

NNAG Clinical Leaders Day write up

December 2018



THE
NEUROLOGICAL
ALLIANCE



Association
of British
Neurologists



Document control

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Contents

Event description.....	1
1. Summary of presentations	2
1.1 A National Perspective – Professor Adrian Williams.....	2
1.2 What is important to Neurology patients – Katharine McIntosh.....	3
1.3 Latest policy developments in specialised neurosciences – Mr Paul Grundy and Professor Steve Sturman	4
1.4 National Service Review of Neurosciences – Professor Adrian Williams and Mr Paul Grundy.....	5
1.5 Neurology Getting It Right First Time – Dr Geraint Fuller	6
2. Summary of discussions.....	8
2.1 Breakout 1 – Regional Groups.....	8
2.2 Breakout 2 – Themed groups	10
3. Next steps.....	12
4. Appendices.....	13
Appendix 1 - Attendees.....	13

Event description

The National Neuro Advisory Group (NNAG) exists to seek alignment between programmes in NHS England, the Department of Health's Arm's Length Bodies and system partners, such as charities relevant to people with neurological conditions, and to guide the strategic development of work to improve outcomes for people living with neurological conditions. One of the aims of NNAG is to bring together all the different professionals that need to work together to achieve improvement in neurology services, including clinicians, patients, commissioners and academics.

On the 5 December 2018 the NNAG held its second Clinical Leaders Away Day. The day was hosted by Professor Adrian Williams, Chair of the NNAG and the Neurosciences Clinical Reference Group and Sarah Vibert, Chief Executive of the Neurological Alliance.

The aims of the day were for Clinical Leaders to:

- Develop relationships regionally and nationally
- Share best practice and new models of care
- Share information on local and national initiatives
- Identify the challenges faced and in Neurosciences and seek solutions

The morning focused on national initiatives with presentations from Professor Williams, Katharine McIntosh (Neurological Alliance), Mr Paul Grundy (Vice-chair, Neurosciences Clinical Reference Group), Professor Steve Sturman (Clinical Lead for the Specialised Neurology Specification) and Dr Geraint Fuller (GIRFT Neurology Lead). In the afternoon delegates split into regional groups to discuss local issues, followed by themed groups to discuss specific issues including:

- Thrombectomy
- Coding
- Care planning
- Neurorehabilitation
- Acute neurology and stroke

This document provides a summary of presentations and discussions held on the day and should be read in conjunction with the corresponding slide pack. The presentations have been kindly made available by the speakers and may be used to support the further exploration of the themes and outcomes of the day.

1. Summary of presentations

1.1 A National Perspective – Professor Adrian Williams

Professor Williams opened the day with an overview of some of the national programmes for Neurosciences, including the Neurosciences Clinical Reference Group, the National Neuro Advisory Group and the Neuro Intelligence Collaborative. He explained that there is the opportunity and willingness for Clinical Leaders to come together with NHS England and Getting It Right First Time (GIRFT) to drive forward service improvements. Although he emphasised that the critical element will be ensuring that efforts are joined up.

Neurosciences Clinical Reference Group

The NHS England Neurosciences Clinical Reference Group (CRG) includes Neurosurgery, Neurology, Neuropsychiatry, Neurophysiology, and Interventional Neuro-Radiology, their remit is Specialised Commissioning.

Professor Williams outlined the main roles of the CRG being:

- The provision of advice and guidance / consultations to questions and reviews coming through parliament e.g. Medicinal Cannabis. They have established a system to co-ordinate the responses to these with the Association of British Neurologists (ABN) and Society of British Neurosurgeons (SBNS).
- The development of service specifications for specialised services.
- Developing links with the Paediatrics, Trauma and Rehabilitation CRG's to create a wider sphere of influence.
- The CRG also has a formal link to NIHR and can identify priorities for future research.

In addition to this, current topics that the CRG is leading on include Thrombectomy, MS and Immunotherapy. They also have a future priority to look at Frailty pathways to ensure that co-morbidities are considered when care planning. This will result in improved decision making as to what intervention is best for the patient, and improved pre and post intervention preparation.

National Neuro Advisory Group

The National Neuro Advisory Group (NNAG) has focused on condition specific workshops throughout 2018. The aim of these days has been to bring different stakeholders together and identify what good looks like for that cohort of patients. The workshops held were:

- Neurorehab
- Neuromuscular
- Parkinson's, Dementia and Psychiatry
- Epilepsy

Write ups from each of the workshops have been published on the Neurological Alliance website (<https://www.neural.org.uk/national-neuro-advisory-group/>)

The Neuro Intelligence Collaborative

The Neuro Intelligence Collaborative is a sub group of the NNAG and bringing together different organisations working with data, such as the Neuro Intelligence Network, Right Care and GIRFT. The aim of the group is to understand where the gaps are in data relating to neurosciences, to co-ordinate efforts to address those gaps, avoid duplication or contradictions, and ensure that data can be used as an effective instrument or lever for service improvement.

In addition to the national programmes there are opportunities for service improvement at regional level, through the regional neuroscience centres, through the STP's and CCG's and through the Academic Health Science Networks. There are also opportunities at local level through Clinical Service Leads and their managers developing business cases for new models of care.

Professor Williams concluded by emphasising that leadership needs to happen at all levels and be joined up to make change happen.

1.2 What is important to Neurology patients – Katharine McIntosh

Katharine McIntosh, Senior Policy and Campaigns Adviser for the Neurological Alliance then presented on 'What is important to neurology patients?' as established by the Neurological Alliance patient experience survey.

The Neurological Alliance is an umbrella organisation for charities campaigning together to improve outcomes and experience for patients with neurological conditions. The Neurological Alliance are currently rolling out their third patient experience survey which gathers evidence on the state of Neuroscience services from the patient perspective. The data also provides an evidence base for the need to improve care in Neurology.

Katharine explained they have changed the methodology for this round with the survey being distributed in clinics as well as online to try and increase the number of responses. If you would like more information on the survey, please contact Katharine (Katharine.mcintosh@neural.org.uk).

Key findings from the last survey, conducted in 2016, were that patients want:

- 1) Timely diagnosis that is communicated in a sensitive manner

Respondents described a fight to be referred to Neurology services, and then once they were referred a long wait for appointments. Nearly a quarter (24%) of respondents saw their GP six or more times before being referred to a neurologist. After seeing a neurologist, the time taken to

receive a confirmed diagnosis ranged from 33% in less than three months to 17% waiting up to 12 months.

2) People want to be able to live life to the full, as far as possible with their diagnosis

Enablers identified to support them in doing this were; optimising physical and mental health, setting individual goals and ensuring financial security. Health professionals played an important role in supporting patients with this.

3) Timely treatment close to home

It is important for patients to receive timely access to treatment or symptom management, when treatment is delayed people feel like they are left in limbo or can't get on with their life. The majority of patients (51%) did report timely access to treatment.

4) Tailored support and information

It is recognised that there is limited time available in clinics to discuss a new diagnosis, however patient organisations can help here by providing the right information for the patient's condition and support them to self-manage.

5) Well-coordinated care

Patients want information to be passed on between teams and to be treated as a whole person, not just a specific condition.

Katharine concluded with a summary of free text responses received, these demonstrated that generally patients praised the healthcare professionals providing their care and were supportive of the NHS and services it offers.

1.3 Latest policy developments in Specialised Neurosciences – Mr Paul Grundy and Professor Steve Sturman

Next Mr Grundy and Professor Sturman described some of the latest policy developments in Specialised Neurosciences, these developments are being led by the Neurosciences CRG.

Mr Grundy explained that there are currently 6 published service specifications for Neurosciences and 1 treatment algorithm¹. The CRG have formed three working groups who are in the process of

¹ <https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-d/d04/>

updating the Neurology and Neurosurgery specifications, and there is a new Neuropsychiatry specification in development.

There are three development phases for new service specifications including 'Clinical Build', 'Impact Analysis' and 'Decision'. The Neurosurgery specification is expected to be published in January 2019, to be followed by the Neuropsychiatry specification in March 2019 and the Neurology specification in April 2019.

The new specifications are not expected to make any significant changes to service provision, the main changes are that the specification is now more concise, removes duplication and has moved away from specifying resources to specifying outcomes and pathways.

Professor Sturman explained how service specifications support equity of care for patients, through setting out obligations for commissioners and providers, and ensuring compliance. He also explained that they may be used for competitive selection and procurement, so it is important that they are correct.

He went on to say that there is a lot of debate in Neurosciences over what is specialised and what is not. An important function of the specifications is to safeguard clinics and pathways to ensure that they maintain their specialised nature. Hand in hand with that is ensuring equity of access for patients and removing the gradient of care between specialist Neuroscience centres and DGH's.

The revisions to the Neurology Service Specification looked at how to resolve these issues, through credentialing clinics, and ensuring that clinicians are part of a bigger network providing multidisciplinary care.

Professor Sturman concluded by emphasising that engaging with the specification process is important as this will provide an opportunity to pool resources, empower clinicians to be part of a bigger specialist network, improve patient flow and ensure the best for patients.

1.4 National Service Review of Neurosciences – Professor Adrian Williams and Mr Paul Grundy

Following the update on the service specifications Mr Grundy and Professor Williams provided an update on the National Service Review of Neurosciences.

Professor Williams began by arguing that for most working in neuroscience centres it feels like the perfect storm is brewing. There are increases in both outpatient and inpatient referrals, increasing expectations and shifting care pathways. Ability to treat the elderly and patients with complex co-morbidities is improving, but there are also concerns being shared about outcomes in neurosciences. As a result of this NHS England have decided to commission a National Service Review.

Mr Grundy explained that in order to ensure that the task remained focused they took the decision to work through some of the more challenging and optimal pathways, from which the learning could be disseminated to other areas.

Neurosurgery is focusing on areas that were identified within the Cranial Neurosurgery GIRFT report which include: sub-arachnoid haemorrhage, brain tumours and pituitary tumours. Neurology is focusing on MS, Immunotherapy and Epilepsy.

In Neurosurgery three working groups have been formed each with a neurosurgeon from each of the 4 regions (North, South, Midlands, London). For Neurology the groups will develop out from the existing CRG sub groups, with a new group being created for Epilepsy.

Other elements for consideration are: Mortality, following the findings of the PHE 2018 report. Access particularly flows in and out of specialised neurology services from CCG commissioned services. And, capacity both current and in the future.

Professor Williams concluded by highlighting that in conjunction with the pathways there is a need to identify the workforce and training requirements to ensure that there are enough people with the right skills to do the job.

1.5 Neurology Getting It Right First Time – Dr Geraint Fuller

The final presentation was from Dr Geraint Fuller, lead for Getting it Right First Time (GIRFT) Neurology.

He explained that GIRFT is built on the principle that if there is unwarranted variation then there is the opportunity to improve it. The GIRFT programme began in Orthopaedics looking at mortality rates, length of stay, infections rate, and cost of elective joint replacements. Rather than trying to improve things through commissioning, the data was shared with the clinicians so that they could see how they were doing compared to everyone else and, through peer engagement at a local level, outcomes were improved.

The GIRFT Neurosurgery programme published its report in June 2018, the final report can be read [here](#). The Neurosurgery review focused on:

- Flow
- Optimising the use of resources
- Minimising variation and championing excellence
- Quality, and concentrating expertise in rare conditions

GIRFT Neurology is in the early stages. As the neurosurgery population is relatively well constrained it was easier to get the data for that review, however in neurology there are a number of challenges

from the outset. There are lots of different disorders, outcomes to measure and outpatient diagnoses are not coded. There is also variation in the services offered in different types of hospital and the organisation of services differs between regions.

For the purpose of the review, and comparison, trusts have been split into 5 categories:

- N1 – Neuroscience centre with both inpatient neurology beds and neurosurgery
- N2 – Neurology centre with in house neurologists and inpatient neurology beds
- N3 – DGH Neurology centre with neurologists based at your trust without inpatient neurology beds
- N4 – DGH with visiting neurologists only
- N5 – No visiting neurologists

The process will be to look at each neuroscience region and then each individual trust. This will enable comparison between regions and the linking of data to population characteristics.

Data for the review will be collected from the GIRFT / ABN national census of neurological services, Hospital Episode Statistics (HES), NHS England workforce data and NHS England Specialist Commissioning data.

A key question that the review will be trying to answer is how many patients with a primary neurological diagnosis should be admitted under neurology. To support this Dr Fuller asked the afternoon Acute Neurology group to review the set of diagnostic codes and consider:

“With this diagnosis being looked after by a neurology team would...

.. definitely...

.. probably...

.. possibly...

..rarely...

...result in a better outcome.”

Dr Fuller concluded by emphasising that there is a need to be ‘agnostic’ about the answers until the data is available. That the data may not be what it seems, so needs to be discussed with clinicians on the ground, and that when you pay attention to something you automatically introduce a bias that you think it is important. So, there is a need to step back and consider what is really important.

2. Summary of discussions

2.1 Breakout 1 – Regional Groups

Midlands and East

Local priorities for improvement:

- 1) Workforce – ensuring the right numbers and skill mix across all professions
- 2) Access to services
- 3) Proper networking and proper regional oversight – breaking down barriers and rivalry between trusts
- 4) Right person / right place / care closer to home

Barriers to improvement:

- 1) Not having shared IT systems and therefore not having the full picture as to what has happened with the patient before
- 2) Not having regional access to imaging
- 3) Access to rehabilitation beds and social care which impacts flow
- 4) Access to good mental health and psychological support

High impact initiatives:

- 1) Development of a pathway to psychiatry and psychology
- 2) Advice and guidance services and improving 1:1 contact with GP's
- 3) Triage referral systems
- 4) Education for non-neurology colleagues e.g. decision tree pathway developed in Shropshire
- 5) ABN services and standards section for sharing good practice.

North

Local priorities for improvement:

- 1) Lack of capacity
- 2) Thrombectomy
- 3) DGH cover

Solutions

- 1) There is sufficient workforce resource it just needs to work differently

High impact initiatives

- 1) Telemedicine
- 2) GP Advice line
- 3) Attending system on the ward

-
- 4) Referral triaging

South

Local priorities for improvement:

- 1) IT – different hospitals silo data
- 2) Demand and capacity
- 3) Lack of continuity of follow up
- 4) More neuropsychology and Neurorehab

Barriers to improvement

- 1) Communication between trusts
- 2) Money
- 3) Don't have enough information on demand
- 4) Not enough training happening

High impact initiatives

- 1) Outcome based commissioning
- 2) Advice and guidance
- 3) Risk stratification
- 4) Supporting GP's in deciding who to refer or not

London

Priorities for improvement:

- 1) Making repatriation work
- 2) The whole system is clogged up
- 3) Supporting flow to Neurorehab
- 4) Over referral for dizziness

High impact initiatives:

- 1) Financial incentives to support repatriation
- 2) Pathways work better when people know one another
- 3) Rehab consultants and therapists into DGH's
- 4) Community neuro teams doing care plans
- 5) Group community clinics for migraine
- 6) Carpal tunnel to neurophysiology, via a community-based pathway
- 7) Headache proforma

2.2 Breakout 2 – Themed groups

Thrombectomy

Different centres are at different stages in implementing 24/7 cover for Thrombectomy. The majority have managed to provide the service in week however are not yet delivering extended hours.

The main challenge faced is staffing, in particular Interventional Neuro-Radiologists and specialist theatre staff. Other issues are the capacity of Angio suites and access to Bi-plane Imaging.

In terms of training the group also discussed the competencies required and how many cases an individual would need to undertake to maintain competency. At the moment as numbers of cases are small it will take a long time to train those who aren't Interventional Neuro-Radiologists to carry out the procedures. Although the GMC is looking at a credentialing programme to support this.

Coding

The Neurology Intelligence Collaborative is looking at data gaps and how to plug them, outpatient coding has been identified as a big gap.

There are many different ways of coding and different trusts tend to use different methods. There is also inconsistency in capturing data between clinicians so even if implemented inevitably some data would be missing.

Improving coding would lead to a better understanding of activity, capturing the right information for financial tariffs, data for research purposes and informing business case development.

Care planning

Care planning is important as it promotes an MDT approach and a longer-term view of the management of someone's condition, it also promotes self-care.

The main discussion focused around whether a care plan needs to be produced with everyone in the room or can be done piecemeal.

The group agreed that a care plan should be a living document that builds up over time, however there should be set parameters for what it should include and guidance for completion. Care plans should support the transfer of responsibility to the patient e.g. self-management, and it is vital to have the individual about whom the care plan refers fully involved in the plan development.

Barriers to care planning include staffing and a lack of integration between systems and providers. In order to take this forward there needs to be a lead, some form of accountability and there should be a review of the evidence around care planning to support implementation.

Neurorehab

Priorities:

- Prevention
- Early mental health involvement
- Early rehab intervention
- Community based rehab and vocational rehab
- Long term cognitive and behavioural management – case management and risk management
- Education – prevention and management of childhood problems
- Long term continuing care

Barriers

- Lack of engagement of neurology professionals
- Silo thinking
- Disconnected services
- Commissioning
- Training (undergraduate)
- National variance and lack of local facilities
- Rare conditions and lack of expertise
- Marginalised groups – homeless, those in prison, asylum seekers

Quick wins

- Neuro navigator / single point of access
- Undergraduate training GMC mandated
- Outcome measures / Quality of Life
- Engaging politicians at a high level
- Vocational rehab demo
- Community rehab demonstration models.

Acute Neurology and Stroke

The Acute group reviewed the diagnostic codes provided by Dr Fuller and discussed which they thought should be admitted under Neurology. This will feed in to the GIRFT Neurology review.

3. Next steps

Actions identified on the day to facilitate service improvement include:

- Regional teams to set up working groups in their local area in order to share best practice, develop networks between organisations, and implement high impact initiatives identified, facilitated by the NNAG team.
- Neurology Intelligence Collaborative to consider how to improve outpatient coding.
- Care Planning sub group to develop guidance on care plans for patients with neurological conditions.
- Trusts to look at employing Neuro-Navigators to support patients along the rehabilitation pathway.
- Neurorehab community to create a national voice for rehabilitation services.

4. Appendices

Appendix 1 – Agenda



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**NHS
England**

National Neuro Advisory Group clinical leaders away day

**Lecture Theatre 3, Education Centre, 1st Floor, Queen Elizabeth Hospital Birmingham,
Mindelsohn Way, Edgbaston, Birmingham, B15 2GW**

5th December 2018

About the event

Professor Adrian Williams, chair of the neurosciences CRG is leading another Clinical Leaders day in Birmingham on 5 December. This is designed to update on national programmes being developed by the CRG and NNAG as well as GIRFT and RightCare initiatives. Many aspects of neurology and neurosurgery and stroke/thrombectomy will be discussed. In the afternoon the plan is to break in to regional groups to discuss more local issues and networks. Key additional themes will be the need to develop care-plans and better coding. This meeting is particularly important as Adrian and his team have just been given the green light for a formal review of neuro-services to form a 3-5 year implementation plan to which all will contribute.

Contact Fiona.tate@neural.org.uk to book a place.

Draft programme

9:30 Arrival, tea and coffee

10:00 Welcome – Chair: Sarah Vibert, Chief Executive, Neurological Alliance

10:10 **Plenary:**

A national perspective – Prof Adrian Williams, Neurosciences Clinical Reference Group Chair/National Neuro Advisory Group Chair

10:40-12:30 **Speakers and panel Q&A**

10:40 What is important to neurology patients? – Katharine McIntosh, Senior Policy and Campaigns Advisor, Neurological Alliance

10:55 Latest policy developments in specialised neurosciences – Mr Paul Grundy and Prof Steve Sturman

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- 11:10 National Service Review of Neurosciences – Prof Adrian Williams and Mr Paul Grundy, Clinical Leads
- 11:30 Neurosurgical Getting it Right First Time – Mr Nick Phillips, GIRFT lead Neurosurgery
- 11:45 Neurology Getting it Right First Time – Dr Geraint Fuller, GIRFT lead neurology
- 12:00 Panel Q&A
- 12.30 **Lunch**
- 13:20 Introduction to afternoon workshops – Chair: Professor Williams, Chair, NNAG and CRG
- 13:30 **Regional network groups** to consider:
- What are the most important priorities locally for improvement?
 - What are the barriers to addressing these?
 - What do you think are the highest impact initiatives that would improve services for people with neurological conditions in both the short and longer term?
- 14:10 Feedback from regional network groups
- 14:35 **Coffee break**
- 14:50 **Themed workshops** groups to consider:
- Acute neurology and stroke
 - Thrombectomy
 - Coding
 - Care planning
 - Neuro rehabilitation
- 15:30 Feedback from workshops
- 16:00 Closing remarks and next steps
- 16:15 **Close**

Appendix 2 – Attendees

First Name	Last Name	Organisation
Sammy	Ashby	SUDEP Action
Andy	Bacon	Sheffield Teaching Hospital NHS Foundation Trust
Manx	Baker	The Royal Wolverhampton NHS Trust
Oliver	Bennett	Manchester Centre for Clinical Neurosciences (MCCN)
John	Bowen	Shrewsbury and Telford Hospital NHS Trust
Ilse	Burger	Salford Royal NHS Foundation Trust
Jeffrey	Cochius	Norfolk and Norwich University Hospital NHS Foundation Trust
Brendan	Davies	Royal Stoke University Hospital
Rejith	Dayanandan	Lancashire Teaching Hospitals NHS Foundation Trust
Rachel	Dorsey- Campbell	Neurosciences & NHSE Clinical Commissioning, Imperial College Healthcare NHS Trust
Ben	Dorward	Sheffield Teaching Hospital NHS Foundation Trust
Rob	Durant	King's College Hospital NHS Foundation Trust
Alison	Dwyer	Salford Royal NHS Foundation Trust
Genevieve	Edwards	MS Society
Hesham	Elnazer	Royal College of Psychiatrists
Sarah	Faulkner	The Royal Wolverhampton Hospital NHS Trust
Kevin	Foy	The Walton Centre NHS Foundation Trust
Geraint	Fuller	GIRFT Lead neurology
Jeban	Ganesalingam	Brighton and Sussex University Hospital
Joshi	George	Salford Royal Foundation Trust
Paul	Grundy	University Hospital Southampton
Eddie	Guzdar	Sanofi
Emma	Hill	Queen Elizabeth Hospital Birmingham
James	Holt	The Walton Centre Foundation trust
Jeremy	Isaacs	Kingston Hospital NHS Foundation Trust
Saiju	Jacob	University Hospitals Birmingham
Fatima	Jaffer	King's College Hospital NHS Foundation Trust
Jozef	Jarosz	King's College Hospital NHS Foundation Trust
Peter	Jenkins	St George's Hospital London
Shelley	Jones	King's College Hospital NHS Foundation Trust
George	Joshi	Salford Royal Foundation Trust
Vishelle	Kamath	St Andrew's Northampton

Rachel	King	King's College Hospital NHS Foundation Trust
Czarina	Kirk	Lancashire Care NHS Foundation Trust
Joanne	Lawrence	ABN
Duncan	Lugton	Sue Ryder
Claire	Lynch	University Hospitals Birmingham NHS Foundation Trust
Godwin	Mamutse	Norfolk and Norwich University Hospital NHS Foundation Trust
Barbara	May	Teva UK Limited
David	McKee	Salford Royal NHS Foundation Trust
Katharine	McIntosh	The Neurological Alliance
Sue	Millman	Ataxia UK
Paul	Morrish	Independent
Niranjanan	Nirmalananthan	St Georges Hospital
Priya	Oomahdat	NHS England
Cass	O'Reilly	Queens Hospital
Joanna	Pawlowska	North Bristol NHS Trust
Leah	Pickering	The Walton Centre Foundation trust
Anne	Preece	University Hospitals Birmingham NHS Foundation Trust
Martin	Sadler	Plymouth Hospitals NHS Trust
Manjit	Sangha	The Royal Wolverhampton Hospital NHS Trust
Dwaipayana	Sen	Salford Royal Hospital
Simon	Shaw	UHNH
Sam	Shribman	ABN Trainee Committee
Shauna	Simango	
Steve	Sturman	Queen Elizabeth Hospital Birmingham
Jon	Sussman	Salford Royal NHS Foundation Trust
Lara	Teare	University Hospitals Coventry and Warwickshire NHS Trust
Nikolaos	Tzerakis	University Hospitals of North Midlands
Sarah	Vibert	The Neurological Alliance
Dan	Waters	Sanofi
Mark	Weatherall	Stoke Mandeville Hospital
Alastair	Wilkins	North Bristol NHS Trust
Adrian	Williams	Neurosciences Clinical Reference Group Chair/National Neuro Advisory Group Chair
Jennifer	Williams	The Royal Wolverhampton Hospital NHS Trust
Martin	Wilson	The Walton Centre Foundation trust
John	Woolmore	Queen Elizabeth Hospital Birmingham

The
Strategy
Unit.

The Strategy Unit

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Midlands and Lancashire
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