d4ac1614&e=b00dac9705) | |  |  |  | | --- | --- | | |  | | --- | |  | |  |  |  | | --- | --- | | |  | | --- | | **Join the People's Commission - have your say on how post lockdown UK society will look** | |  |  |  | | --- | --- | | |  | | --- | | https://mcusercontent.com/9dd6577cf3f36af3c2f6682ed/images/cd655240-cebd-480d-9592-ec03a7935283.jpg | |  |  |  | | --- | --- | | |  | | --- | | The think tank Demos has opened a debate about Britain's future, and wants members of the Patients Association to contribute.   As Demos observes, life has changed for ever. Not just the way we work, support each other, travel, shop and spend, but also the roles people play in society. The past few months have been challenging for the UK on every level. Demos is establishing   The People's Commission on Life after COVID and is inviting you to have your say on how our country should change after this crisis. | |  |  |  | | --- | --- | | |  | | --- | | [**Take the survey**](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=77c1efb493&e=b00dac9705) | |  |  |  | | --- | --- | | |  | | --- | |  | |  |  |  | | --- | --- | | |  | | --- | | **RSM offers free tickets to summer webinar series – next week, using patient data** | |  |  |  | | --- | --- | | |  | | --- | | https://mcusercontent.com/9dd6577cf3f36af3c2f6682ed/images/55c3bb38-1749-47b2-a69d-05ef87bb141f.jpg | |  |  |  | | --- | --- | | |  | | --- | | Next Wednesday 22 July 2020, the Royal Society of Medicine hosts the next in its series of webinars, [Brainwear: Lessons learned from using patient-recorded data](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=9af683d1c5&e=b00dac9705). Dr Matthew Williams and Dr Seema Dadhania from the Computational Oncology group at Imperial College London will explore the lessons learned from using patient-recorded data from brainwear.   The first ten readers to email [digitalhealth@rsm.ac.uk](mailto:digitalhealth@rsm.ac.uk) with the subject TEN61 will each receive a free ticket for the webinar. | |  |  |  | | --- | --- | | |  | | --- | | [**Claim your free ticket**](mailto:digitalhealth@rsm.ac.uk?subject=TEN61) | |  |  |  | | --- | --- | | |  | | --- | |  | |  |  |  | | --- | --- | | |  | | --- | | **More lockdown adjustments** | |  |  |  | | --- | --- | | |  | | --- | | https://mcusercontent.com/9dd6577cf3f36af3c2f6682ed/images/795e05b7-36d2-411a-be15-8b036b9a5dcb.jpg | |  |  |  | | --- | --- | | |  | | --- | | Changes and tweaks to lockdown rules have continued across the UK. In Scotland these have been substantial, with a major relaxation of the [rules around when different households can meet](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=713b2724d6&e=b00dac9705). Additionally, [face masks](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=a03d462d95&e=b00dac9705) are now compulsory in shops in Scotland, and on public transport in Northern Ireland.  Don’t forget, you still have time to tell us about your coronavirus experiences. | |  |  |  | | --- | --- | | |  | | --- | | [**Take the survey**](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=fc6b88e745&e=b00dac9705) | |  |  |  | | --- | --- | | |  | | --- | |  | |  |  |  | | --- | --- | | |  | | --- | | **From the helpline** | | |
| |  |  | | --- | --- | | |  | | --- | | https://mcusercontent.com/9dd6577cf3f36af3c2f6682ed/images/2697a8bb-7cde-4f81-b45e-2822e1d0cc52.jpg | |  |  |  | | --- | --- | | |  | | --- | | Maria\* called from Colchester seeking advice about the poor care she is receiving from her GP.  She told our helpline adviser that she felt her GP doesn't listen to her, is unwilling to refer her to a consultant, and that although she has asked her practice on several occasions not to be seen by a particular GP, the request has not been acknowledged and she still has appointments with them.  Additionally, Maria has not received her repeat medication for the past month, nor has she had a reply to a letter of complaint she sent the practice manager some months ago.   Our adviser ran through process of complaining about one’s GP and advised her to read our online, downloadable complaints leaflet. The adviser also suggested she contact the CQC to tell the regulator about her experience of care with her practice.    We also suggested Maria consider finding a new GP practice and signposted her to the NHS.uk website and explained how she may search for a new practice.  \*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](mailto:helpline@patients-association.com). See our website for more ways to get in touch. | |  |  |  | | --- | --- | | |  | | --- | |  | |  |  |  |  | | --- | --- | --- | | |  |  | | --- | --- | | |  | | --- | | **What our team is reading this week** | | |  |  |  | | --- | --- | | |  | | --- | | [**We must let patients choose how to access primary care**](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=b08b69ec28&e=b00dac9705) | |  |  |  | | --- | --- | | |  | | --- | | [**The inside story of how UK's 'chaotic' testing regime 'broke all the rules'**](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=1feb9f8557&e=b00dac9705) | |  |  |  | | --- | --- | | |  | | --- | | [**Dementia patients 'deteriorating' without family visits**](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=4091df90a8&e=b00dac9705) | |  |  |  | | --- | --- | | |  | | --- | | [**Asymptomatic testing extended to thousands of workers in England**](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=4d7fb394e5&e=b00dac9705) | |  |  |  | | --- | --- | | |  | | --- | | [**UK has opted out of EU coronavirus vaccine programme, sources say**](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=e9ea853b50&e=b00dac9705) | | |
| |  |  | | --- | --- | | |  | | --- | |  | |  |  |  | | --- | --- | | |  | | --- | | **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](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=db01955ea2&e=b00dac9705). | |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | | |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | | |  |  |  |  |  |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | | |  |  |  |  |  |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | | |  |  |  |  | | --- | --- | --- | --- | | |  |  |  | | --- | --- | --- | | |  |  | | --- | --- | | [Share](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=cf2ed660de&e=b00dac9705) | [Share](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=a29479a5b6&e=b00dac9705) | | |  |  |  |  |  | | --- | --- | --- | --- | | |  |  |  | | --- | --- | --- | | |  |  | | --- | --- | | [Tweet](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=b5a7c6275e&e=b00dac9705) | [Tweet](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=7110aee346&e=b00dac9705) | | |  |  |  |  |  | | --- | --- | --- | --- | | |  |  |  | | --- | --- | --- | | |  |  | | --- | --- | | [Forward](http://us5.forward-to-friend.com/forward?u=9dd6577cf3f36af3c2f6682ed&id=cb2cb5394d&e=b00dac9705) | [Forward](http://us5.forward-to-friend.com/forward?u=9dd6577cf3f36af3c2f6682ed&id=cb2cb5394d&e=b00dac9705) | | | | | | |  |  |  | | --- | --- | | |  | | --- | | *Copyright © 2020 The Patients Association, All rights reserved.* You are receiving this email because you subscribed to the Patients Association Weekly News. If you no longer wish to receive it and wish to unsubscribe, please follow the links contained in this email.  **Our mailing address is:**  The Patients Association  PO BOX 935  London, England HA1 3YJ  United Kingdom  [Add us to your address book](https://patients-association.us5.list-manage.com/vcard?u=9dd6577cf3f36af3c2f6682ed&id=6e2a14ef7a)  Our full privacy policy [is available on our website](https://patients-association.us5.list-manage.com/track/click?u=9dd6577cf3f36af3c2f6682ed&id=90fe951c47&e=b00dac9705).  Want to change how you receive these emails? You can [update your preferences](https://patients-association.us5.list-manage.com/profile?u=9dd6577cf3f36af3c2f6682ed&id=6e2a14ef7a&e=b00dac9705) or [unsubscribe from this list](https://patients-association.us5.list-manage.com/unsubscribe?u=9dd6577cf3f36af3c2f6682ed&id=6e2a14ef7a&e=b00dac9705&c=cb2cb5394d) | |  |  |  | | --- | --- | | |  | | --- | | *The Patients Association is a registered charity in England and Wales (1006733).  A company limited by guarantee.  Registered company in England and Wales (02620761) Registered address:  P Block, Northwick Park Hospital, The North West Hospitals NHS Trust, Watford Road, Harrow, Middlesex, HA1 3YJ* | | |