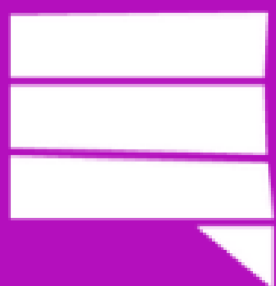


Impact Report 2022



NeuroLifeNow

It's time to make your story heard

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About NeuroLifeNow

NeuroLifeNow was launched in January 2021 to enable people to meaningfully share their stark daily realities of living with a neurological condition(s), and to inform positive change within public policy and services.

NeuroLifeNow captures real-time evidence, at scale, from people across the UK. Working directly with people affected by neurological conditions, an innovative web-based technology has been developed and continues to evolve, along with ways for people without access to digital technology to also share their daily realities.

Through NeuroLifeNow people share how neurological condition(s) have impacted every aspect of their life. From accessing treatment, care, and support, to home life, work and finances. People do so with confidence that what they share is treated sensitively and handled securely.

NeuroLifeNow has enabled us to unify and amplify your voices to drive improvements that will transform the lives of millions.



Snapshot of 2022

1,376 questionnaires were completed between January and December 2022.

Together, your responses represented:

- More than **1,840** appointments with health and care services.
- **112** conditions.
- Almost all of the United Kingdom, with responses from **94%** of postcode areas.

Your realities highlighted that:

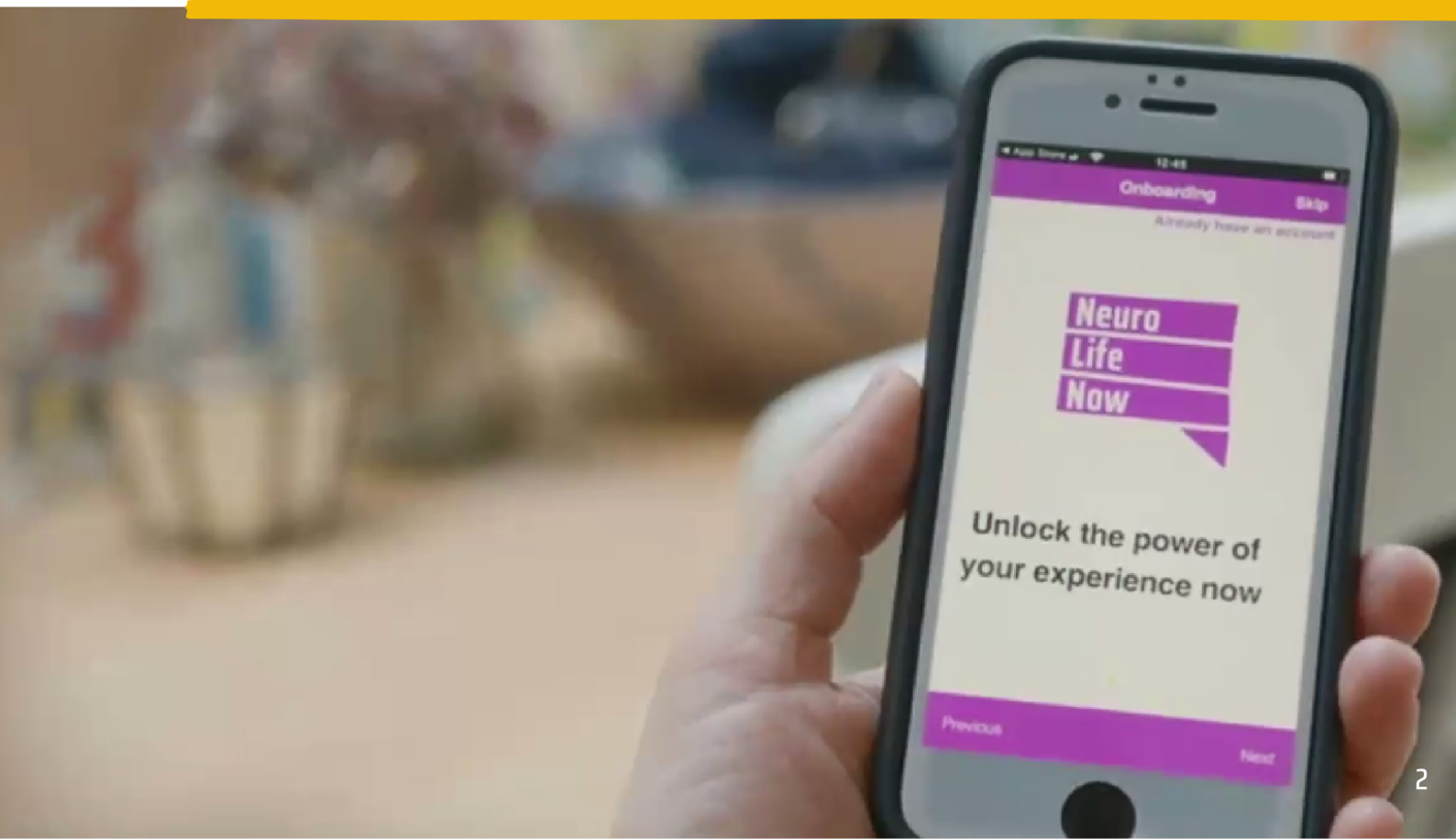


Nearly **2** in **3** people reported to have feelings of **anxiety** or **hopelessness**.



About **1** in **5** people reported having **poor** or **very poor** healthcare experiences overall.

“The NeuroLifeNow app has changed the way I can add my voice and make a difference. Being able to see the results and full report from each questionnaire means I feel heard and can really see the impact I’m making.”



Background

The individual, societal and economic impacts of neurological conditions has never been more clear - neurological conditions are the leading cause of **disability** worldwide [1], the second leading cause of death globally, accounting for approximately **10 million deaths per year** [2].

As global populations continue to grow and age, the impact is set to increase. In 2020, the total cost of neurological disorders in Europe was **\$1.06 trillion**, equivalent to the cost of heart diseases, cancer and diabetes combined [3]. The World Health Organization (WHO) estimates that half of the worldwide economic impact of disability will be due specifically to brain-related conditions by 2030 if we do not change this trajectory [4].

In the UK, at least **1 in 6** live with a neurological condition. Since the beginning of the pandemic, waiting lists in England for NHS neurology have **doubled**, but the investment and workforce to deliver services has not. That means people are waiting longer for care, often without the support they need.

NeuroLifeNow in 2022

Over the last year, nearly 1,400 experiences from people affected by neurological conditions have been shared via NeuroLifeNow, and more people are participating every day. Never has your voice been more important, given the significant impact of the cost-of-living crisis and overwhelming pressures on the health and care system.

These often stark and emotive experiences are making our community heard and provide a powerful insight into the daily realities of living with a neurological condition. Together with the Neurological Alliance's 'Back the 1 in 6' campaign, you are **driving positive change** and calling on governments across the UK to improve services for people affected by neurological conditions.

In an extremely difficult political and policy climate, your realities shared through NeuroLifeNow have helped to **secure hard fought wins** in public policy. In collaboration with other charities, you helped secure a much-needed uplift in disability benefits, as announced by Chancellor Jeremy Hunt in November 2022.

Despite positive steps forward in the last year, your experiences show **further change is needed** as more and more people are reporting poor experiences of healthcare and worsening mental health needs:

"After 18 months of seeing specialist doctors and having had MRI and CT scans (private and NHS), finally I have confirmed spinal CSF leak. I'm still waiting for epidural blood patch from January 2022 - it's been months and still don't have a date. My condition is deteriorating, every month I have more symptoms with most of my life I spent in bed, in pain."

The future

We have a philosophy of **"continual improvement"** that underpins NeuroLifeNow, to ensure it is a valuable platform for anyone affected by any neurological condition. We have been engaging directly with you, and others affected by neurological conditions, to find out how NeuroLifeNow can benefit the community.

Alongside this, we have been working with policy makers and service delivery organizations to refine how your lived experience insights can be most effectively used to lead urgently needed positive change.

Our plans for the immediate future are ambitious: to **improve the experience of engaging** with NeuroLifeNow so that more of our community can contribute in a safe and trusted way; to **improve representation** of our community across the UK; to **partner with organizations and academic institutions** to accelerate the impact of NeuroLifeNow on policy, treatment, care and support.

We'd like to take this opportunity to say thanks to our funding partners in 2022/23 - National Lottery Community Fund, The Peter Sowerby Foundation, Garfield Weston Foundation, Irwin Mitchell, Boston Scientific and UCB.

The biggest thanks, however, goes to you, for continuing to share your journey and lived experience. It is only thanks to your powerful insights that together, we can drive overdue positive change!

Please do remember that The Brain & Spine Foundation's Helpline, run by neuroscience nurses, are here for you, providing practical and emotional support relating to any neurological condition(s). You can get in touch for free by calling 0808 808 1000 (Mon-Fri, 9am – 4pm) or email helpline@brainandspine.org.uk.

Thank you so much.



Marc Smith
CEO, Brain & Spine Foundation

**Brain & Spine
Foundation**



Georgina Carr
CEO, The Neurological Alliance (England)

 **THE
NEUROLOGICAL
ALLIANCE**

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Our research not only asks people questions with fixed answers to choose from, but also provides our community opportunities to share their realities in their own words.

Below are some examples of what people have shared....



"It is **really difficult to get answers and support** after diagnosis. I had a 6-minute phone call with my specialist 8 weeks after brain surgery. That is the **only contact** I have had, and I have so many questions. After being classed as having a disability, I have had **no support** financially after having to leave my career due to my condition...."



"I feel **trapped** in my home. I can't walk to work. I can't afford to go out. I have a hole in my roof I can't afford to repair. That's before the **worries of food and energy**"



"I'm **not sure how to run all of my medical equipment**. I'm tube fed on a pump, have breathing machines, air mattress, hospital bed, ceiling joists, through floor lift - **all need electricity**."

"...social care for those of us with these conditions is really **lacking**. So far I have received help with benefits, but the help **stops** there. There is **no real care** for the effects of your symptoms on your day-to-day life."

Thanks to you, we are able to share the voices of our community and place them at the heart of public policy. We have achieved important progress in the past year, including:

- **Secured a recommitment to publish a high-level UK Government strategy for acquired brain injury (ABI) and other neurological conditions.** The strategy could have been under threat, following the abolition of other long-term condition strategies e.g. cancer, dementia, and mental health. Thanks to a strong and vocal ABI and neuro community, we prevented this from happening.
- **Worked with NHS England on a new neurology outpatient dashboard, which sets out key metrics of care.** This is the first time such a dashboard has been developed at a national level. We are working with the NHS England team to ensure the dashboard captures experiences of people living with neurological conditions.
- **Worked with NHS England to secure the continuation of the neuroscience transformation programme** to improve equity of care and access to neurology and neurosurgery services in England.
- **Collaborated with charities across the sector to secure a much-needed uplift in disability benefits, as announced by Chancellor Jeremy Hunt in November 2022.** More than 10 million people in total will see their benefit payments rise from April 2023 as a result. This followed feedback from NeuroLifeNow participants about the impacts of the cost-of-living crisis, and to ensure financial support for the extra costs of living with a disability were paid in line with inflation. More than 10 million people in total will see their benefit payments rise from April 2023 as a result. In addition, 6 million people across the UK on eligible 'extra costs' disability benefits, Personal Independence Payment (PIP) will receive a further £150 Disability Cost of Living Payment in 2023-24. According to the latest available public data (January 2023), 412,289 people with neurological conditions were claiming PIP.
- **New National Clinical Directors (NCD's) for neurology and, spinal surgery and neurosurgery have been appointed** following substantial pressure from the Neurological Alliance, the Brain and Spine Foundation and our allies within the neurological sector.



Key findings

Across 2022 we asked you:

- Who are your appointments with?
- How are your appointments taking place – face-to-face, online, or by telephone?
- Are you finding your appointments helpful?
- What is your overall experience of your care?
- Is your care meeting your mental health needs?

These questions reflect the ongoing challenges many people are experiencing in seeing specialists and in accessing holistic, personalised care that can meet their needs.

Your realities have shown that across 2022:

- The most seen health professional for medical appointments were GPs (37.7%), followed by specialist nurses (20.4%), and then neurologists (15.2%).
- In **January-February, 1 out of every 5 appointments reported were with a GP, and in November-December, 1 out of every 2 appointments were with a GP.**
- Of the more than 1,840 appointments shared by users of NeuroLifeNow, 67% were face-to-face appointments and 30% were held by telephone.
- As of July 2022, **22% of first neurology outpatient appointments and 43% of follow-up neurology outpatient appointments in England were delivered remotely.**
- Overall, **7 out of 10 appointments** shared were felt to be helpful.

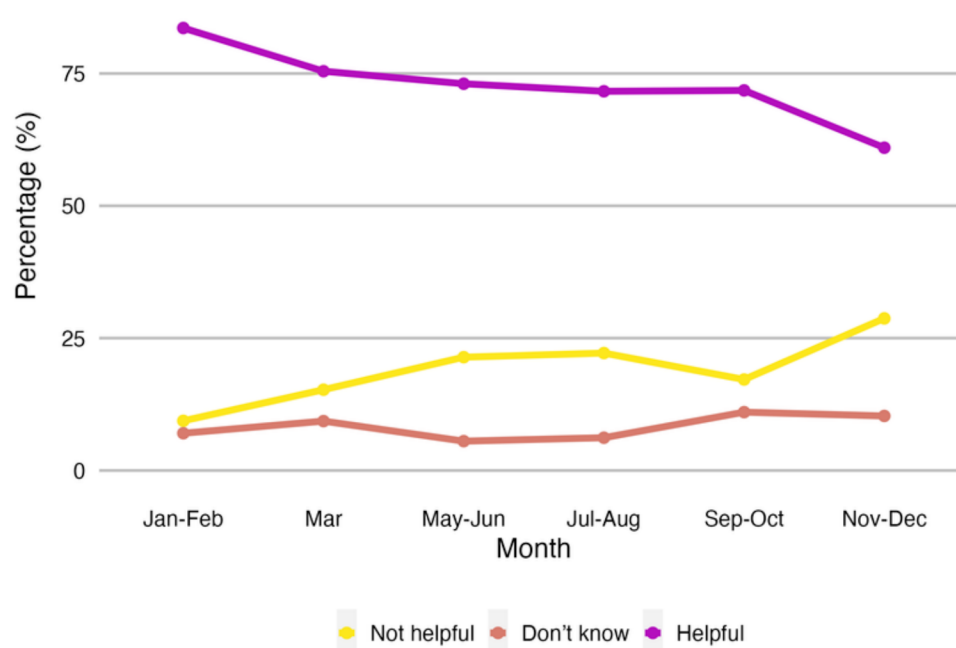


Figure 1: Helpfulness of the medical appointments in the past 8 weeks at the time they answered the questionnaires across months.

Key findings

- Despite this, **1 out of 5 (22%)** said their overall experience of healthcare was poor or very poor, compared to a third (34%) who said their overall experience was good or very good.
- In fact, **the percentage of people who reported “poor” or “very poor” experiences has been steadily increasing**, from 7% in January-February to 35% in November-December.

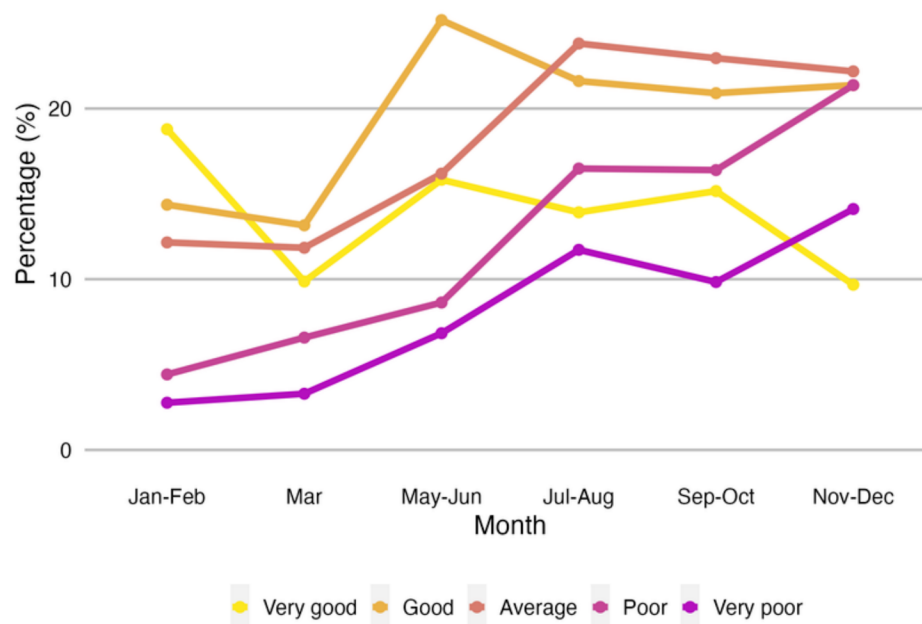


Figure 2: Experience with health services across different months of 2022.

- Themes that emerged from people's descriptions of poor experiences of care included:
 - **Lack of continuity in care**
 - “I was in receipt of social care until August 2019 when my carer left on maternity leave. The agency & social services were unable to find a replacement. Since the pandemic I have been told there is no chance of having a replacement although my needs were assessed as requiring more hours. I have been told no one suitable can be found and demand is so great that it is unlikely I will receive a care package now.”
 - **Overstretched health and social care systems**
 - “The people who have been here have expressed frustration that their hands are tied by the financial restrictions imposed on them”
 - **Long waiting times**
 - “I have been living with bowel incontinence, due to the Autonomic Neuropathy, for four years now and am still waiting for help regarding what I can use to help me with this problem.”
 - **Feeling discriminated or patronised** by their service providers
 - “Judgements made by nurses and physio staff about my condition, not knowing about it and refusing to believe me”
 - “I feel even more isolated. I am just a job, not a human being to them.”

- Overall, **a third of respondents (33%) said that their mental health needs were not met at all**. This peaked In November/December, nearly 4 In 10 (39%) of respondents said their mental health needs were not being met at all.

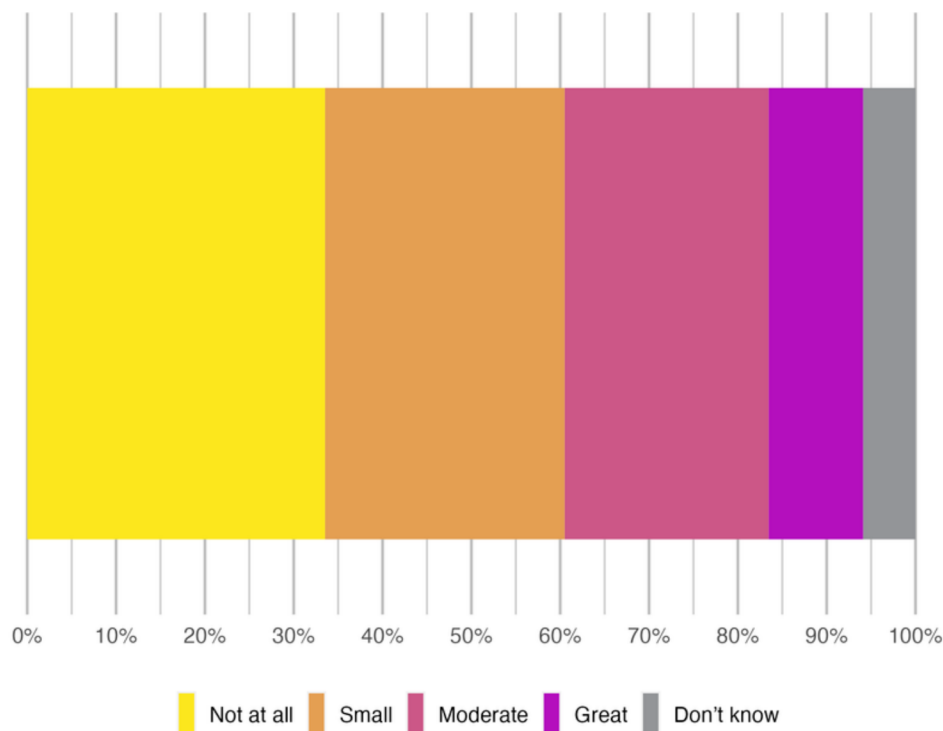


Figure 3: Extent mental health needs are met.

- Nearly **2 in 3** people reported having feelings of **anxiety** or **hopelessness**.
- The **cost-of-living crisis** was repeatedly mentioned as having a significant impact on people's mental health due to the uncertainties many people are facing:
 - “I’m very worried about the increase of the cost of living.”
 - “Really anxious about how I can afford to pay bills and afford to eat”
 - “My anxiety has gone through the roof, I am scared of being very cold this winter.”
 - “The fear of rising costs is adding to my mental strain. This is almost as bad as when it actually happens”

- [illegible]

- **30%** of people said they were **skipping meals**, and this increased to 40% in those living with more than one neurological condition
- Other changes people were having to make to cope with the increasing cost of living include:
 - 48% had their heating on less
 - 39% reduced their travel by car
 - 16% said they would increase their debt
 - 15% told us they would miss a bill payment
- Of particular concern, **23%** said that they would have to **reduce their spend on healthcare**:
 - “I’m not sure how to run all of my medical equipment. I’m tube fed on a pump, have breathing machines, air mattress, hospital bed, ceiling joists, through floor lift - all need electricity.”

Keep battling for a better, more supportive and caring health and support system for those afflicted by limiting health conditions. We are invisible in plain sight and you are NOT alone.

It was only in December 2021, after having had symptoms for 3 years, that I finally got a referral to a hospital for a possible Functional Neurological Disorder.

Results from previous MRI scans could not be found and new ones had to be done. The scans showed my spinal cord being **severely compressed**, along with the nerve bundles in my lumbar spine, by a herniated disc. I underwent an emergency **decompression surgery**.

I felt agonising pain 2 or 3 weeks after, and another surgery had to be done. The surgeon removed part of the disc that was "left in place" along with some debris, despite all of them being visible from the previous scans.



My surgeon continued to assist and support me. She explained that my spine had been impacted from my **working life**, and I had more herniating discs in my neck and the lumbar area, which meant future spinal operations would need to happen.

I am now in **constant pain**, 24/7. My medication has little or no impact on relieving this pain and instead, my symptoms have just increased due to weight gain.

I have **oxygen therapy** to help me out with the severe fatigue and breathing issues, as well as **deep tissue massage**. I find **meditating** helpful for my multiple conditions.

However I now have a walker due to my mobility issues, increasing my spasms and fatigue. I try to put into practice what I was taught in hospital, but the reality is that once discharged from the FND physiotherapy, there is abjectly **little or no care support**.

I really miss living independently, and feel like I am a constant burden to my wife who has to care for me every hour of everyday. She also has felt ignored as a carer.

The Brain and Spine Foundation has **helped me immensely**. Without their help I would not have a home to live in. I attend events each week, where I can meet others and share experiences.

For people with neurological conditions, I strongly believe the **government is responsible** for the negative impact on our symptoms. Whilst we are trying to deal with our serious health issues and get an accurate diagnosis, we also end up having to fight NHS Trusts, DWP, and Local Councils. Aren't these organisations there to support those in need? Health and support systems are truly failing.

We are sufferers and victims.

We only ask for **appropriate treatments**. It adds insult to injury having to go cap in hand to Government departments to obtain financial support at a time when we are at our most vulnerable - it is mentally damaging and soul destroying.

I would advise someone newly diagnosed with a health condition, firstly to **be kind to yourself**.

Secondly, pace yourself as everyone's health issues affect us all in different ways.

Thirdly, look to others and support groups run by the Brain & Spine Foundation to help you. They are more in touch with your condition, and they can **bring invaluable experience** and support to help you on your new journey in life.

Plainly, please support each other.



Participation, growth, credibility, impact and sustainability

In 2023 we have five core areas of focus, with each leading to maximizing the impact that lived experiences can have on policy and service development.

Improve the experience of participating in NeuroLifeNow and provide more ways for people to share their daily realities.

We will continue to work directly with people affected by neurological conditions to design and develop NeuroLifeNow, so that people can share their realities in a way that is accessible to them no matter what their situation. We want NeuroLifeNow to be responsive and able to accurately reflect their experiences, thoughts, and feelings; we want it to encourage continued participation and sharing; and we want to ensure people can trust that their personal experiences and information are handled securely and sensitively.

Reach new audiences and grow participation levels across all demographics.

We will work with organisations across the wider neuro sector, service providers and cultural hubs to reach new audiences and continue to grow participation levels across all demographics. We are developing a campaign that highlights the challenges faced by our community and points towards NeuroLifeNow and a unique and powerful means of influencing change. Through this, we will gain richer insights by including more people from across the UK.

Continue to highlight the issues that matter to the neuro community.

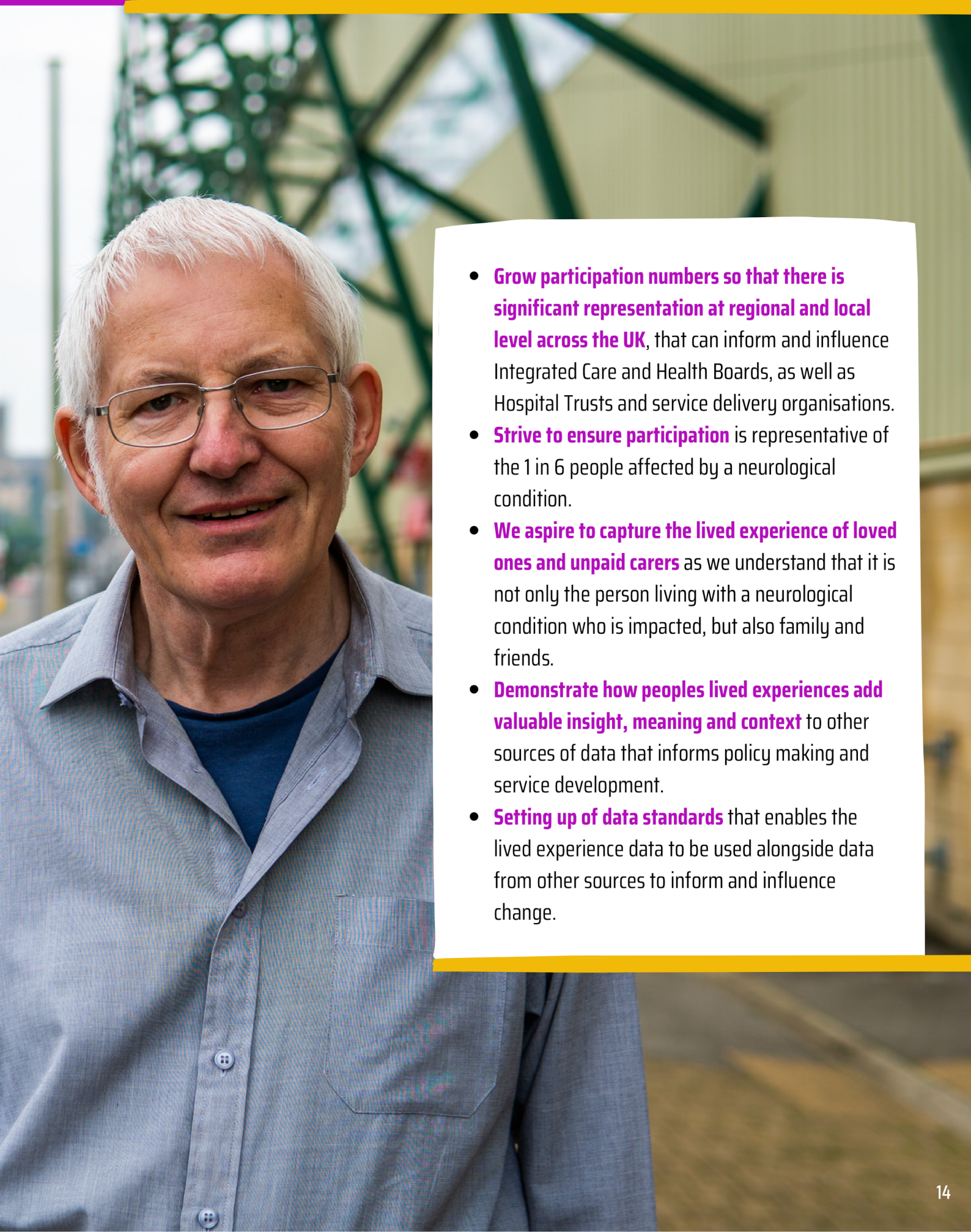
We will continue to listen to our community, analyse the findings and monitor the external environment. We will adapt and evolve our research to ensure we continue to capture the issues that matter to people affected by neurological conditions and have the greatest chance of making a noticeable impact.

Explore new ways that people's daily realities can be used to drive positive change.

We will explore and seize opportunities that inform and influence public policy and service development. We will work and collaborate with service delivery organisations and key decision makers. We are exploring partnerships with academic institutions that can accelerate and amplify this mutual ambition through established or new programs.

Ensure NeuroLifeNow is built on sustainable foundations.

We will ensure that NeuroLifeNow is built on sustainable and scalable resources and technical foundations. While ensuring our social research agenda is relevant to allow people to share their daily realities and so that the insights can influence and inform change.



- **Grow participation numbers so that there is significant representation at regional and local level across the UK**, that can inform and influence Integrated Care and Health Boards, as well as Hospital Trusts and service delivery organisations.
- **Strive to ensure participation** is representative of the 1 in 6 people affected by a neurological condition.
- **We aspire to capture the lived experience of loved ones and unpaid carers** as we understand that it is not only the person living with a neurological condition who is impacted, but also family and friends.
- **Demonstrate how peoples lived experiences add valuable insight, meaning and context** to other sources of data that informs policy making and service development.
- **Setting up of data standards** that enables the lived experience data to be used alongside data from other sources to inform and influence change.



Thank you for your support

neurolifenow.org

To access the Insights & Data document, [click here](#).

Brain & Spine
Foundation



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The Neurological Alliance (England) registered charity no. 1039034