

Welcome to the Patients Association's Weekly News

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NHS Digital delays plan to share patient data with third parties



The Government announced this week that NHS Digital would postpone its proposed collection of GP patient data until 1st September, to allow more time for the public to understand the process and opt out, if wanted.

We, along with Healthwatch England, National Voices, and the Richmond Group of Charities welcomed this pause in NHS Digital's plans and issued the following statement:

"We welcome today's move by the Government to extend the deadline for the GP data opt-out and allow NHS Digital and colleagues across the NHS, particularly those in primary care, to have the time and space to engage properly with patients and the wider public on these plans.

"In [previous engagement work](#) the public have told us that they are in favour of the NHS using their data for medical research if they understand how this information will be used and can opt out if they so wish.

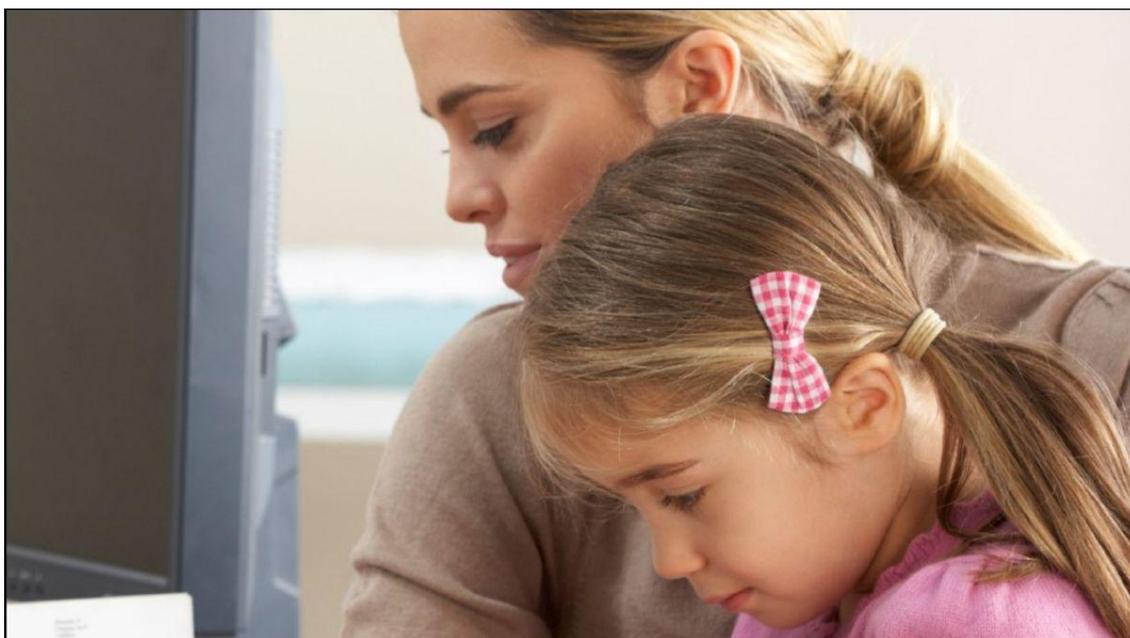
However, ongoing public support for this depends on complete transparency and clear communication from the NHS when things change.

“Over the next few months we need to see a proper nationwide campaign on this, reaching out to people so they can make an informed choice about how their own individual medical records are used to support research. This is a complex issue, and so we will all be working with the NHS to help build awareness and understanding.”

We, along with the other charities, will work with NHS Digital to ensure its proposals have patients' full confidence. Meanwhile, if you'd like to more information about how the NHS uses patient data, click the button below.

[Read more](#)

Our submission to the Government on its proposed women's health strategy



We welcome the Government's plan to develop a Women's Health Strategy but in our submission to the consultation we explain why we feel a broader approach needs to be taken, one that includes factors that shape women's health needs, and their experience of health and care.

We believe that the action taken because of this strategy will have the greatest impact if they are also aligned with action on wider issues that affect women's health in complex ways. Disadvantages experienced by women interact with, and are often compounded by, disadvantages arising from other reasons, including but not limited to housing, welfare benefits, and work policy, all of which are almost the entirety of domestic government policy.

Among the specific points we make are that women's voices are often not heard in their care, and that they often have to put caring responsibilities ahead of their own health. Other issues we raise are: improving the quality and accessibility of information and education on women's health, ensuring the health and care system

understands and is responsive to women's health and care needs across the life course; maximising women's health in the workplace; ensuring research, evidence and data support improvements in women's health; and understanding and responding to the impacts of COVID-19 on women's health.

Our response to the Government draws heavily on what we were told by women who responded to our survey: thank you to everyone who took part in the survey we ran earlier this year.

[Read more](#)

Have your say: effects of health conditions on partners and family members



The lives of partners and family members are often affected by a person's health condition, but this important impact is often ignored.

Researchers at Cardiff University have created a simple questionnaire, the Family Reported Outcome Measure (FROM-16), to measure this. They are seeking your help to test this questionnaire before it can be used routinely to better understand and care for the health and social needs of partners and families.

If you have any health condition, or your partner or a family member (aged 18 or over) does, please complete the five-minute survey.

[Take the survey](#)

Lay members sought for cancer screening research advisory committees

[Find out more](#)

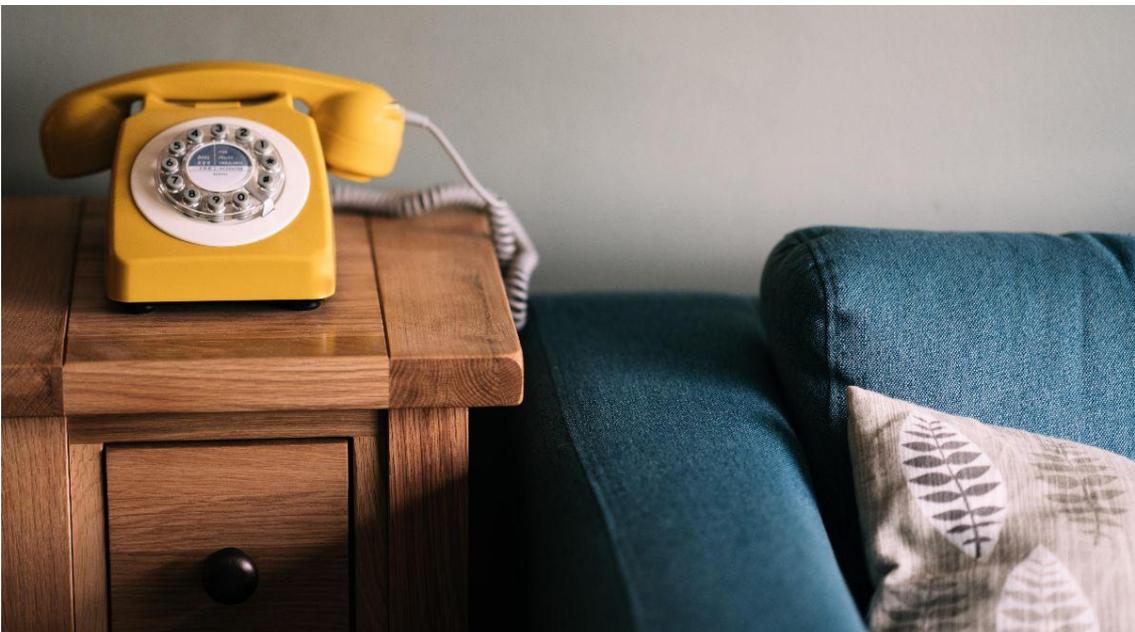
Still open for your opinions



Our shared decision-making survey will be closing soon. It's an important part of our work to empower patients to have a greater say in decisions about their care & treatment, so if you've not completed it yet, please do it today.

[Take the survey](#)

From the helpline



Billy*, who lives on the Wirral, called our free helpline to ask how to make a complaint about his daughter's GP.

His daughter, Gemma, is 33 and has several disabilities, including severe eczema for which her GP prescribes creams and shampoos. An occupational therapist has been working with Gemma and recommended a special bathtub for which a GP's letter would be needed for the equipment purchase to proceed.

Billy asked the GP for such a letter. The GP said Gemma didn't have eczema, despite having written prescriptions for the condition for several years, and claimed Gemma was bed-ridden and suffered from bed sores, neither of which is true.

The conversation caused Billy to lose confidence in the GP, who appeared out of touch with his daughter's medical conditions and history. He also asked our adviser how to get Gemma moved to a new GP.

Our adviser suggested Billy write to the practice manager to raise his concerns, including changing GP within the practice. The adviser also explained the NHS complaints process and advised that it's better to try to resolve the matter at the GP level before resorting to NHS England. We also signposted him to the complaints leaflet on our 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.org.uk. See [our website](#) for more ways to get in touch.

What our team is reading this week

[UK health minister says need full investigation into COVID-19 origins](#)

[UK going in wrong direction on COVID cases with 'pockets' of unvaccinated people, says government health chief](#)

[Staff burnout in health and social care putting safety at risk, say MPs](#)

[Big win for patients: Global Patient Safety Action Plan 2021–2030 adopted by 74th World Health Assembly](#)

[Ethnic health inequalities: turning evidence into action](#)

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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