



Welcome to the Patients Association Weekly News



NHS health information available through Amazon's Alexa



The NHS has announced a new partnership with Amazon to provide health information from the NHS website to people through voice-assisted technology. The move will allow elderly people, blind people and other patients who cannot easily search for health advice on the internet to access the information through the artificial intelligence (AI)-powered voice assistant Alexa.

But the move has [split expert opinion](#) among AI experts and data ethicists. The NHS has increasingly partnered with companies to offer access to its services. Notably, various providers allow video appointments with GPs to be made remotely. Amazon has said all data will be kept confidential.

In comments featuring in [The Times](#) (£) and [Metro](#), Rachel Power, Chief Executive of the Patients Association, said:

“It’s exciting to see new technologies play an increasing part in healthcare and we welcome the move to provide accurate health information to people through voice-assisted technology. People who are blind or living with disabilities will welcome the convenience, and it is reassuring to know that official NHS advice will be the default and primary source of information for people making simple health enquiries.

“Having said this, we would be very interested to see the evidence base that the Secretary of State has used before making this decision. While the Patients Association supports technological change where it maximises benefits for patients, major changes such as these should be introduced carefully and after a thorough evaluation of the evidence and likely impact. Patient safety must be of paramount importance at all times: adequate safeguards must be in place to ensure the utmost protection of patients’ personal data – this is particularly the case with big tech companies such as Amazon, following recent reports that Alexa speakers retain recordings and shares information with other companies. The roll-out of technology across the NHS must be done in a measured, responsible and safe manner.”

[Read more](#)

Help shape our new programme of work



Later this year we will be commencing a programme of work on patient experience, and we [need your views](#) to help us define the topics we will cover. We want to know about your experience of being a patient – this includes your thoughts on the care that you, or someone close to you, has recently experienced, and anything else that has mattered to you while you (or they) have needed care.

As this is a preliminary survey to help us define the scope of the work, we are not looking for as big a sample as normal. So if you'd like to contribute, be sure to respond quickly – once we have 100 responses, the survey will close! If you miss out, don't worry – there will be a longer, in-depth survey later this summer, which we will develop using these initial answers.

By completing [the survey](#), you'll inform our future campaigning work and play a role in our work to improve things for patients. The survey asks you to think about a period when you needed health or social care, either currently or in the past, so please only begin the questionnaire if you are happy to think about those experiences.

If you have any questions about this piece of work or would like more information, email policy@patients-association.com

Have your say

Last chance to join our workshop in Leeds next Friday



Have you been switched from a 'biological' medication to a new 'biosimilar' drug? The Patients Association is hosting a workshop in Leeds **next Friday** to learn more about how people who are taking these new medicines can be better supported and to understand how their experiences could be improved. This is an exciting and unique opportunity to shape, influence and co-produce guidance directly with clinicians which will help different types of patients to be better equipped to make decisions and will allow them greater control over their own health and wellbeing.

Biologic medications are usually liquids given via a drip or injection pen. They are often used to treat long-term conditions including Crohn's disease, ulcerative colitis, psoriasis and arthritis, but patients with diabetes and people with some forms of cancer may also be taking biologics. Biosimilar drugs work in the same way and are newer versions of the original biological medications.

If you've recently been switched onto a new biosimilar medicine and live in or near Leeds, we'd love for you to join our workshop next Friday, 19 July. The session will run from 10am to 2pm, and your feedback will help to shape our work. Places are limited so please contact anna.shears@patients-association.com for more information and to reserve your place. Lunch and light refreshments will be provided, and we are also offering a high street voucher to participants for giving their time.

[Read more](#)

Patients who have received private care: attend our focus group in London on 29 July



Have you opted for private treatment over NHS care in the past? Has your treatment been funded by an employer through medical insurance as part of a benefits package? Attend our focus group with the [Independent Healthcare Providers Network](#) (IHPN) in London on 29 July and help us develop a new resource for patients receiving private treatment.

IHPN is the representative body for private sector healthcare providers and they are working with us to provide relevant and appropriate information for patients receiving private treatment. The new resource will be designed to give patients the information they need to make informed decisions about their treatment – from the decision to proceed with receiving private care through to the end of the patient journey when treatment is no longer required.

We'll be hosting a focus group in central London on **Monday 29 July** with patients who have undergone private treatment and would like to invite you to join us. If you have recently had care privately or know someone who has, please get in touch by emailing Abdullah Mahmood at abdullah.mahmood@patients-association.com. Whether your experience was very good or one that could have been improved, we would like to hear from you. Refreshments will be available on the day and reasonable travel expenses will be reimbursed. We are also offering a high street voucher to participants for giving their time.

For more information, email Shivani.Shah@patients-association.com or call 020 8423 9111.

[Read more](#)

Knee problems? Join us to create new guidance to inform and empower patients



We've partnered with Oxford University to produce new patient information about the recommended treatment options for meniscal problems of the knee, and we'd like to hear from you if you currently have knee problems and are considering surgery, are waiting for a procedure or have recently had an operation.

We want to recruit a diverse group of patients to pilot a new approach to creating guidance that will inform and empower patients. Structured clinical guidance is central to the delivery of care in the NHS, and it is crucial that this guidance is developed with meaningful involvement from patients and the latest, best quality evidence.

As well as working with Oxford University, the project is also supported by the NHS Getting It Right First Time programme and the British Association for Surgery of the Knee. Participants will need to be able to attend a meeting in Oxford on **Friday 6 September from 10.30am to 3pm**. Travel expenses will be reimbursed. If you are interested in taking part please contact Heather Eardley on heather.eardley@patients-association.com.

Express an interest

From the helpline: issues with GP practice



This week we heard from Martha*, who got in touch following a recent conversation with her GP. Martha had recently seen her doctor about a suspected cancer. Without conducting any further examination, the GP diagnosed Martha with an advanced stage of cancer and referred her to specialists at hospital. Martha was understandably upset and distressed after hearing the news, but after extensive tests at hospital, she was told that her cancer wasn't at an advanced stage after all.

Martha was unhappy with the way her GP communicated the information about the diagnosis and wanted to raise her concerns to ensure other patients did not go through the same experience. Notwithstanding this incident, Martha enjoys a positive relationship with her GP and did not want to make a formal complaint.

Our helpline adviser suggested that Martha should have an informal conversation with the Practice Manager regarding her concerns. Martha asked if an advocate could be present for this conversation, so we provided contact information for her local advocacy service. We also shared general information about getting a second opinion on clinical matters. Although doctors are not legally obliged to offer patients a second opinion, it is considered to be good practice to do so. Our advice to people is to politely request a second opinion on the basis that they want to be assured that they are receiving the best treatment for their condition.

We asked Martha to contact us if we could provide any additional information. If you need advice about any aspect of health and social care, you can contact our helpline on 020 8423 8999, or email helpline@patients-association.com. You can find out more about our helpline and advice service [here](#).

*Name changed

Contact our helpline



Helpline Live Chat:
Weekdays from 2pm to 5pm



What our team is reading this week

Good gut bacteria 'helps starving children'

More patients 'struggling to reach GP on phone'

Teachers to work with NHS to support mental health of young people in schools

Are sugary drinks causing cancer?

NHS teams up with Amazon to bring Alexa to patients

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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