

## Neuro News Summer 2023

*A round-up of local, regional and National news to support people with any neurological condition or disability*

### National Focus

#### **Social care complaints difficult**

The Equality and Human Rights Commission (EHRC) has published their report into challenging social care decisions made by local authorities in England and Wales highlighting that making social care complaints difficult.

The EHRC found that the system is failing those who need it. It's hard to navigate around the complaints system, with long delays. Key concerns include;

- people fear that if they do challenge decisions, they will face negative consequences and lose access to care
- some users are concerned at a lack of independence from the person making the decision
- data collection and analysis is not good enough, so patterns and trends are being missed

[www.equalityhumanrights.com](http://www.equalityhumanrights.com)

#### **Mental Health**

An NIHR report highlights the need for wider access to mindfulness therapy benefits patients with recurrent depression. Access here;

[www.nihr.ac.uk/case-studies/wider-access-to-mindfulness-therapy-benefits-patients-with-recurrent-depression](http://www.nihr.ac.uk/case-studies/wider-access-to-mindfulness-therapy-benefits-patients-with-recurrent-depression)

#### **Northern Power Grid (NPG)**

The NPG Priority Services Register is a UK-wide free service to support people with additional needs during a power cut or interruption to supply of electricity, gas or water.

A new website has been designed to support organisations across the utility regions to guide vulnerable people to the register and have the support they could need.

[www.thepsr.co.uk](http://www.thepsr.co.uk)

#### **The Hewitt Review**

Rt Hon Patricia Hewitt has published an independent review of Integrated Care Systems. The review considered and made recommendations on:

- how to empower local leaders to focus on improving outcomes for local populations, with greater control and more accountability for performance and spending
- the significant reduction in national targets which NHS ICBs should be held accountable for and supported to improve by NHS England and other national bodies, alongside local priorities reflecting the particular needs of communities
- how the role of the Care Quality Commission (CQC) can be enhanced in system oversight

[The Hewitt Review: an independent review of integrated care systems \(publishing.service.gov.uk\)](https://www.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1144442/the-hewitt-review-an-independent-review-of-integrated-care-systems.pdf)

# NEURO KEY

An Alliance supporting people with neurological conditions

## New National Clinical Director

Dr Niran Nirmalanathan, NHSE has been appointed the National Clinical Director for Adult Neurology. National Clinical Directors are practicing clinicians from across England who work part-time at NHS England, providing clinical leadership, advice, input and support across distinct areas of NHS conditions. In his role, Dr Nirmalanathan Chairs the Neurology Clinical Reference Group and provides leadership to the NHSE neuroscience transformation programme.

## Regional Focus

### VONNE

In a 'Temperature Check' Survey conducted by the VONNE VCS Mental Health sub-group to underpin Mental Health Transformation in North East and North Cumbria ICS, findings indicated that VCS involvement in the transformation of mental health services as co-designers and co-creators has not been robust or consistent across the different localities that make up the ICS.

The survey defined the frustration that opportunities for genuine innovation and creativity are being missed, especially in terms of new roles, alternative models of service provision and community developments that could be co-produced with the VCS.

[www.vonne.org.uk](http://www.vonne.org.uk)

## NE Regional Stakeholder Network for Disability (RSN)

The Cabinet Office/Disability Unit will shortly will be running a UK Panel Survey with 2000 disabled people. The survey will target data gaps, increase understanding on the cost of equipment, how demographics and vulnerabilities also impact disabled people.

Directing stakeholder engagement primarily on energy, transport and food, especially the upcoming energy support schemes consultation on social tariff, the RSN Chairs will pursue specific cross-government engagement with monthly updates.



## Healthwatch

This year Healthwatch Darlington has;

- Provided up to date information people can trust
- Helped people access the services they need
- Helped people access NHS dentistry
- Supported people during the cost-of-living crisis

[www.healthwatchdarlington.co.uk/report/2023-07-03/healthwatch-darlington-annual-report-2023](http://www.healthwatchdarlington.co.uk/report/2023-07-03/healthwatch-darlington-annual-report-2023)

## Neuro Key

### North East Neuro sub-group

Hosted by VONNE, Neuro Key have contributed to a document on a range of issues reported by attendees from the VCS interested in driving strategic development. The next meeting in September will aim to select priorities and take forward to the ICS networks.

### Peer support

- Neuro Key delivers a peer support group for adults with or parents of neurodiverse young people. The group is moving to Lingfield Meeting Hall, 78 Lingfield Ash Coulby Newham TS8 0SU - first Tuesday in every month 5.30pm to 8pm. We offer a drop in on a Thursday afternoon.

<http://aadhd-ne-uk.weebly.com/>

The volunteer who manages the peer support delivers 'Hiding neurodiversity in plain sight', a lifetime of masking suppressing and acting blog;

<https://neurologically-challenged.co.uk/hiding-neurodiversity-in-plain-sight-a-lifetime-of-masking-suppressing-and-acting/>

- A pan-neuro peer group meets monthly at Richmond Cricket Club, North Yorkshire. This vital group receives NHS and allied professional referrals from across North Yorkshire.

Meets on the third Tuesday every month from 1-3pm

- Community member, the pain friendship group offer peer support at Thornaby library on the last Friday every month, 1-3pm.

This group contribute their lived experience to the Neuro Key Education programme, working with medical and psychology students to improve professional practice.

- Community member Headway Teesside deliver peer support on the second Wednesday of every month.

### My Life Tool

In partnership with Teesside University, Neuro Key have been working on the evaluation of My Life Tool for the National Institute of Health Research (NIHR), due to be completed in October.

After a series of meetings with Peer Research Assistants (PRAs), the group have now designed a Patient Charter for self-management of long-term conditions which is to be launched on October 25<sup>th</sup> at an event at Hardwick Hall Hotel. Publicity and registration out soon.

In addition, senior lecturer, Dr Kiling recruited participants to review the Tool and adapt for Long Covid. Now published via Healthwatch and the link, you can download a PDF for each of the booklets.

<http://mylifetool.co.uk/LongCovid.html>

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## Project for neurodiversity

The unique Specialist Community Navigator for neurodiverse people role has been prepared by people with lived experience. Neuro Key is now distributing a survey across the region to gather data to garner the needs of the neurodiverse community. Neuro Key is piloting the role to deliver support, information and advocacy, reporting to Tees, Esk and Wear Valley Mental Health Trust in December.

## Major Conditions Strategy

Neuro Key, Dr Kiliņ and an associate professor from Teesside University met the call for evidence for the national strategy, stressing the need for self-management tools to focus on actively preventing people with long term conditions sliding into early disability.

## Neurological Alliance (NA)

Since 2005, we have forged our impact, education/research and learning tools and thriving network from a people-centred, pan-neuro approach. As a Disabled People Organisation (DPO), we draw attention to the lived experience of less prevalent conditions and the impact on mental well-being.

We have in-house experience of 32 neurological conditions and disabilities. Our advocacy service takes referrals from public sector organisations for our expertise and to reduce rural isolation.

After communication since February to support issues at James Cook University Hospital (JCUH) Neurology Department, a meeting between Neuro Key, the CEO of the NA, Georgina Carr and representatives from JCUH took place on June 19<sup>th</sup>. Subsequent email correspondence on June 20<sup>th</sup> revealed that Georgina Carr had plans to exclude Neuro Key, usurp our network, expertise, operational integrity and standards to collude with colleagues from national Charities and benefit her job role in other regions.

We are not prepared to tolerate such purposeful intent to undermine our model, impact or credibility. We have already withstood similar attacks in 2012 and 2017 by some national Charities demanding 'professional' supremacy over lived experience.

Securing a mandate from Neuro Key Governing Board, we have written to the NA Chairman resigning our affiliation with immediate effect, all reference to us on their website to be deleted.

We will continue, as always, to provide a local service for local people managing neurological conditions, injuries, impairments, neurodiversity or disability and broker lived experience as a driver for change.



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with neurological conditions



Demand for our expertise has increased by 20% since April 2023.

Please contact us with updates, questions or news via;

E; [admin@na-tvdny.org.uk](mailto:admin@na-tvdny.org.uk)

T: 01642 641825

W: [www.na-tvdny.org.uk](http://www.na-tvdny.org.uk)

Twitter: @na\_tvdny

Facebook: NeuroTVDNY

Although Smile Amazon has now closed, the Charity is registered on digital fundraising platforms, Paypal Giving and Give As You Live. As the leading cause of disability and the most marginalised of NHS client groups, we harness lived experience to champion a route past the barriers that people with and caregivers of someone with a neurological condition, injury, disability or neurodiversity face.

Hope you can join us in campaigning for inclusion of the neurological community to improve understanding, service delivery and support in 2023.