

National Neuro Advisory Group

Impact Report 2019

1. Introduction

The National Neuro Advisory Group (NNAG) was formed in 2016 to provide a leadership structure for neurology in place of a National Clinical Director model. This impact report outlines the approach the neurological community has taken to address the challenges facing neurology since the formation of NNAG. It considers the group's successes, areas for improvement and NNAG's future plans. This report was primarily authored by Hannah Verghese, NNAG Programme Manager who undertook interviews and collected feedback from our members and stakeholders to compile this report (Appendix 1).

“Without NNAG I think the space would be far more fragmented therefore impact in neurological services would be less likely to succeed; NNAG strengthens the voice of neurology. Projects such as coding and review and improvement of pathways across different specialties are changing the neurology landscape”

Dr Catherine Mummery, Consultant Neurologist, Chair of the Services Committee, ABN, Neurology Vice Chair, Neurosciences Clinical Reference Group

2. Background

2.1 About neurological conditions and services

Neurological conditions are disorders of the brain, spinal cord or nerves. They can have a range of causes including genetic factors, traumatic injury and infection. The causes of some of these conditions are still not well understood. For many neurological conditions there are no treatments available. There are a large number of neurological conditions, some very common and some are comparatively rare.

The Neurological Alliance report that 71% of patients with a neurological condition experience moderate, severe or extreme pain or discomfort; 70% are restricted in their activities frequently, most or all of the time. For people with intermittent neurological conditions, such as epilepsy or migraine, the unpredictability of their condition can also have a huge impact on their day to day lifeⁱ. The 2013-14 NHS England survey of patients of GP practices found that people with long-term neurological conditions have the lowest health-related quality of life of any long-term conditionⁱⁱ.

According to the latest estimates, the total number of neurological cases in England has now reached 16.5 million. This equates to at least 1 in 6 people in England living with a neurological conditionⁱⁱⁱ. This figure will continue to rise. This increase is due in part to advances in neonatal healthcare. More significant however is the impact of an ageing population. This is highlighted by Public Health England's 2018 Neurology Mortality report which shows that the number of deaths in England relating to neurological disorders rose by 39% over 13 years, while deaths in the general

population fell by 6% over the same period^{iv}. Improvements in scanning and other diagnostic techniques is also contributing to increased diagnosis.

Neurological conditions cause a significant amount of NHS activity and spend^v:

- There were 1,654,577 hospital admissions with a mention of neurology, stroke or dementia in 2016/17. This is a 24% increase over the five years to 2016/17
- There were 1,009,021 emergency admissions with a mention of neurology, stroke or dementia in 2016/17. This is a 21% increase over the five years to 2016/17
- If all CCGs were to achieve the neurological admission rates of their best demographically similar peers, a saving of at least 10% (£50 million) could be achieved
- Neurological conditions (including stroke and dementia) accounted for 12,736,365 bed days in 2016/17
- NHS expenditure on neurological conditions alone amounted to £4.4 billion in 2012/13, which represents an expenditure increase of 200% since 2003. This excludes any social care or voluntary sector spend for which information is unavailable.
- Social care expenditure on care services for people with a neurological condition amounted to approximately £2.4 billion in 2013 - nearly 14% of adult social care spend

2.2 About NNAG

The NNAG aims to develop a system-wide approach to improvement by bringing together all the different parts of the health system currently working on neurology. In particular the NNAG was set up to seek alignment between programmes in NHS England, the Department of Health's Arm's Length Bodies and system partners, such as clinicians, professional bodies and charities relevant to people with neurological conditions. Together NNAG guides the strategic development of work to improve outcomes for people living with neurological conditions. The NNAG is not a decision-making body but does make formal recommendations to NHS England about the commissioning of services through the NHS England Clinical Policy Unit and NHS England Long Term Conditions team. The NNAG takes a whole pathway approach, focusing particularly on the areas that do not come under the specialised remit of the Neurosciences Clinical Reference Group.

Our mission: To improve outcomes and experience for neurology patients

Our three strategic aims:

- 1 Ensure alignment across all current neuroscience initiatives of national significance
- 2 Trouble shoot emerging issues and problems in neuroscience service delivery that fall out of the scope of the Neurosciences Clinical Reference Group
- 3 Develop and coordinate new service improvement initiatives, which will lead to improved quality of care and patient outcomes.

The group's logic model/theory of change is available [here](#).

Resources: The group is co-chaired by Professor Adrian Williams, Consultant Neurologist and chair of NHS England Neurosciences Clinical Reference Group, and Sarah Vibert, Chief Executive, The Neurological Alliance.

The group is supported by a Programme Manager approximately 5 days a month. This role costs £21,000 per year and is funded by The Neurological Alliance and its charity partners. Additional administrative support is provided by The Neurological Alliance.

Additional meetings and conferences are funded by other sources including hospital budgets and pharmaceutical industry contributions. Speaker and delegate travel expenses are met by individuals or their organisations.

Our network: The NNAG brings together the different parts of the health system that need to work together to achieve improvement in neurology services. The structure ensures that NNAG's core group listen to and provide a platform for views, experiences and opinions from across the neurological community. This includes people living with neurological conditions and their families, clinicians, commissioners and provider organisations.

The neuro community are also represented by the members of our core steering group which includes: NHS England, Public Health England, Neurological Alliance, Association of British Neurologists (ABN), The Society of British Neurological Surgeons, British Society for Clinical Neurophysiology, Patient Groups, British Society of Neuroradiologists.

Additionally, representatives from all nationally significant improvement initiatives in neurology are invited to the core steering group meetings. At present these members include NHS RightCare, NHS England's Neuroscience Transformation Project, Getting It Right First Time, Public Health England's Neurology Intelligence Network, The National Stroke Programme and The Dementia Access Taskforce.

The engagement of NHS England has been fundamental to the early success of NNAG. From the early days of agreeing to the new model, through to ongoing engagement in the group's activities. The ongoing commitment from NHS England, both in terms of senior level buy-in and day to day engagement with meetings and events, is critical to NNAG's longer term impact.

Our operating model: The NNAG has established the following ways of working in order to make progress towards its three strategic aims:

- NNAG Core steering group meetings (four annually) – to which we have invited speakers from national programmes such as GIRFT, the National Stroke Programme and NHS RightCare to patient groups academics and professional bodies to ensure coordination with current neuroscience improvement initiatives.
- Development of the Neurology Intelligence Collaborative (NIC) - a subgroup of NNAG focusing on bringing together all current data and intelligence related initiatives to achieve coordination

between existing initiatives and development of new data projects to fill gaps in data and intelligence about neuro.

- Development of work streams to focus on particular issues including care planning and mental health
- NNAG Clinical Leaders Away Days – September 2017 and December 2018 –with speakers including Sir Bruce Keogh, Medical Director NHS England, Dr Geraint Fuller, Neurology Lead, Getting it Right First Time (GIRFT) and Dame Julie Moore, CEO, University Hospital Birmingham
- NNAG Patient Group Forum Meetings (two annually). The forum ensures that the voluntary and community sector perspective is expressed and used to constructively challenge, influence and help develop NNAG’s strategies. It also promotes co-production in respect of the NNAG work programmes.
- NNAG Condition Specific Away Days. The aim of these days is to bring together clinicians, patient organisations and commissioners to articulate what good looks like for specific patient cohorts and to identify the key challenges to delivering this. Published write ups are available for Neurorehabilitation, Neuromuscular conditions, Epilepsy and Parkinson’s, Dementia and Psychiatry
- NNAG is represented at external events by the group’s chairs including the Neurology Service Managers’ Network meeting, Headache and Migraine summit in the House of Commons and

The ABN annual conference.

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| 232 Neurology leaders have attended our annual Clinical Leaders Away Days | 94 patient groups engaged with NNAG via the Patient Group Forum | 174 representatives from across the neuro community have attended our Condition Specific Away Days |
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3. NNAG’s achievements

Alignment across national initiatives and national visibility: The NNAG has been successful in giving greater visibility to neurology. Across the system we are seeing more focus on neurology. The structure of the group ensures that the work undertaken reflects the priorities of the community. This gives more traction and “teeth” to influence national initiatives. Our Clinical co-chair’s position on the Neurosciences Clinical Reference Group and clinical leadership role within NHS England has been instrumental in ensuring that the unified voice of the neurological community is represented at top level policy decision making. The previous National Clinical Director Model was not as effective in allowing this level of joined up working and community engagement across neurology.

“Hearing about national policy, as well as national data initiatives was very useful”

“Sharing best practice and new models of care was helpful, as were practical tips on writing business cases”

Feedback from delegates at the 2018 NNAG Clinical Leaders Away Day

This has led to:

- The NHS England Neurosciences Review and securing the three additional work streams: Parkinson's, MND & muscular dystrophy and headache.
- Supporting a new model for Clinical Reference Group working – a whole pathway approach – which is now being formally piloted in three disease areas.
- NNAG involvement in the national stroke programme, particularly in relation to rehabilitation, to align and integrate plans and priorities
- Alignment of neurology intelligence initiatives between GIRFT, NHS RightCare, Neurology Intelligence Network and the Neurological Alliance's patient experience survey under the Neurology Intelligence Collaborative. An early product has been the development of the Neurology Data Catalogue published on the Public Health England website.
- An increased engagement in neurology by NHS RightCare, as reflected in the increased number of neurology related toolkits underway.
- NNAG representation at external events and networks, particularly NHS England-led meetings of clinical leaders from across specialities.

“Neurology intelligence overall has taken a significant step forward due to the NNAG. The Neurology Intelligence Collaborative brings all the intelligence groups together to align and feed into the various work strands. It gives a forum to link up the work between charities and statutory agencies in a way that wouldn't otherwise happen”

Cam Lugton Programme Lead, National Mental Health Dementia & Neurology Intelligence Network, Public Health England

Providing a unified voice for the neuro community: The role of the NNAG to bring the neurological community together and provide a unified voice across the system is one of its' most celebrated successes to date. NNAG steering group members have come together to develop responses to selected consultations and undertake other joint policy lobbying activities.

The NNAG's activities have strengthened communication channels and joint working between patient and professional groups more widely. It provides a platform to share resources and for patient groups to feed into national initiatives such as the CRG, NNAG and the work of the NIC. Feedback from our Clinical Leaders Away Days highlighted the benefits of bringing the community together, and networking regionally, nationally and cross-specialty.

"The relationship between the Association of British Neurologists (ABN) and the Neurological Alliance is stronger than ever before. This means a true patient/clinical partnership and alignment of our work and messages. The NNAG has been the catalyst to this. It has encouraged and fostered that relationship."

Sarah Vibert, Chief Executive Neurological Alliance, Co-Chair NNAG

Clinical involvement in national programmes and activities: The structure of the group ensures greater clinical and expert involvement in activities and outputs than would be possible if the members undertook these projects alone. The operating model ensures that the NNAG uses the assets of local clinical leadership and spreads knowledge to local level by increasing leaders' knowledge. This aligns with the new operating model for the NHS and as such is paving the way to improving outcomes in neurology over the long term.

"The NNAG provides a great forum to support the development and dissemination of our products and messages. Having all the key players around the table means we can ensure alignment with other messages and work out there in neuro"

Vittoria Polito, Pathways Lead, NHS RightCare

Troubleshooting emerging issues and problems in neuroscience service delivery: The structure of the NNAG allows the group to act like a think tank and consider and respond to emerging issues and problems in neuroscience service delivery.

This has led to:

- Strengthening the relationship with NICE and establishing the NNAG as the "go to" voice for the wider neuro community. This allow us to influence guidelines and secures our involvement from the outset as new guidelines and standards are developed to ensure improved outcomes for patients in the long term.
- Strengthening relationships between professional bodies and national initiatives for Stroke, particularly in relation to Stroke rehab.
- A number of specific service improvements where issues were highlighted and NNAG was able to intervene.

Coordination of service improvement priorities across neurology: The outcomes of our away days and core activity have begun to identify and address cross cutting priorities for neurology.

These include:

- Prioritisation of an NNAG mental health and neurosciences work stream in collaboration with the National Clinical Director for Mental Health.
- Prioritisation of an NNAG neurology care planning work stream
- Establishment of the Parkinson's Excellence Network mental health hub following the Parkinson's, Dementia and Psychiatry Away Day
- Development of the care pathway for people with Parkinson's and dementia by the London dementia clinical network, following the Parkinson's, Dementia and Psychiatry Away Day
- Wide clinical and patient group support and engagement in NHS RightCare's neuro toolkits and neurology GIRFT
- Development of a system of outpatient coding for neurology, working with several neurology centres across the country, as well as the national GIRFT team.
- Establishment of a neurology service managers network in partnership with Wilmington, including a one-day focused neurology managers meeting as part of the HSJ Integrated Care Summit in September.

4. Areas for improvement

Developing our strategic plan: Stakeholders have noted there can be a lack of clarity about the NNAG's priorities and expectations, as well as how it will go about delivering on its' strategic aims in the long term. This is in part due to the speed with which the NNAG has had to respond to immediate developments and issues within neurology and the lack of resources it has to support the group. The NNAG runs the risk of spreading itself too thinly in its efforts to tackle the vast challenges facing neurology. More needs to be done to consider how our priorities can get us on the agenda of those we want to influence to ensure uptake and sustainability of the good work that is being done. This impact report is the first attempt at documenting our progress, but a clearer system of reporting on progress toward our outcomes will achieve greater momentum.

Communicating our work:

The NNAG has become increasingly more transparent since it has been set up. The group has a section on The Neurological Alliance's website which includes its' logic model, terms of reference and work to date. However, more could be done to ensure that the wider neuro and non-neuro

More work is needed to clarify the work plan and understand how the NNAG is going to achieve its outcomes and strategic aims. This will allow the group to be more focused to reflect on the most appropriate levers to influence change. It is important to get this right because the NNAG provides the best opportunity to improve outcomes in neurology."

Val Buxton, Director of Strategic Intelligence and Excellence, Parkinson's UK

community feel regularly informed, involved and up to date with the work of the NNAG. This will ensure that we are able to influence at a local delivery level to improve outcomes. Development of more formal regional clinical networks and regular newsletter communications will support this.

Funding and resources: The motivation of NNAG's members is a key driver of its successes to date. There has been a lot of resource and energy put in to understand key strands of neurology and neurosciences and to ensure successful engagement in its activities and outputs. However, the group requires more resources to effectively develop and implement a strategy of work that can ensure a positive impact on outcomes in neurology over the long term. The current funding provided for the group is disproportionately propped up by the third sector which raises questions about sustainability and commitment to the group's future.

5. Our plans for the future - growing our impact in 2020 and beyond

We have ambitious plans to build on the momentum of activities in 2018/19 and ensure that the needs of neurology patients are prioritised and the outcomes which truly matter to them and their families are achieved. This is a pivotal time for the NHS and CRG, and while we are excited and encouraged by the various initiatives underway, we must not take our foot off the pedal.

Our priorities include:

- Continuing to support and enhance the work of the Neurosciences CRG
- Taking responsibility for the four additional Neurosciences Service Review work streams which will be led by the condition specific charities and the NNAG Programme Management team.
- Ensuring that the various quality improvement initiatives such as GIRFT, NHS Rightcare, Neurosciences review, Elective Care programme currently taking place are properly aligned and focused on the needs of patients.
- Delivering the 2019/20 programme of away days to include: Neurosciences and Mental Health, Headache, and Neurology Outcomes
- Developing the work of the care plan subgroup to deliver on planned outputs and outcomes
- Developing and clarifying the NNAG strategic workplan, ensuring that we reflect cross-cutting priorities across neurology, to ensure we offer the best possible vehicle for improving outcomes within our resources
- Expanding our stakeholder engagement and collaborative working approach, ensuring engagement all the way from national to local level. Ensuring that our membership includes all system improvement programmes that cover neuro
- Developing our communication channels to ensure that the work of the NNAG can effectively inform, involve and influence a wider audience, from clinicians to policy makers to commissioners and service managers, in order to achieve our strategic aims.
- Securing ongoing funding and commitment to the NNAG to ensure we can operate effectively to fulfil our aims.

6. Closing remarks

The NNAG has made significant strides towards achieving its strategic aims since it was first established. Already we are able to demonstrate the benefit a collaborative approach to lobbying, pathway development and neurology intelligence can have for improving outcomes for people with neurological conditions. The lessons learned so far, feedback, opportunities and challenges that are highlighted in this report require the unified approach which the NNAG provides. As the number of neurological cases in England continues to increase this is the time to strengthen and build on the work and plans thus far. Critical to achieving our full potential and ensuring an impact for patients is the commitment, support and engagement of our membership and wider neuro community to the NNAG over the long term.

“The NNAG has the freedom to be innovative and responsive in order to effectively support the wider system. The structure of the group allows NNAG to act like a think-tank reflecting the priorities and insight of the wider neuro community. This provides a sustainable model to enhance the work of the CRG in the long term.”

Professor Adrian Williams, Consultant Neurologist and Chair of the NHS England Neurosciences CRG, Co-Chair NNAG

Contact:

Hannah Verghese, NNAG Programme Manager

hannah.verghese@neural.org.uk

Appendix 1:

Organisations contributing written and verbal feedback

Association of British Neurologists (ABN)

Public Health England

Epilepsy Action

Sue Ryder

Neurological Alliance

NHS England, Clinical Policy Unit

NHS England, NHS RightCare

Parkinson's UK

Endnotes:

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- ⁱ Neurological Alliance, Falling short: How has neurology patient experience changed since 2014? March 2016
- ⁱⁱ <https://www.england.nhs.uk/statistics/2014/07/03/gp-patient-survey-2013-14/> (checked June 2019)
- ⁱⁱⁱ Neurological Alliance, Neuro Numbers 2019, March 2019
- ^{iv} National Neurology Intelligence Network National End of Life Care Intelligence Network, Public Health England, *Deaths associated with neurological conditions data analysis report. January 2018*
- ^v Neurological Alliance, Neuro Numbers 2019, March 2019