

Welcome to the Patients Association's Weekly News

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Chair and Chief Executive present Patient Partnership strategy at AGM



Chair of the Patients Association, Lucy Watson, told yesterday's AGM that patient partnership can make such a difference at every level of care, from face-to-face meetings, right through to the development of health policy.

In a brisk, business-only AGM, Lucy and our Chief Executive, Rachel Power, took members through last year's minutes, which were approved; this year's voting on resolutions, which were all approved; the work of the charity during 2020; and plans for this year, including the formation of a lived-experience panel and a forthcoming members survey.

Additionally, our treasurer Isaac Egberedu reported that 2020 had been a challenging year for the charity's finances, but that we had worked hard to ensure income exceeded expenditure. This was achieved by cutting back on expenditure and delaying the appointment of staff.

Talking about our five-year strategy to embed patient partnership in health and social care, Rachel said it was about sharing power and Lucy added that we would be campaigning to make it a reality and said now was a very exciting time of the Association.

- A recording of the AGM will be available on our website shortly, as will our 2020 Annual Review.

Help us develop patient information to improve nutrition in sick patients



We are recruiting for a focus group that will help in the development of resources for patients with disease-related malnutrition that will educate, support and empower them to effectively manage their nutritional care.

Supported by an educational grant from Nutricia, a company that specialises in therapeutic food and clinical nutrition, the Patients Association is working with Emily Walters, a dietician who is also editor on the website [MedicalNutrition.today](https://www.medicalnutrition.today), a resource for healthcare professionals who use medical nutrition to care for their patients.

The focus group will be convened for two virtual meetings to provide input on educational and self-care resources for patients facing disease-related malnutrition. The first meeting is likely to be at the end of August and the second will be held before the end of October.

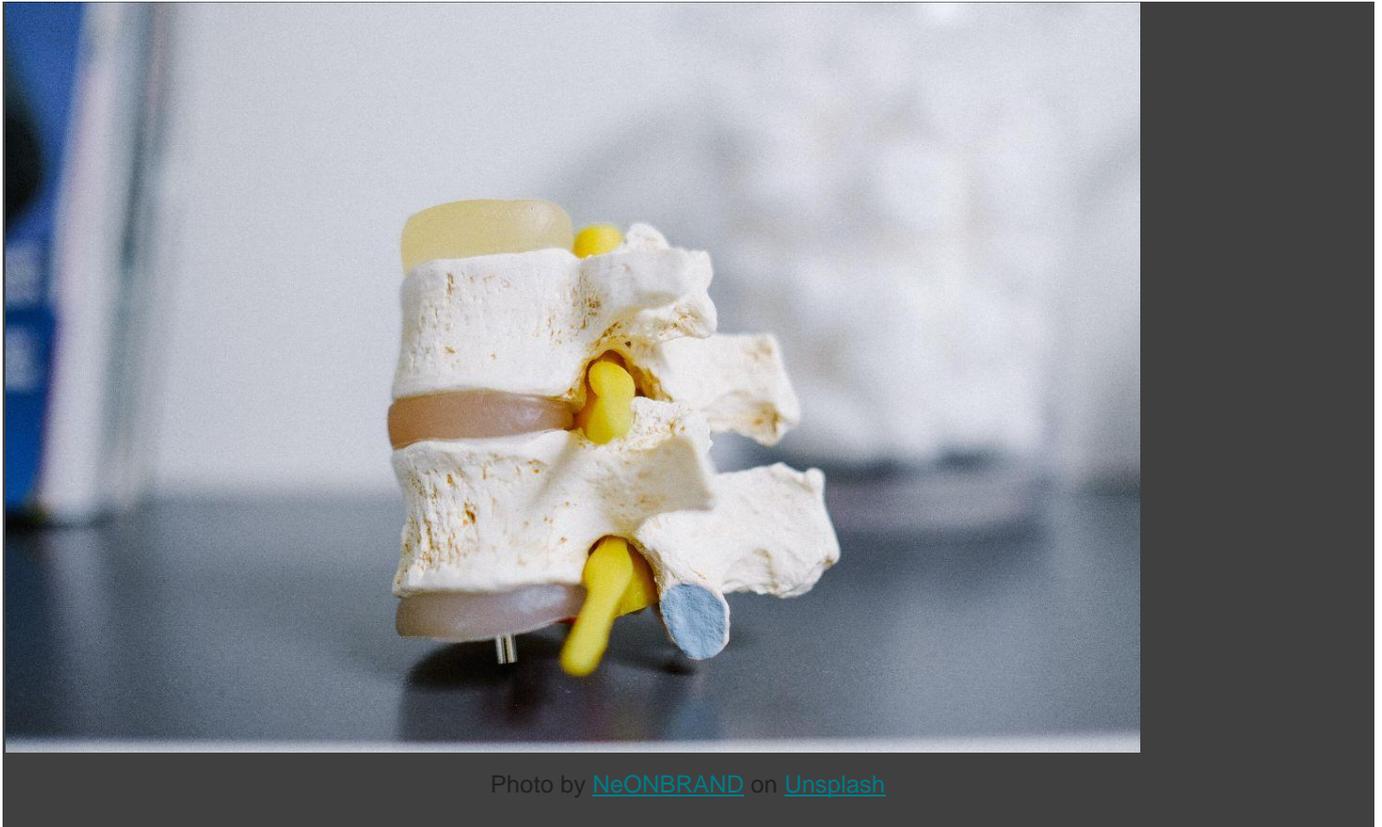
The goals of the resources members of the focus group will review, are to:

- Raise awareness of unintentional weight loss and/or low BMI in disease-related malnutrition and how proper nutrition and hydration can support health management and contribute to good health.
- Support all patients to manage their health and empower them to make choices or ask for help and support around nutritional care.

- Give people the confidence to identify their own risk of manipulation.

Participants will receive a £80 voucher for participation in the group. If you would like to be considered for the focus group, please contact Sharrie McIntosh at sharrie.mcintosh@patients-association.org.uk

Osteopaths' regulator looks for patient input on education and joint working



The General Osteopathic Council is looking for patients who have been under an osteopath's care to join one of two groups that will help it update the way osteopaths are regulated.

GOC is consulting on an updated version of the Guidance for Osteopathic Pre-registration (GOPRE) and the Standards for Osteopathic Education and Training (SET). It is recruiting osteopathic patients to participate in an online focus group on **Thursday 15 July 2021 at 2pm** to discuss the updated guidance and to help it explore:

1. Whether you think there are any gaps in our GOPRE guidance?
2. Whether it is fit for purpose (including issues around patient safety)?
3. Are there any further equality, diversity and inclusion issues you would like us to consider?

The session is expected to last 1 hour and 15 minutes and GOC is offering participants £25 as a thank you for their time and feedback.

If you would be willing to share your experience, please get in touch with Rachel Heatley: rheatley@osteopathy.org.uk

The other focus group is for people who feel they have received better treatment because their osteopath has

worked collaboratively with other health professionals, such as your GP or physiotherapist.

This workshop will enable osteopathic patients to share their experience to help raise awareness of the importance of collaboration and the benefits that it can deliver – for both osteopaths and patients.

Participants will receive £25 as a thank you for their time and feedback.

If you would be willing to share your experience, please get in touch with Stacey

Towle: stowle@osteopathy.org.uk

The GOC regulates osteopaths in the UK.

Patient members sought for antenatal and new born research advisory committee



Public Health England is looking for people to represent the public and patient voice on the NHS antenatal and new born (ANNB) screening programmes research advisory committee (RAC).

The committee reviews applications to carry out research involving NHS screening programme participants, or requiring access to screening data or samples. It considers the risks and benefits of each research proposal for the screening programme and participants, as well as the public interest in carrying out the study. Based on this assessment, the RAC decides whether to support the research.

To be considered for this position you need to live in England and ideally have:

- An interest in ANNB screening programmes
- Good communications skills, enthusiasm and reliability
- Access to appropriate technology (such as a computer or tablet) for emails and remote meetings.

An understanding of health research and ethics, and experience of reading scientific papers, would also be useful but if you don't PHE will support new patient members undertake their role.

Meetings take place four times per year and are currently held using Microsoft Teams. In the future, there may be face-to-face meetings and any travel costs and expenses would be reimbursed.

More information, including how to apply, is available in the full advert. The closing date for applications is 28 July 2021.

Please contact screening.research@phe.gov.uk if you have any questions.

[Read more](#)

Cancer doctors pledge to improve care for LGBTQ+ patients



A coalition of clinicians and charities has made an open commitment to improve education and awareness of the care needs of LGBTQ+ patients with cancer.

A statement released by the Joint Collegiate Council for Oncology - a collaborative advisory group on cancer issues headed by The Royal College of Radiologists and the Royal College of Physicians - and the Association of Cancer Physicians outlines the need for better understanding of the requirements of patients from sexual and gender minority groups and commits to 10 actions to improve the cancer care community's understanding, oversight and inclusion of these groups.

The actions range across medical education, patient monitoring, research and inclusion, to be promoted and pursued by medical Royal Colleges, their members and the wider clinical community.

The statement, timed to mark Pride Month, has been endorsed by other expert professional bodies, including the UK Oncology Nursing Society, the Royal College of Physicians of Edinburgh and the Royal College of Physicians and Surgeons of Glasgow, who agree to help enact the commitments.

LGBTQ+ support groups backing the statement include Switchboard, Stonewall, Live Through This and the

LGBT Foundation. Cancer Research UK and the Teenage Cancer Trust are also supporting the statement.

You can read the full statement including the 10 actions online.

[Read more](#)

Consultation on community and public health nursing open



The Nursing and Midwifery Council has opened its draft standards for community and public health nursing to public consultation.

The consultation looks at post-registration standards for the next generation of community and public health nurses working in health and social care. These include occupational health nurses, community learning disability nurses, community children's nurses, school nurses, community mental health nurses, district nurses or general practice nurses.

The draft standards will ensure this diverse group of professionals have the right qualifications and skills to support and care for people in a rapidly changing world.

If you'd like to give your opinion on the new standards you can find the proposed standards and a survey to gather your feedback online. You have until 2 August 2021 to share your opinions.

[Read more](#)

Something for readers in Yorkshire



West Yorkshire and Harrogate Health and Care Partnership and the West Yorkshire Violence Reduction Unit are launching an anti-racism movement at the end of August and are asking people to get involved.

The movement, a recommendation from the West Yorkshire and Harrogate Health and Care Partnership review in October 2020 into the impact of COVID-19 on health inequalities, is being developed with a wide range of organisations, including the NHS, councils, Healthwatch and the voluntary community social enterprise sector.

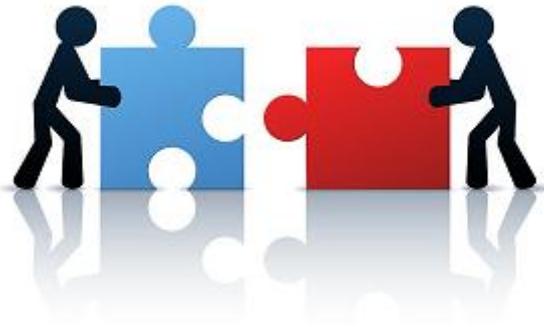
Already, more than 150 organisations have pledged their support – including housing associations, universities, West Yorkshire Police, unions, community groups and sports foundations, including Keighley Cougars, Community Foundation at Wakefield Trinity, and Bradford Bulls Foundation.

The movement is part of an ongoing commitment to tackle structural and institutionalised racism, as well as addressing health and social inequalities across the area. And individuals are welcome and encouraged to pledge their support too.

You can get involved by registering your support by completing this registration form and you will be sent a free communication toolkit.

[Read more](#)

It's co-production week 5-9 July



Health Data Research UK is inviting readers of Weekly News to a series of online events next week all about patient and public engagement and involvement.

Details of the sessions and how to join are available online.

HDR UK is the national institute for health data science.

[Read more](#)

From the Helpline Problems with recording next of kin



Over the last few months, we have had many calls to our free helpline asking out next of kin. Our information about next of kin is also one of the most read pages on our website. The call this week from Alice* is typical of the calls our advisers are receiving.

Alice wanted to know it's possible to have two family members listed as next of kin when a loved one is in hospital. She was prompted to call because she has concerns the hospital is neither sharing information nor allowing a second blood relative visit a family member who is on a ventilator in hospital and cannot express their wishes.

Our adviser told Alice that hospitals can record more than one next of kin, however, it would only contact the second person if couldn't reach the first person listed as next of kin. Also, hospitals expect the first next of kin to communicate information with other family members.

Our adviser also suggested Alice get in touch with the Patient Advice and Liaison Service at the hospital to seek support.

* 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

[Build Back Fairer in Greater Manchester: Health Equity and Dignified Lives](#)

[Pregnant women in England denied mental health help because of Covid](#)

[Covid: NHS plans booster jab for those 50 and over before winter](#)

[The return of Sajid Javid will define the government. Will he side with the PM or the Chancellor?](#)

[Revealed: Dozens of baby deaths after errors at one of UK's largest hospitals](#)

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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