NNAG National Neurosciences Advisory Group

Neurology Outcomes Discussion

September 2021
National Neurosciences Advisory Group (NNAG)

Author: Hannah Verghese
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Acknowledgements

Thank you to all the event speakers, facilitators and delegates for their contribution to the discussion. We would also like to thank the NNAG Outcomes Steering Group for their continued time and input into this important work.
The discussion was made possible by the support of our event sponsor, the University Hospitals Birmingham Charity, and we thank Mike Hammond, Chief Executive in particular for this.

On behalf of everyone involved we express our gratitude to NHS England and NHS Improvement Medical Director Professor Stephen Powis for providing the keynote speech, and for his continued support to improve services for people with neurological conditions and to NNAG.

Contents

1. Foreword

The development of outcome measures for the treatment care and support of people with neurological conditions is by no means a simple and straightforward undertaking. Outcomes for people with neurological conditions can often be distant, hard to measure, and hampered by the lack of treatments in some specialties. Additionally, implementing consistent measures across local systems requires innovative solutions to overcome the complex challenges presented by IT systems, lack of consistent outpatient coding and the workforce crisis.

The complexity of this task must not deter collective efforts. The time to act is now. The recent publication of the neurology Getting it Right First Time (GIRFT) report and incoming reforms to the NHS in England highlight the timely need to build consensus and define the outcome measures that will bring about meaningful transformation in the design, delivery and commissioning of care and treatments for people with neurological conditions.

This report marks an important step forward in the mission to improve outcomes and experience of care for people with neurological conditions. But there is still much work to be done and we must not lose momentum. It is now critical that NHS England and NHS Improvement, alongside the neurological community, take forward the recommendations in this report to address how we understand, measure and improve care for people with neurological conditions. Collaboration and co-production with people affected by neurological conditions is fundamental to the design, development, implementation and evaluation of outcome measures.

Looking ahead, the implementation of the GIRFT recommendations, optimum clinical care pathways and evolving treatment options present opportunities to transform neurological care. As we move forward to a reformed NHS and care system clear measures and expectations of treatment and care, underpinned by a robust outpatient clinical coding system and insight driven data analysis, will allow us to critically understand and invest in services that are fit for the future. Most importantly, they will allow us to improve treatment, care and support that enable the greatest positive impact for people with neurological conditions.

Georgina Carr and Prof. Adrian Williams
Co-Chairs of the National Neurosciences Advisory Group (NNAG)

2. About the report

This report summarises the online NNAG Neurology Outcomes Discussion on 14th September 2021. The purpose of the event was to bring together the neurological community to support the development of common service and patient experience outcomes for people living with neurological conditions. This work, led by NNAG, focuses on the optimum clinical pathway areas developed via the NHS England and NHS Improvement Neuroscience Transformation Programme and NNAG.

This report summarises the key points from the panel discussions, presentations, and breakout groups. We also set out recommendations to be taken forward by NHS England and NHS Improvement, NHS Digital, NNAG and the wider neurological community.

The following online resources accompany this report and should be used alongside it:

- **Neurology Outcomes Discussion: Event recording**
- **Information on the optimum clinical care pathways for neurology**

3. About NNAG

NNAG is a collaboration of professional bodies, patient groups, national and local policy and commissioning leads. We exist to improve treatment, care and support for people with neurological conditions. As the only national, multidisciplinary expert group working to improve treatment, care and support for people with neurological conditions, NNAG plays a central role in helping to understand the impact, as well as rebuild, during and after the COVID-19 crisis.

4. Executive summary

Prior to the COVID-19 pandemic people with neurological conditions faced significant unwarranted variation in treatment, care and support across neurological services. Experience of neurological care is significantly variable across the country,[1] as is spend on services.[2] The COVID-19 pandemic has had a farreaching adverse impact on people with neurological conditions, neurological services and the workforce.[3] Of particular importance in the immediate term is addressing the significant backlog of neurological, neurosurgical, and outpatient rehabilitation appointments due to the pandemic.

As the NHS priorities focus on recovery and reform, it is essential that neurological services are not left behind. Developing and implementing an efficient and effective set of outcomes in neurology will improve standards of care, and help the NHS to make longstanding improvements to neurology healthcare quality: effectiveness, experience, safety, availability, timeliness, and cost-effectiveness. Robust measures, that are valued by patients and clinicians, are essential to support commissioning based on optimum care. This will ensure that people with neurological conditions get the treatment, care and support they need.

The September 2021 NNAG Neurology Outcomes Discussion marked an important step forward in the development of an agreed set of outcome measures. The recommendations from the discussion set out what must happen next to progress this work.

- Agreed outcome measures, implemented and used consistently across the system, are critical in addressing health inequalities, unwarranted variation and the improvement of services for people with neurological conditions.
- There is a plethora of work undertaken in this area, and data that is already being collected, to assist in the development of agreed outcome measures.
- The collection of outcome data must be simple and easily recorded digitally through normal clinical practice to ensure buy in from clinicians and patients. It must be underpinned by a robust, standardised system of neurology outpatient coding.
- A patient expectation framework has the potential to judge service standards and enable services to develop efficiently.
- A multidimensional approach to an expectation framework, considering the needs of patients, clinicians, larger workforce, trusts and Integrated Care Systems (ICSs) will allow assessment of what is needed across the system to improve patient outcomes and experiences.

[1]McIntosh, K, Vibert, S 2018/19 National Neurology Patient Experience Survey **https://www.neural.org.uk/resource_library/neuro-patience -** Accessed on 19 Oct 2021

[2]Geraint Fuller, Maddy Connolly, Cath Mummery, Adrian Williams (2019) GIRFT Neurology Methodology and Initial Summary of Regional Data, **https://gettingitrightfirsttime.co.uk/wp-content/uploads/2017/07/GIRFT-neurology-methodology-090919-FINAL.pdf -** Accessed 19 Oct 2021

[3]Verghese H, Carr C (2021) Lessons Learnt from the COVID-19 pandemic. Priorities in care for people with neurological conditions. A report by the National Neurosciences Advisory Group **https://www.nnag.org.uk/publications** – Accessed 19 Oct 21

- Patient co-production is critical in the design of successful outcome measures, frameworks and service design.
- Collaboration with the neurological community, represented by NNAG, Neurological Alliance and the Association of British Neurologists (ABN), alongside the NHS England and NHS Improvement Neuroscience Transformation Programme, GIRFT, the Outpatient Transformation Programme, Neuroscience Clinical Reference Group (CRG), NHS RightCare and local ICSs, is essential for both designing and ensuring the implementation of outcome measures for neurology in the reformed NHS.

5. Our recommendations

1. The ABN, alongside patient groups, and NNAG should set out a multi-dimensional expectation framework - based on the optimum clinical care pathways and findings in this report - to guide long-term improvement of care and patient outcomes.
2. NHS England and NHS Improvement should work with NNAG, the Neuroscience Intelligence Collaborative (NIC), patient groups, people with neurological conditions and professional bodies to establish clear nationally standardised measurements of care for neurology. These measures should support the narrowing of health inequalities and a richer understanding of unwarranted variation in access, outcome and experience of care for people with neurological conditions.
3. NHS England and NHS Improvement should mandate a robust system for neurology outpatient coding which is clinician led.
4. NHS England and NHS Improvement should mandate a national audit for neurology.
5. Local and national organisations and systems should work in partnership with people with neurological conditions to co-produce pathway and service design and evaluation from the earliest stages, ensuring that they are central to work to develop and implement measurements of care in neurology.
6. NHS England and NHS Improvement programmes - including GIRFT, the Neuroscience Transformation Programme, the Outpatient Transformation Programme, Neuroscience CRG, NHS RightCare and ICSs should work in collaboration with NNAG, the Neurological Alliance, and the ABN, to ensure alignment across all programmes to improve outcomes for people with neurological conditions.

6. Summary of presentations, panel discussions and breakout groups

Chair and Keynote speeches:

Welcome and introduction to the event

Professor Adrian Williams, Chair of the NHS England and NHS Improvement Neuroscience CRG, Co-Chair of NNAG

You can watch Professor Williams' presentation in full **here** (02:33 - 06:22)

- Good outcome measures lead to better care. It is therefore a priority to define such measures as has been done in neurosurgery and stroke.
- This is an important time for neurology and as such this discussion is very timely:
  - The NHS England and NHS Improvement GIRFT neurology report has very recently been published
  - The NHS England and NHS Improvement neuroscience CRG, with NNAG and the ABN has led the development of 12 sub-specialty neurology and 4 cross cutting theme optimum clinical care pathways
- Whether generic or pathway specific, outcome measures must be co-produced with people with neurological conditions.
- The purpose of this discussion is to gain consensus on measures to leverage better care not to "create a stick to beat us with".
- Importantly the measures we agree must be easy to do and record through normal clinical practice.

Keynote speech

Professor Stephen Powis, National Medical Director, NHS England and NHS Improvement

You can watch Professor Powis's presentation in full **here** (11:24 - 26:56)

- During the pandemic NHS England and NHS Improvement have also been thinking about non-COVID priorities, specifically the delivery of the long-term plan. The pandemic has shone a huge light on health inequalities, for example, and this is rightly prioritised in the plan.
- Outcome measures can help reduce and tackle health inequalities.
- The following 3 lenses should be considered when developing outcome measures:
  1. The 3 different view points on outcomes:
     - Patient and public point of view - Patient Reported Outcome Measures (PROMS) are the best known of such outcomes but not the only ones
     - Clinicians' point of view
     - Managers/planners/ commissioners point of view (these may be the same as clinicians and patients with a bit more of a focus on process)
  2. Use what is already out there:
     - A lot is already measured by clinicians across the NHS in England, and therefore is relevant to what we have
     - Developing it further is a place to start
     - The easier an outcome is to measure (ideally through a digital system) the more buy in there will be

3. Addressing unwarranted variation:

    - One of the great benefits of measuring outcomes is not just for us, patients and the public to see our clinical and operational performance, but that we can use this to see where unwarranted variation occurs and understand where best practice isnot being applied
    - The GIRFT programme does exactly this

- Outcome measures that fulfil all 3 criteria mentioned above, if possible, are ideal.
- As neurologists and people with a special interest in neurology you know this best.
- The GIRFT programme and The Quality Team are avenues to explore to put this work into practice.

Session 1

Priorities for outcome measures in neurology - where are we trying to get to?

Panel discussion
David Martin, Chief Executive of the MS Trust (Chair)

You can watch the panel discussion in full **here** - (27:22-1:27:33)

Georgina Carr, Chief Executive, Neurological Alliance, Co-Chair of NNAG

- What good care looks like, and what the outcomes that go along with that are important if we are going to drive forward standards of care.
- It is valuable for people to know what the end goal is in their care, supporting adherence, decision-making and experience.
- Good, agreed outcomes of care can also help to close the perception gap between patients and clinicians. This should be underpinned by good care coordination and good care planning.

Dawn Golder, Executive Director, FND Hope UK

- People with Functional Neurological Disorder (FND) experience care in an inequitable way.
- People with FND are moved around the system and can get stuck in a cycle of GP, A&E, Neurology, and often discharged or put on an unsuitable pathway.
- Community rehab services are often not commissioned to work with FND patients.
- People with FND face significant stigma and many lose faith in the health system. They can become anxious, depressed and suicidal.
- People with FND can wait months or even years for specialist help which has additional health, social and economic impacts.
- The average duration for diagnosis to treatment for FND patients is around 2 years.
- Patients should be referred and seen by an appropriate health professional in a timely manner. They should be assessed in a timely manner, be given information and a care plan.
- Patients should be seen locally and have rapid access to appropriate treatment. This will improve quality of life and have significant health and social care savings.

Professor Mark Edwards, Consultant Neurologist, St George's University Hospitals NHS Foundation Trust

- Patient knowledge and experience is fundamental in designing outcomes.
- Capturing outcomes is complex. Certain clinical outcomes or changes may not translate to people's experience of their condition, or changes to whether they can live well and have better quality of life. Additionally objective social and economic changes (such as use of health services) might be noticed despite no change in patient reported outcomes.
- A multi-dimensional approach to assessing outcomes - considering mechanistic, patient experience, patient knowledge and control, objective clinical and economic changes - is really important. If we don't take a multi-dimensional approach we may be missing things that treatments or services are doing.
- Some outcomes will be common across conditions and we may be able to find universal measures that apply across neurological and neuropsychiatric conditions, and other condition areas.

Professor Jeremy Hobart, Consultant Neurologist, University Hospitals Plymouth

- Consider the following carefully in the following order:
  - Why are we interested in measuring outcomes?
  - What to measure
  - How to measure it
- Services can be measured against specific patient expectation measures. This is a way to judge service standards and enabling services to develop.

Group discussion

- The long term outcomes for people with neurological conditions are often very distant.
- The concept of meeting expectations could avoid arbitrary, poorly designed measures. If we do not design this outcomes will be imposed on us. A conceptual framework will allow us to decide where to pitch outcome measures at a particular time.
- An expectation framework is close to both the optimum clinical care pathway and GIRFT approach.
- An expectation framework could be broadened to a multidimensional approach, starting with patient expectation and building beyond (commissioner expectations, clinical expectations and so on).
- Patient organisations have been engaging with people with neurological conditions and are well placed to develop expectation frameworks.
- If services are co-designed with patients this would set patient expectations at the outset.
- Workforce and resource will be relevant to the ability for services to meet expectations.
- Cultural differences will influence patient expectations and that is an important consideration in the development of an expectation framework.

Session 2

Neurology GIRFT National Speciality Report

Dr Geraint Fuller, Clinical Lead for Neurology GIRFT, NHS England and NHS Improvement

You can watch Dr Fuller's full presentation **here** (1:35:03 - 1:55:30)

You can read the Neurology GIRFT report **here**

- Access to a service, or not, is an outcome measure.
- Be cautious about diagnostic dependent measures which rely on accurate diagnosis.
- It's important to capture the whole relevant population rather than just those who get to see a neurologist/ access a service.
- Systematically collected data, such as the Sentinel Stroke National Audit Programme (SNAPP), has the power to improve services.
- We need to try to align our data collection and our clinical activity so that the information is collected routinely.
- Data collected should encourage good practice rather than lead to unintended "target driven" behaviour.
- The GIRFT data set provides a context and framework of how our services are delivered. We need to build on this with a systematic collection of information to allow us to move forward.
- The GIRFT report proposes a neurology dashboard as one way forward.

Why do outcomes matter for the 'system'?

Panel discussion:
Sammy Ashby, Deputy Chief Executive, SUDEP (Chair)

You can watch the panel discussion in full **here** - (1:55:02 -2:28:45)

Michael Jackson, Head of Health Intelligence (Neurology and Dementia), Public Health England

- Outcomes are an integral part of the public health agenda. They help us understand health inequalities, where unwarranted variation exists, and areas for improvement. They are relevant to both secondary prevention (prompt, early accurate diagnosis), and tertiary prevention (good management of the health condition following a diagnosis through treatment and care plans).
- The consequences of poor outcomes in public health prevention could be a late diagnosis resulting in emergency rather than elective diagnosis, impacting prognosis and quality of life, greater health and economic cost, and impact on service capacity.
- Requirements for measuring outcomes in relation to data include agreed definitions of outcome measures and their context which allows the triangular of data collection of pertinent issues, minimum dataset of what needs to be collected and how it is collected, training and guidance for data collectors, data collection systems to allow the flow of data, and agreed approaches for analysis of data.

Professor Hedley Emsley, Consultant Neurologist, Lancashire Teaching Hospitals, NHS Foundation Trust

- The concept of an outcome being measurable is critical. This enables us to review outcomes and establish standards.
- Standardised neurology outpatient coding is important for measuring outcomes.
- There is currently no routine standardised system for neurology outpatient coding nationally.
- Optimal service design requires detailed activity data, not limited just to the volume of activity but describing activity in diagnostic terms. As well as informing service design, diagnostic coding will support work on clinical outcomes.
- We need robust clinical engagement and clinical leadership to ensure change.
- The capture of coding data must be quick, simple and pragmatic, linked to the capture of outcomes, with maximal clinical engagement to be successful.
- SNOMED-CT is more likely to get engagement because it includes clinical terminology. Visualising data in diagnostic terms is incredibly powerful for influencing service design and thinking about how we are operating.

Dr Niranjanan Nirmalananthan, Consultant Neurologist, St George's Hospital, Chair of the Neuroscience Network for South West London and Surrey ICS

- The NHS reforms and changes to commissioning for neuroscience will require us all to work more collaboratively and across commissioning boundaries. It is a huge opportunity to improve care, and absolutely critical that we agree the right outcome metrics from the outset.
- The system's goal is the same as patients and clinicians, that is to improve patient outcomes and experience. From the system perspective there is a fixed budget and a lot of competing priorities. Decisions need to be made regarding quality, safety, effectiveness and equity. There may be trade-offs in care, and so there must be some comparability of services when you look at outcomes.
- ICSs provide an opportunity to look holistically, beyond just secondary and tertiary care to primary and community care too.
- Currently most of our commissioning decisions are monitored through process based outputs which measure the process of delivering care but don't tell you anything about outcomes or patients. They tend to tell us about demand fo services rather than the needs of the patient community.
- As well as experience and service level outcomes it is also worth looking at strategic outcomes at an ICS level. For example the goal of the NHS England and NHS Improvement long-term plan of delivering care closer to home and equitable access.
- The data must be consistent across services, simple to collect, and be reviewed systematically consistent data will speak to a wide variety of audiences.
- When we work closely as regional networks with outcome measures we can support patient flow and collect some of the non standard outcome measures as part of routine practice.

- To understand the system as a whole you need a combination of input metrics (service location, workforce etc.) and activity and prescribing data.
- Outcome metrics need to be minimal core data sets, similar to SNAPP for stroke but accounting for the heterogeneity of neurological conditions.
- Pulse surveys are a good way to measure patient experience.

Session 3

Proposed outcome measures in neurology pathways

Georgina Carr, Chief Executive, Neurological Alliance, Co-Chair of NNAG (Chair)

You can watch the presentation and feedback in full **here** (2:39:03 - 2:46:07)

- Consultations on the draft optimum clinical care pathways and input from the ABN Advisory Groups have enabled us to gather intelligence on key outcome areas in neurology and split them into 3 key areas:
  1. Clinical and commissioning outcomes
  2. Health and care system activity
  3. Patient-reported outcome measures (PROMS) and patient-reported experience measures (PREMS)
- Delegates were separated into breakout groups, reflecting each of the 3 themes, to consider the following questions:
  - What is desirable to collect in practice? Why?
  - What is feasible to collect in practice? Why?

Breakout Group 1: Clinical and commissioning outcomes

- Basic Principles/Domains:
  - Quality: Access to services- patient and commissioner; Psychometric robustness of measures
  - Referrals
  - Agency: Patient Activation
  - Adverse effects of treatment: Harm
  - Morbidity and mortality
  - Quality of life
  - Efficacy
  - Safety
  - Patient experience/expectation
  - Efficiency
- Need to capture both the generic measures - which need to be high level - and the condition specific measures:
  - Generic allows the comparability between services- this should be where the next conversation starts- what would work well to compare services across neurology
- Balance of outcomes used is important eg: patient with epilepsy: seizure free vs poorer QoL.
- Mapping outcome measures against domains will enable us to see where they fall:
  - Consider a matrix of measures identifying domains and expected outcomes
- When capturing data it is best if it is commissioned and there is payment linked to it.
- It is important what level the data is captured at- what is generic and can be applicable across the pathway?
- Continuity of measure across patient pathway is important to capture the community aspect.
- Local Rehab prescription that defines need can be used as a tool for monitoring.

Breakout Group 2: Health and care system activity

- Neurology GIRFT recommended outcomes are being used - number of primary care referrals, time to first appointment in general neurology, unplanned diagnosis, number of patients previously diagnosed and admitted more than once in the last year, staffing numbers.
- A central digitalisation is needed so that we are capturing the data correctly.
- Examples of specific recommended outcomes:
  - MS drug usage
  - No. of Parkinson's disease patients referred to regional services
  - No. of epilepsy patients referred for surgery
- A focus is needed on the beginning of the pathway which will allow the rest of the pathway to flow. Consider the following 3 outcome areas:
  - Implementing the outcomes
  - Time to referral
  - Investigation, diagnosis and care plan
- Therapy outcome measures are already in use, and the metrics can be used without the need to reinvent the wheel. These understand progress of condition, independence of person, participa-tion levels and intervention classification.
- Qualitative data from patients is important. The question "what could we have done better for you" can lead to a great understanding of what is required.

Breakout Group 3: Patient-reported outcome measures (PROMS) and patient-reported ex-perience measures (PREMS)

- The group were encouraged by the concept of expectation frameworks and consideration should be given to this going forward.
- Consensus around what would be a realistic expectation is needed.
- There are commonalities in the optimum clinical care pathways. For example, care planning and care coordination, for example, run across all. These can provide building blocks for more detailed consideration.
- There is a concern regarding accountability of the system to use what we come up with. However if we can collaborate and agree this as a community then we are well placed to make the case for its structural reforms are implemented.

Closing remarks

Professor Adrian Williams, Chair of the NHS England and NHS Improvement Neuroscience CRG, Co-Chair of NNAG

You can watch Professor Williams' closing remarks in full **here** (3:32:27 - 3:34:59)

- We will look back on this meeting as a big step forward.
- Our next steps are to look at the long outcome list within the context of this discussion.
- NNAG takes a deliberative democratic approach and we hope to reach a consensus across all perspectives with the outcome set.
- Thank you to everyone who has been involved, contributed and supported this work. This is only the beginning.

7. Appendixes

Appendix i

Neurology Outcomes Discussion Attendees

Name	Surname	Job Title	Organisation
Hannah	Verghese	Programme Manager	NNAG
Dawn	Golder	Executive Director	FND Hope UK
Rachel	Dorsey-Campbell	Senior Neurosciences Pharmacist	Imperial College NHS Trust
Anne-Marie	Logan	Consultant Physiotherapist in Headache	St George's University Hospitals, London
Adine	Adonis	Clinical Specialist Physiotherapist Neurology	ACPIN
James	Mitchell	Lecturer Neurology and Rehabilitation	MoD, University of Birmingham
Amanda	Swain	Consultant Practitioner, Neurorehabilitation	NAABIC Ltd, NHS, UKABIF
Carol	Amirghiasvand	Interim CEO	PSPA
Maria	Gogou	Senior Clinical Fellow in Paediatric Epilepsy	Department of Neurology, Evelina London Children's Hospital
Jeremy	Hobart	Consultant neurologist/Prof health measurement	NHS/Plymouth University
Sammy	Ashby	Deputy Chief Executive	SUDEP Action
Angie	Pullen	Epilepsy Services Director	Epilepsy Action

Name	Surname	Job Title	Organisation
Shelley	Jones	Consultant Pharmacist, Neurosciences	Kings College Hospital
Donna	Malley	Occupational Therapy Clinical Specialist	The Oliver Zangwill Centre for Neuropsychological Rehabilitation
Laura	Cockram	Head of Policy and Campaigns	Parkinson's UK
Jon	Dickson	Senior Clinical Lecturer and GP	The University of Sheffield
Peter	Jenkins	Consultant neurologist	Hampshire Hospitals Trust
Katherine	French	Service Improvement Programme Manager	Parkinson's UK
Bobby	Ancil	Head of Health Service Development and Campaigns	Muscular Dystrophy UK
David	Martin	CEO	Ms Trust
Richard	Greenwood	Neurologist	NHS
Rob	Music	Chief Executive	The Migraine Trust
Jon	Sussman	Consultant neurologist	Manchester Centre for Clinical Neurosciences
Alex	Massey	Policy manager	Motor Neurone Disease Association
Alasdair	Coles	Prof of Neuroimmunology	University of Cambridge
Neil	Bindemann	Exec Director	Innervate Ltd
Pam	Enderby	Emeritus Prof Community Rehabilitation	Sheffield University

Name	Surname	Job Title	Organisation
Lee	Morgan	Student dietitian	University of Plymouth
Colin	Bannon	Healthy living clinic doctor	Torbay NHS Trust
Sandra	Bartolomeu Pires	PhD candidate and Research Sister in Neuro	University Hospital Southampton NHS Foundation Trust
Susan	Mitchell	Head of Policy	Alzheimer's Research UK
Michael	Jackson	Head of Health Intelligence (Neurology and Dementia)	Public Health England
Mark	Edwards	Neurologist	St George's University Hospitals, London
Sally	Davies	Regional Neurological Director	Sue Ryder
Niranjanan	Nirmalananthan	Consultant Neurologist	St George's University Hospitals, London
Ambra	Caruso	Senior Transformation Manager	SWL Clinical Networks
Nicola	Giffin	Consultant neurologist	Royal United Hospital, Bath
Duncan	Blair	Civilian Medical Practitioner	Defence Primary Healthcare
Arani	Nitkunan	Consultant Neurologist	Croydon University Hospital and St George's Hospital
Rowan	Wathes	Associate Director Parkinson's Excellence Network	Parkinson's UK
Sophie	Molloy	Consultant Neurologist	Imperial College London

Name	Surname	Job Title	Organisation
Julie	Riley	Divisional Director of Neurology	The Walton Centre
Cheryl	Craigs	RightCare product manager	NHS England
Jon	Sussman	Consultant Neurologist	Manchester Centre for Clinical Neurosciences
Camille	Carroll	Associate Professor Neurology	University of Plymouth Faculty of Health
Victoria	Wareham	Director of Operations and Development	Dystonia UK
Stuart	Weatherby	Consultant Neurologist	Plymouth
Anne-Marie	Logan	Consultant Physiotherapist in Headache	St Georges University Hospitals NHS Foundation Trust
Jon	Sussman	Consultant Neurologist	Manchester Centre for Clinical Neurosciences
Michael	Dilley	Consultant Neuropsychiatrist	King's College Hospital
Amanda	Swain	Director, NAABIC. UKABIF Vice Chair. NHS ABI	UKABIF
Peter	Jenkins	Consultant Neurologist	Imperial College London
David	Martin	CEO	MS Trust
Lisa	Collard	Programme Associate	NHS England
Richard	Greenwood	Consultant Neurologist	UCH
Paul	Cooper	Consultant Neurologist	Salford Royal

Name	Surname	Job Title	Organisation
Catherine	Mummery	Consultant Neurologist, Chair ABN services committee	Queen Square Institute of Neurology
Dawn	Golder	Executive Director	FND Hope UK
Sue	Millman	Chief Executive	Ataxia UK
Martin	Wilson	Consultant neurologist	Walton Centre
Chris	Bradshaw	Chair of Trustees	Dystonia UK
Waqar	Rashid	Consultant Neurologist	St George's University Hospitals, London
Paul	Morrish	Neurologist	
Elaine	German	Consultant Clinical Neuropsychologist	King's College Hospital
Marc	Smith	CEO	The Brain and Spine Foundation
James	Mitchell	Clinical Lecturer Neurology	Defence Medical Rehabilitation Centre
Oliver	Bandmann	Professor of Movement Disorders Neurology	University of Sheffield
Eileen	Joyce	Professor of Neuropsychiatry	UCL Queen Square Institute of Neurology
Diane	Playford	Professor of neurological rehabilitation	BSRM
James	Mitchell	Neurology Registrar and ABN Fellow	University of LIverpool
Maria	Gogou	Senior Clinical Fellow Paediatric Epilepsy	Evelina London Children's Hospital
Sam	Mountney	Policy and External Affairs Manager	The Neurological Alliance
Sally	Hughes	Assistant Director of Care	Motor Neurone Disease Association

Name	Surname	Job Title	Organisation
Michaela	Regan	Senior Health Policy Manager	Muscular Dystrophy UK
Kripen	Dhrona	Operations	The British Polio Fellowship
Laura	Cockram	Head of Policy and Campaigns	Parkinson's UK
Sandra	Bartolomeu Pires	Research Sister and PhD candidate	University Hospital Southampton NHS Foundation Trust
Frances	Quinn	Trustee and Expert Panel deputy chair	British Polio Fellowship
Ben	Sanders	Senior Project Manager	NHS England
Brendan	Davies	Clinical Lead and Consultant Neurologist	Neurology, University Hospital North Midlands
Sam	Shribman	Neurology Registrar	UCL Queen Square Institute of Neurology
Ralph	Gregory	Neurologist	
Poole Hospital and Dorset County Hospital	Joyce	Professor of Neuropsychiatry	UCL Queen Square Institute of Neurology
Zeshan	Mahmood	Service Transformation Manager	NHS England
Julia	Brown	Helpline Team Leader	PSP Association
Najma	Khan-Bourne	Consultant Clinical Neuropsychology	Division of Neuropsychology
Andria	Merrison	Consultant Neurologist	North Bristol NHS Trust
Phil	Tittensor	Consultant Nurse	The Royal Wolverhampton NHS Trust

Appendix ii

NNAG Outcomes Steering Group

- Professor Adrian Williams, Chair of the NHS England and NHS Improvement Neuroscience CRG, Co-Chair of NNAG
- Georgina Carr, Chief Executive, Neurological Alliance, Co-Chair, NNAG
- Professor Chris Kipps, Consultant Neurologist, University Hospital Southampton NHS Foundation Trust
- Dr Cath Mummery, Consultant Neurologist, National Hospital for Neurology and Neuroscience, UCLH
- Hannah Verghese, Programme Manager, NNAG
- Dawn Golder, Executive Director, FND Hope UK
- Professor Hedley Emsley, Consultant Neurologist, Lancashire Teaching Hospitals, NHS Foundation Trust
- Dr Jon Sussman, Consultant Neurologist, Manchester Centre for Clinical Neurosciences, Sal-ford Royal Foundation Trust
- Dr Martin Wilson, Consultant Neurologist and Clinical Director,The Walton Centre NHS Foundation Trust
- Fredi Cavander-Attwood, Policy Manager for Health and Social Care, MS Society
- Michael Dilley, Consultant Neuropsychiatrist in Brain Injury,King's College Hospital NHS Foundation Trust

NNAG National Neurosciences Advisory Group

Contact:
Hannah Verghese
NNAG Programme Manager
hannah.verghese@neural.org.uk