



The Neurological Alliance Members' Conference 2019: Towards a national plan for neurology

The national policy context

The Neurological Alliance Chief Executive Sarah Vibert and Professor Adrian Williams, Chair of the Neurosciences Clinical Reference Group (CRG), kicked off the event by giving an overview of the status of neurology in terms of national policy attention. Professor Williams described the work underway as part of the Neurosciences Transformation Programme, including pathways for epilepsy, MS and auto immune disease; plus, additional pathways being led by charities to look at Parkinson's and Movement disorders, MND and Muscular Dystrophy, headache and Functional Neurological Disorder. (More on this programme below).

Sarah spoke about the paradox that exists in that neurology is not a stated national priority – for example the word 'neurology' does not appear in the Long Term Plan - but there are a plethora of national improvement initiatives now focussing on neurology. She spoke about the challenge in translating these initiatives locally given the devolved NHS created by the Health and Care Act. Sarah noted that people living with neurological conditions are not yet feeling the benefit of improvement initiatives, and that rare neurological disease is often not included. Finally, Sarah questioned whether it is appropriate and sustainable for so many improvement initiatives to be resourced by the charity sector rather than NHS England.

The NHS England Neurosciences Transformation Programme

Priya Oomahdat, Head of the Neuroscience Transformation Programme and Lead Commissioner for NHS England and NHS Improvement spoke about the Neurosciences Transformation Programme, a 3-5-year NHS programme aiming to improve access to specialised and specialist neurology services.

The programme launched in 2018, with the first two years focused on development, and years 3-5 focused on implementation. A key part of successful implementation is defining specialised neurology at the development stage. The current definition is unclear, causing variation and gaps in services, as well as a range of capacity issues and an overall failure in effective commissioning.

So far, the Programme has identified what good practice looks like for three pathways: MS, epilepsy and neuro autoimmune. The process of designing the model is underway, and they hope to refine it and develop plans for implementation by August 2020.

After that, we heard directly from a panel of Patient and Public Voice representatives on patient group involvement in developing neurology pathways. The panellists were Caroline Morrice – Chief Executive of the GAIN charity; Angie Pullen – Epilepsy Services Manager at Epilepsy Action; and Georgina Carr – Head of Campaigns and External Relations at the MS Society. Overall, they spoke of a positive experience of taking part in the programme but stressed the importance of involving people with neurological conditions in the development of the final pathways.

Getting It Right First Time (GIRFT)

Our next speaker was Dr Geraint Fuller, Consultant Neurologist and Clinical Lead for GIRFT Neurology. Getting It Right First Time (GIRFT) is an NHS England and Improvement initiative designed to improve the quality of care within the NHS by reducing unwarranted variations in service delivery. The programme is clinically led, helping NHS trusts to share best practice and tackle variations in order to improve care and patient outcomes efficiently. Each clinical lead is tasked with compiling data and insights to produce a report that is shared and discussed with each Trust. Areas covered in discussions include concerns and variations highlighted in the report, and to share best practice and solutions that have proven successful in reducing variation.

Geraint outlined some challenges for the Neurology GIRFT programme such as the difficulty of measuring outcomes for a wide range of disorders, and the lack of coding of outpatient diagnoses. There are also problems at the organisational level, such as different services being offered in different types of hospital; the organisation of services differing by region; and significant activities like ward referrals not being unrecorded. Due to the different regional models that have developed over time, the Neurology GIRFT team created 'Neuroscience regions' based on current referral patterns, which provide a mechanism to compare services across England

Key findings to date include:

- Most regions provide care for patients within their region
- There is marked variation in service provision and organisation, both between regions and within regions
- A minority of patients admitted with neurological disorders are under neurologists
- Specialised Commissioning rules need revision in light of an unwarranted variation in spend per CCG, which inhibits development of local neurological services

GIRFT published its methodology and regional findings earlier in 2019. The full report and recommendations are anticipated later in 2020.

Learning from other disease areas: The National Stroke Programme

Mark McDonald, Deputy Director of Policy and Influence at the Stroke Association presented on the difference that RightCare and GIRFT have made to stroke care, as well as the extent to which having a National Stroke Programme has improved services.

Mark described the campaigning that was undertaken by The Stroke Association, based on robust data about need for improvements in care. As a result, stroke is listed as a clinical priority in the NHS Long Term Plan, and there is now a National Stroke Programme to deliver this policy commitment. The Stroke Association is closely involved in delivering the Stroke GIRFT programme, NHS RightCare pathway and sits on the National Stroke Programme board.

Mark shared key learnings from campaigning for stroke to become a national priority and subsequently supporting the delivery of the National Stroke Programme:

- There's no textbook. Be confident and learn from mistakes.
- Concentrate on a few people you trust to be able to pull the levers and be your allies.
- Don't beat yourself up or navel-gaze too much about the challenge of balancing being an emerging systems leader with an independent voice for patients and carers. If it doesn't feel right, take a different path.
- Don't be afraid to call out where things are going wrong.
- Work together with others as a sector to achieve change.

- Relentlessly champion the involvement of those with lived experience.

Elective Care Transformation Programme – Wave 5 neurology programme

Just before lunch, we heard from Amanda Woolley, Senior Policy and Implementation Manager for NHS England and NHS Improvement. The Elective Care Transformation Programme supports local health and care systems to manage rising demand for elective care services, and improve patient experience and access to integrated and personalised care. The programme consists of five waves of rapid testing to enable knowledge-sharing across the country in 14 high volume elective specialities.

Some of the ideas and interventions tested in neurology during Wave 5 include:

- Rethinking referral pathways
- Shared decision making and self-management support
- Transforming outpatients

Achievements in 100 days: a regional case study from North East Essex

- Implemented a new and improved headache pre referral guidance form.
- GP education around the existing standardised headache and migraine pathway.
- Increased responsiveness to GP calls for Advice and Guidance from 43.4% to 78%, by using out of area consultants via Consultant Connect. 72% of calls avoiding a referral to secondary care.
- Collaborative working between GP with Special Interest (GPwSI) providing existing community clinic and hospital based neurologists.
- Developed patient questionnaire to explore the patient experience.
- Overall waiting times for patients to see a neurologist reduced from 28 weeks to 25 weeks. Three months later this had further reduced to 24 weeks.

Overall the programme recommended that the purpose of outpatient care must be re-evaluated and aligned with modern day living and expectations. This requires trusts to be more flexible, allowing patients more control over when and how they receive care. You can be part of the Elective Care community of practice by emailing ECDC-manager@future.nhs.uk to request to join.

The neurology workforce

The final presentation was given by Dr Catherine Mummery, Consultant Neurologist, Chair of the Services Committee at the Association of British Neurologists (ABN), and Vice Chair of the Neurosciences Clinical Reference Group. She spoke about the latest data and trends concerning neurology staff in England, and the implications for the future of the neurological workforce.

Key facts include:

- There is a global shortage in the neurology workforce. The UK in particular is severely understaffed compared to other high income countries.
- New research by the ABN shows that a significant number of neurologists are less than full time, and almost all neurologists continue to do general neurology even if they specialise.
- Neurology depends on workforce from Europe more than all medicine does in terms of training, so there is pervasive worry about Brexit.
- Burnout and the recent pensions crisis are often cited as reasons for the shortage, as well as general insufficiency in training numbers.

- Fixing the problem will require training in critical areas such as thrombectomy, joint training with general medical practice, and new models of staffing.

Workshops

The conference closed with workshops. Members split off into groups to discuss the strengths and weaknesses of existing national improvement initiatives, and the pros and cons of continuing to call for a national plan for neurology. This fed into a final discussion on where The Neurological Alliance should focus our national policy activity over the next 12 months. Conclusions from the discussions include:

- We need to focus on implementation because we have developed the toolkits, so now is the time to get them into practice.
- We need to continue efforts to improve data (especially for rare disease) because “what gets measured, gets done”, and where there is existing data, we must work out how to use it to improve patient experience.
- We need to provide some coherence to the many different initiatives already underway to improve neurology. One way may be to write these up into a national plan and ask NHS England to endorse this.
- We need to create the collaborative space to achieve all these goals by bringing together clinical networks and teams who want to take on the improvement challenge.
- We need to prioritise creating a directory of conditions, so that people can get the information they need while they are on the pathway to diagnosis.
- Co-production with patients must be at the heart of our work.

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