



House of Commons  
Committee of Public Accounts

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# Services for people with neurological conditions

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Seventy-second Report of Session  
2010–12

*Report, together with formal minutes, oral and  
written evidence*

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## Committee of Public Accounts

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Eric Joyce (*Labour, Falkirk*)  
Rt Hon Mrs Anne McGuire (*Labour, Stirling*)

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### Publications

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### Committee staff

The current staff of the Committee is Philip Aylett (Clerk), Lori Verwaerde (Senior Committee Assistant), Ian Blair and Michelle Garratty (Committee Assistants) and Alex Paterson (Media Officer).

### Contacts

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## Summary

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Two million people in the UK have a neurological condition, including for example those with Parkinson's disease, motor neurone disease and multiple sclerosis. The figure excludes people with migraine. In 2005, the Department of Health (the Department) published the National Service Framework for Long-term Conditions (the Framework) to improve services for people with neurological conditions. Health spending on neurological conditions increased by 38% in real terms, from £2.1 billion in 2006-07 to £2.9 billion in 2009-10. Spending on social services for people with neurological conditions was an estimated £2.4 billion in 2009-10, and has remained flat since 2005-06. While there have been some improvements, such as reduced waiting times, services remain well below the quality requirements set out in the Framework.

People with neurological conditions need a wide range of services that can cross boundaries between health and social care, employment and benefit services, transport, housing and education. Despite these complex needs, coordination of care for individuals is poor, and there is a lack of integration between health and social services. There is still a lack of neurological expertise, both in hospitals and in the community, and access to services varies widely. Implementation of the Framework lags behind those for cancer and stroke care, even though many neurological conditions severely affect quality of life and cause lifelong disability. Of particular concern is the 32% increase in emergency admissions, and the increased rate of readmissions to hospital within 28 days from 11.2% to 14%, since the introduction of the Framework. Rates are well above those for the NHS as a whole, and represent poor outcomes for people with neurological conditions and poor value for money for the NHS.

Unlike the Cancer and Stroke strategies the model used to implement the Framework has not worked. Implementation was left to local commissioners without the national leadership necessary to drive improvements. No baseline for services or outcomes was established when the Framework was introduced. There was no monitoring of progress, and local commissioners were not held to account for implementation.

There are key lessons to be learnt as the Department develops its proposed new health and social care landscape. The Department intends to decentralise and localise decision-making, with central monitoring, and it will be vital that it sets clear objectives for the outcomes and services for people with neurological conditions. The delivery model needs to work better and put patient needs at its heart if services and outcomes are to improve. There needs to be stronger central and local leadership, and commissioners need to be held to account for outcomes. The Department's central monitoring of services must enable it to intervene where services are failing. We would like the National Audit Office to follow

up on progress against our recommendations in 2014.

On the basis of a Report by the Comptroller and Auditor General,<sup>1</sup> we took evidence from the Department about its implementation of the Framework, and its proposals for improving services for people with neurological conditions.

## Conclusions and recommendations

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- 1. Implementation of the Framework lacked leadership at both national and local level, which led to a lack of impetus, focus and direction.** The Department accepts that leaving implementation solely to local bodies has not delivered. Unlike other treatment areas, such as stroke and cancer, neurology does not have a dedicated National Clinical Director or local networks to coordinate services. The proposed NHS Commissioning Board should appoint a dedicated National Clinical Lead for neurology to provide leadership on the commissioning and design of neurological services. It should also establish local neurological networks, coordinated by the NHS, with clearly responsible and accountable local leadership.
- 2. The Department lacks the data to measure the effectiveness of services for people with neurological conditions.** The Framework lacked an empirical baseline from which progress could be measured nationally or locally for health and social care, and the Department has no way of assessing what resources and activities result in the best outcomes. The Department should develop a neurological data set covering resources, services and outcomes, which should include linking existing health and social care data using the patient's NHS number. Key indicators from the data set, including emergency admissions and readmissions for neurological conditions, should be included in the NHS and Adult Social Care Outcomes Frameworks with appropriate targets for reduction.
- 3. The quality of services for people with neurological conditions varies around the country, with some areas having insufficient expertise both in hospitals and in the community.** The compliance of individual Primary Care Trusts with the Framework's quality requirements has been poor and so the support and treatment available to people continue to depend on where they live. The Department should set out in its reply to us how it will ensure all people with neurological conditions have appropriate access to services. We would expect this to include how the Department will drive improvements through the quality section of the NHS Standard Contract, the Commissioning Outcomes Framework, the Joint Strategic Needs Assessments and the Health and Wellbeing Boards.
- 4. Despite people with neurological conditions requiring a wide range of services, health and social services are poorly integrated.** Poorly integrated services can result in, for example, increased emergency readmissions to hospital. Less than 5% of overall NHS and social care budgets are spent through joint arrangements such as pooled budgets. In its Commissioning Outcomes Framework, the Department should mandate joint health and social care commissioning of neurological services, supported by Health and Wellbeing Boards through the Joint Strategic Needs Assessment.
- 5. Individual care is often poorly coordinated, with only 22% of people with Parkinson's disease, multiple sclerosis and motor neurone disease having a personal care plan.** Specialist nurses can play an important role in helping people navigate their way through the range of support they need. While the Department cited a figure of 80% of people with all long-term conditions having care plans, this related to a wider range of conditions and only serves to further underline the disparity between the support available to people with neurological conditions and that available to people with other long-term conditions. The Department should set out in its Commissioning Outcomes Framework

that every person with a neurological condition should be offered a personal care plan, covering both health and social care. The evidence suggests that this is best done by a single professional, for example a specialist nurse or care coordinator.

**6. The Quality Standards planned by the National Institute for Health and Clinical Excellence (NICE) will not cover all neurological conditions.** We welcome the announcement at our hearing that NICE will be developing Quality Standards for Parkinson's disease, multiple sclerosis and motor neurone disease. However, these will not cover other neurological conditions. In addition to the three Quality Standards announced, the Department should instruct NICE to develop a generic Quality Standard covering other neurological conditions.

# 1 Implementing the Framework

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1. Approximately two million people in the United Kingdom have a neurological condition, including for example those with Parkinson's disease, motor neurone disease and multiple sclerosis. The figure excludes people with migraine. Some neurological conditions can be life threatening, and many severely affect quality of life and cause lifelong disability. Neurological conditions also have a significant impact on the carers and families of those living with the condition.<sup>2</sup> People with neurological conditions need a wide range of services including health and social care, employment and benefit services, transport, housing and education.<sup>3</sup>

2. In March 2005, the Department published its National Service Framework for Long-term Conditions (the Framework) which focused on neurological conditions. The Framework set out 11 quality requirements to improve services for people with neurological conditions, which were to be fully implemented by 2015.<sup>4</sup> Since the introduction of the Framework, health spending on neurological conditions has increased by 38% in real terms, from £2.1 billion in 2006-07 to £2.9 billion in 2009-10. Between 2005-06 and 2009-10, social care spending on people with a physical disability has remained flat in real terms (£9.6 billion in 2009-10). An estimated £2.4 billion of this was spent on people with neurological conditions in 2009-10.<sup>5</sup>

3. The Department accepted that the model it used to implement the Framework had not worked.<sup>6</sup> There was too much reliance on local commissioners to deliver the Framework with a lack of central leadership. Unlike other treatment areas such as cancer and stroke, neurology does not have a National Clinical Director.<sup>7</sup> Clinical leadership at a local level, where individuals take responsibility for designing local services, has also been absent in many areas.<sup>8</sup>

4. The Department also acknowledged that it had not put in place mechanisms for monitoring progress in implementing the Framework or for holding local commissioners to account for implementation.<sup>9</sup> For example, there was no baseline of services established at the introduction of the Framework.<sup>10</sup> Reports by Neurological Commissioning Support and the North East Public Health Observatory found that Primary Care Trusts' compliance

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2 C&AG's Report, paras. 2, 1.2, 1.4

3 Qq 15, 85, 102; C&AG's Report, paras. 3, 1.5, Fig. 3

4 C&AG's Report, paras. 4, 5, 1.6-1.8

5 C&AG's Report, paras. 6, 2.1-2.2, 2.3-2.4, Figs. 5 and 6

6 Qq 31-33, 51-52, 74, 76, 103

7 Qq 6, 33-34, 71

8 Qq 5, 9, 90

9 Qq 12, 51-52

10 Q 68

with the Framework's quality standards has been poor.<sup>11</sup> In 2009, only 51% of Primary Care Trusts had a written action plan to implement the Framework.<sup>12</sup>

5. Strategies for cancer and stroke had more levers to drive implementation, including a National Clinical Director and national monitoring and targets.<sup>13</sup> A greater priority was given to these strategies than to neurology, with neurology not appearing in any of the NHS Operating Frameworks over the last five years. The strategies for cancer and stroke have been more successful in improving treatment.<sup>14</sup> The National Clinical Director for cancer has been effective in bringing together local clinicians and providing training and support to enable them to provide local leadership.<sup>15</sup>

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11 Q 103; C&AG's Report, paras 12, 2.28

12 C&AG's Report, para. 2.7

13 Qq 6, 31, 106

14 Qq 5, 28, 56-58, 63, 76

15 Qq 103, 105

## 2 Current services for people with neurological conditions

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6. Access to hospital services has improved. Waiting times for inpatient and outpatient neurology have improved since 2007 with the number of elective neurological operations being performed also increasing.<sup>16</sup> However, local commissioning organisations such as Primary Care Trusts have given different levels of priority and funding to services for people with neurological conditions. This has resulted in variable access to health services depending on where people live.<sup>17</sup> A survey of hospital trusts by Parkinson's UK highlighted the variation in access to expert Parkinson's disease services such as physiotherapy, occupational therapy, and speech and language therapy. While 84% of trusts provided expert physiotherapy, 68% occupational therapy and 81% speech and language therapy, fewer trusts reported universal access to expert physiotherapy (52%), occupational therapy (41%), and speech and language therapy (49%).<sup>18</sup>

7. Social care is also a vital element of services for people with neurological conditions.<sup>19</sup> Data show that while social care spending on all people with a physical disability has remained flat in real terms from 2005-06 to 2009-10, the number of adults receiving care has fallen by just under 100,000 (8%) over the same period.<sup>20</sup> Of these, 25% are estimated to have a neurological condition.<sup>21</sup> Provisional data for 2010-11 indicates that this trend is continuing with a further reduction of just under 100,000 in the number of adults with a physical disability receiving services from 2009-10 to 2010-11.<sup>22</sup>

8. Throughout the NHS, health and social services remain poorly integrated.<sup>23</sup> There is no integrated health and social services data to understand what services individuals are receiving and the level of services required by different groups.<sup>24</sup> Commissioning is rarely joined-up, with less than 5% of overall health and social care budgets spent through joint arrangements such as pooled budgets.<sup>25</sup>

9. People with neurological conditions need a wide range of services across a number of organisations.<sup>26</sup> A University of Oxford survey, commissioned by the Department, showed that only 22% of people with Parkinson's disease, multiple sclerosis and motor neurone disease had a personal care plan. The Department stated that their larger survey of people with a wider range of long-term conditions showed a significantly higher figure of 80%

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16 Qq 5, 92-93; C&AG's Report, paras. 11, 2.14-2.17

17 Qq 25, 103

18 C&AG's Report, paras. 16, 3.10

19 Qq 85, 89

20 C&AG's Report, Fig 12

21 C&AG's Report, para. 2.4

22 National Adult Social Care Intelligence Service, NHS Information Centre

23 Qq 13-14

24 Q 102

25 Q 61; C&AG's Report, para. 3.10

26 Qq 15, 85

having a care plan. The Department accepted that increasing the number of people with a personal care plan was a key area for improvement.<sup>27</sup>

10. The multiple sclerosis service in East Kent highlights how coordination can be improved. The service is designed around multiple sclerosis nurses who act as ‘navigators’ with anyone diagnosed with multiple sclerosis put in touch with a multiple sclerosis nurse. As a result, the number of admissions to hospital has reduced. Key to success was the local clinical leadership. This brought together the key stakeholders across Kent and gained the support of the Primary Care Trust.<sup>28</sup>

11. The number of neurologists in England is below the European average, with a disproportionate number of neurologists located in London.<sup>29</sup> People with neurological conditions admitted to district general hospital as an emergency are unlikely to be treated by a neurologist.<sup>30</sup>

12. Neurological emergency admissions to hospital have increased by 32% between 2004-05 and 2009-10, compared to 17% for the NHS as a whole. Over the same period, emergency readmissions within 28 days of discharge for Parkinson’s disease, multiple sclerosis and motor neurone disease have increased from 11.2% of discharges to 14%.<sup>31</sup> The Department stated that the growth in neurological emergency admissions might be exaggerated due to improved diagnosis, but accepted that overall the increase in emergency admissions was a problem, both for people with neurological conditions and for the efficient running of the NHS.<sup>32</sup>

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27 Qq 97-102

28 Q 9

29 Qq 59, 96

30 Qq 9, 95-96; C&AG’s Report, para. 3.15

31 C&AG’s Report, paras. 2.19, 2.22

32 Qq 43, 48

## 3 Improving services in the new health and social care landscape

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13. Under the proposed new health and social care landscape, the Secretary of State will hold the NHS Commissioning Board to account using an annual mandate which will set out the Government's priorities and objectives. Central to the mandate will be the NHS Outcomes Framework which will set out the outcomes and corresponding indicators that will be used to hold the NHS Commissioning Board to account.<sup>33</sup> The NHS Outcomes Framework will include a number of indicators to measure the outcomes for people with long-term conditions. The Department confirmed the importance of being able to identify people with long-term neurological conditions within these indicators so outcomes for this group can be measured.<sup>34</sup>

14. The NHS Commissioning Board management structures are still being designed. The Department is looking to organise the NHS Commissioning Board around the core elements of the NHS Outcomes Framework, with lead clinicians responsible for episodic care, patient experience, patient safety, reducing mortality and improving the quality of life for people with long-term conditions. The use of other clinicians, such as National Clinical Directors, to support the lead clinicians has not been finalised. The Department accepted that national clinical leadership for neurology needed to be strengthened to deliver improvements in outcomes.<sup>35</sup>

15. The Department acknowledged that the implementation of the Framework had lacked structures to hold local commissioners to account and that these would need to be strengthened in the new landscape.<sup>36</sup> A key element of this will be quality standards developed by NICE.<sup>37</sup> The Department told us that NICE are now developing quality standards for Parkinson's disease, multiple sclerosis and motor neurone disease.<sup>38</sup>

16. Another key element of the accountability structure will be the Commissioning Outcomes Framework which will set out the improvements the NHS Commissioning Board will expect from local clinical commissioning groups.<sup>39</sup> The Department confirmed that the Commissioning Outcomes Framework would include short-term indicators to identify where things were going wrong, potentially including emergency readmissions.<sup>40</sup>

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33 Q 104

34 Qq 35-36

35 Q 34

36 Qq 50-51

37 Q 104

38 Q 36

39 Q 82

40 Q 43

# Formal Minutes

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**Monday 27 February 2012**

Rt Hon Margaret Hodge, in the Chair

Stephen Barclay

Matthew Hancock

Chris Heaton-Harris

Meg Hiller

Fiona Mactaggart

Nick Smith

James Wharton

Draft Report (*Services for people with neurological conditions*) proposed by the Chair, brought up and read.

*Ordered*, That the draft Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 16 read and agreed to.

Conclusions and recommendations 1 to 6 read and agreed to.

Summary read and agreed to.

*Resolved*, That the Report be the Seventy-second Report of the Committee to the House.

*Ordered*, That the Chair make the Report to the House.

*Ordered*, That embargoed copies of the Report be made available, in accordance with the provisions of Standing Order No. 134.

Written evidence was ordered to be reported to the House for placing in the Library and Parliamentary Archives.

[Adjourned till Wednesday 29 February at 3.00pm]

## Witnesses

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### Wednesday 18 January 2012

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**Steve Ford, Chair**, Neurological Alliance, and **Dr Steve Pollock**, Lead Clinician in Neuroscience

Ev 1

**Sir David Nicholson KCB CBE**, Chief Executive, NHS, **Una O'Brien**, Permanent Secretary, Department of Health, and **Dr Chris Clough**, Chair, National Clinical Advisory Team

Ev 6

## List of printed written evidence

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1	Association of British Neurologists	Ev 17
2	M.A.C Partnership LLP	Ev 19
3	Royal College of Physicians	Ev 21
4	National Audit Office	Ev 23
5	Department of Health	Ev 23

# List of Reports from the Committee during the current Parliament

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The reference number of the Government's response to each Report is printed in brackets after the HC printing number.

## Session 2010–12

First Report	Support to incapacity benefits claimants through Pathways to Work	HC 404
Second Report	Delivering Multi-Role Tanker Aircraft Capability	HC 425
Third Report	Tackling inequalities in life expectancy in areas with the worst health and deprivation	HC 470
Fourth Report	Progress with VFM savings and lessons for cost reduction programmes	HC 440
Fifth Report	Increasing Passenger Rail Capacity	HC 471
Sixth Report	Cafcass's response to increased demand for its services	HC 439
Seventh Report	Funding the development of renewable energy technologies	HC 538
Eighth Report	Customer First Programme: Delivery of Student Finance	HC 424
Ninth Report	Financing PFI projects in the credit crisis and the Treasury's response	HC 553
Tenth Report	Managing the defence budget and estate	HC 503
Eleventh Report	Community Care Grant	HC 573
Twelfth Report	Central government's use of consultants and interims	HC 610
Thirteenth Report	Department for International Development's bilateral support to primary education	HC 594
Fourteenth Report	PFI in Housing and Hospitals	HC 631
Fifteenth Report	Educating the next generation of scientists	HC 632
Sixteenth Report	Ministry of Justice Financial Management	HC 574
Seventeenth Report	The Academies Programme	HC 552
Eighteenth Report	HM Revenue and Customs' 2009-10 Accounts	HC 502
Nineteenth Report	M25 Private Finance Contract	HC 651
Twentieth Report	Ofcom: the effectiveness of converged regulation	HC 688
Twenty-First Report	The youth justice system in England and Wales: reducing offending by young people	HC 721
Twenty-second Report	Excess Votes 2009-10	HC 801
Twenty-third Report	The Major Projects Report 2010	HC 687

Twenty-fourth Report	Delivering the Cancer Reform Strategy	HC 667
Twenty-fifth Report	Reducing errors in the benefit system	HC 668
Twenty-sixth Report	Management of NHS hospital productivity	HC 741
Twenty-seventh Report	HM Revenue and Customs: Managing civil tax investigations	HC 765
Twenty-eighth Report	Accountability for Public Money	HC 740
Twenty-ninth Report	The BBC's management of its Digital Media Initiative	HC 808
Thirtieth Report	Management of the Typhoon project	HC 860
Thirty-first Report	HM Treasury: The Asset Protection Scheme	HC 785
Thirty-second Report	Maintaining financial stability of UK banks: update on the support schemes	HC 973
Thirty-third Report	National Health Service Landscape Review	HC 764
Thirty-fourth Report	Immigration: the Points Based System – Work Routes	HC 913
Thirty-fifth Report	The procurement of consumables by National Health Service acute and Foundation Trusts	HC 875
Thirty-seventh Report	Departmental Business Planning	HC 650
Thirty-eighth Report	The impact of the 2007-08 changes to public service pensions	HC 833
Thirty-ninth Report	Department for Transport: The InterCity East Coast Passenger Rail Franchise	HC 1035
Fortieth Report	Information and Communications Technology in government	HC 1050
Forty-first Report	Office of Rail Regulation: Regulating Network Rail's efficiency	HC 1036
Forty-second Report	Getting value for money from the education of 16- to 18-year olds	HC 1116
Forty –third Report	The use of information to manage the defence logistics supply chain	HC 1202
Forty-fourth Report	Lessons from PFI and other projects	HC 1201
Forty-fifth Report	The National Programme for IT in the NHS: an update on the delivery of detailed care records	HC 1070
Forty-sixth report	Transforming NHS ambulance services	HC 1353
Forty-seventh Report	Reducing costs in the Department for Work and pensions	HC 1351
Forty-eighth Report	Spending reduction in the Foreign and Commonwealth Office	HC 1284
Forty-ninth Report	The Efficiency and Reform Group's role in improving public sector value for money	HC 1352
Fiftieth Report	The failure of the FiReControl project	HC 1397

Fifty-first Report	Independent Parliamentary Standards Authority	HC 1426
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Fifty-fifth Report	Formula funding of local public services	HC 1502
Fifty-sixth Report	Providing the UK's Carrier Strike Capability	HC 1427
Fifty-seventh Report	Oversight of user choice and provider competition in care markets	HC 1530
Fifty-eighth Report	HM Revenue and Customs: PAYE, tax credit debt and cost reduction	HC 1565
Fifty-ninth Report	The cost-effective delivery of an armoured vehicle capability	HC 1444
Sixtieth Report	Achievement of foundation trust status by NHS hospital trusts	HC 1566
Sixty-first Report	HM Revenue and Customs 2010-11 Accounts: tax disputes	HC 1531
Sixty-second Report	Means Testing	HC 1627
Sixty-third Report	Preparations for the roll-out of smart meters	HC 1617
Sixty-fourth Report	Flood Risk Management	HC 1659
Sixty-fifth Report	DfID: Transferring cash and assets to the poor	HC 1695
Sixty-sixth Report	Excess Votes 2010-11	HC 1796
Sixty-seventh Report	Whole of Government Accounts 2009-10	HC 1696
Sixty-eighth Report	Ministry of Defence: The Major Projects Report 2011	HC 1678
Sixty-ninth Report	Rural payments Agency – follow up of previous PAC recommendations	HC 1616
Seventieth Report	Oversight of special education for young people aged 16-25	HC 1636
Seventy-first Report	Reducing costs in the Department for Transport	HC 1760
Seventy-second Report	Services for people with neurological conditions	HC 1759
Seventy-third Report	The BBC's efficiency programme	HC 1658
Seventy-fourth Report	Preparations for the London 2012 Olympic and Paralympic Games	HC 1716

# Oral evidence

## Taken before the Committee of Public Accounts on Wednesday 18 January 2012

Members present:

Margaret Hodge (Chair)

Mr Richard Bacon  
Jackie Doyle-Price  
Meg Hillier

Fiona Mactaggart  
Austin Mitchell  
Nick Smith

**Amyas Morse**, Comptroller and Auditor General, NAO, and **David Moon**, Director, NAO, gave evidence. **Ashley McDougall**, Director of Parliamentary Relations, NAO, and **Marius Gallagher**, Alternate Treasury Officer of Accounts, were in attendance.

### REPORT BY THE COMPTROLLER AND AUDITOR GENERAL

#### Services for people with neurological conditions (HC 1586)

##### Examination of Witnesses

*Witnesses:* **Steve Ford**, Chair, Neurological Alliance, and **Dr Steve Pollock**, Lead Clinician in Neurosciences, gave evidence.

**Q1 Chair:** Welcome to the two of you. Can I just explain the purpose of this session? It is an innovation that we have introduced in the Committee to try to spend a bit of time, before the main session in which we question the accounting officers for this area of work, discovering the key issues we ought to focus on. We are not trying to catch you out on anything; we are hoping that you can help us and inform the later questioning.

To start, I will throw a general question at you. A lot of extra money has been invested in this area, but from reports you have put forward and from other bits of evidence we have—it is not very strong evidence—it looks as though we have not had value for money. What went wrong, and what would you do from here onwards?

**Steve Ford:** Thank you, Chair, that is a really good starting point, because there has been an increase in neurological spend. Our issue, and the feedback from people living with a neurological condition, is that that has not been targeted resource. As we have seen from the Report, a significant chunk of the additional expenditure has gone on an increase in emergency admissions, which is actually when the system has failed, effectively, and let someone down.

Our concern is that what was a great plan—the National Service Framework launched in 2005—which had wide support and really provided a platform for us to put in place integrated services that really would meet the challenging needs of people living with long-term conditions, had no impetus behind it at all. As a consequence, it was left to local areas to do what they could, and we have a real patchwork of services: some are really good, but they are quite rare, and there is a variable quality of service.

The first point is that we do not know where the money has gone—there is no means of measuring this and measuring the outcomes—but we do not believe

it has been spent in the most effective way to meet the really challenging needs of people living with long-term neurological conditions.

**Q2 Chair:** What would you do from here onwards, given the new landscape we have in health, under the Health and Social Care Bill?

**Steve Ford:** The new landscape gives a really good opportunity. What we are looking for is an outcomes strategy for neurology which means that we can have a really clear vision about what we want to achieve, and then make sure that there are the mechanisms and support to encourage local clinical commissioning groups, working together through networks, to have a look at services, to use the resources in the most effective way and to involve service users in that. We are looking for leadership at a national level, and we would like to see a national clinical director who can really provide the focus, the impetus and the challenge that are needed to knock some heads together and make this work.

**Q3 Chair:** Looking at the new outcomes framework proposed by the NHS—we had a submission from Roche, although I do not know whether other Members have it with them—I cannot quite see how you get anything specific about neurology in there.

**Steve Ford:** No, that is the point. The NHS is talking about an outcomes framework for long-term conditions.

**Q4 Chair:** What do you want in there?

**Steve Ford:** We want a neurology outcomes strategy.

**Q5 Chair:** Which means what? Be really specific.

**Steve Ford:** Okay. What we would like to see is a clear statement from the NHS at senior level that sets out the vision for neurology services across primary, secondary, social care and public health; that provides

leadership; that sets out arrangements to support the NHS—the emerging commissioners—to understand and promote best practice; and that promotes neurological networks to support the commissioning of neurology services at local level. What we are looking for is an outcomes strategy for neurology.

It is really important to look at the significant improvements that the NHS has made in stroke and cancer. What we are saying is that neurology deserves the same kind of focus and attention. Resources are being deployed into neurology; we have seen the increase in resources. We want to make sure there is value for money and that the money is really used effectively.

**Dr Pollock:** Can I tell you how it looks to me as a clinical neurologist? Neurology is slightly complicated, because it is a heterogeneous set of conditions, which have different outcomes. It is not like diabetes, where there is a single measure to tell you whether or not you are going to run into problems. Measuring neurology is always going to be a little bit difficult.

When the NSF came out, people recognised this and resiled from it—they did not want to get involved in something that was complicated, so they picked the one thing that they could easily understand, which was the 18-week pathway for out-patients. The net result was that a huge amount of money was poured into reducing out-patient waiting lists. This was very good—the out-patient waiting lists we had before were unacceptable—but it had two consequences.

First, it was completely unregulated; there were no checks or balances. What happened was that the thing just went on a “predict and provide”, so a lot of the money that was spent on out-patient work was not being spent particularly well. There is a comment from the King’s Fund that “not all referrals are clinically necessary” and a “substantial element is discretionary and avoidable”. There is recent evidence to show that anything up to a third of the patients who are referred to neurology do not really have neurological problems. That is one side where I do not think the money was being terribly well spent. Although it did achieve some good outcomes, it had a disastrous effect, in my opinion, on the two other facets of neurology. Neurology consists not only of out-patients, but of in-patients. We have seen from the Report and we know from studies that are done everywhere, up and down the country, that neurology is very commonly admitted into acute admissions, and it is very badly handled. Most patients never get to see a neurologist.

The other thing that is missing because all the time is spent on seeing these new patients, is that that you do not get the clinical leadership that is necessary to set up the networks of care and the programmes of care that are absolutely essential for the development of the management of long-term conditions. What has been lacking in sorting out epilepsy, multiple sclerosis and Parkinson’s disease is a central clinical leader working within a PCT or an acute trust, who is there to say, “I’m responsible for setting up this service. What are the resources that you can give me? I will work within those resources. I will work for more resources, and I will try to tie in these things in an

integrated manner, so that we take in the third sector, private medicine where it is necessary and social services.” Instead, what happens is that these people are busy seeing more and more out-patients. The number is just climbing and climbing—it goes up 10% per annum—in a completely unregulated way.

The problem, exactly as Steve said, is that we do not have any central steer or any kind of driver to try to sort this out. The problem we will have to deal with is how to fit this into the new world. It is quite right that much of neurology should be devolved into the commissioning groups, but in order to do that, we need to know what we are commissioning. Right now, that is not happening.

**Q6 Austin Mitchell:** I am a bit simplistic in my views, but what I got from what we looked at in cancer treatment was that it was a success because there was national clinical direction, and targets and timetables were fixed and defined. How far is it the case that you could not do that with neurology, into which we poured money? Apparently, it did not go in the right direction—not like the cancer money. Is it not possible to fix targets like that? Is it too fuzzy to define? Is the problem really that people are best not treated in a hospital, because that is expensive, but supported in the community? Are these the two things that precluded success in this strategy?

**Dr Pollock:** Absolutely. The stroke strategy was immensely helpful in getting stroke away from the position it was 20 years ago, which is where neurology is now. It is because it had a clear direction, it had a clinical director and it had teeth. The NSF for long-term conditions has lots of good ideas, but it was woolly. It did not tell us what to focus on, and because neurology is more complicated than stroke, it was very difficult to get a proper steer on it. There was nobody over the last five or six years in the Department of Health who was giving that steer for when you came up with good ideas, such as devolving services to the community.

The Government themselves ran a very successful programme called Action on Neurology, and there was the Modernisation Agency. They were full of ideas as to how you could make neurology work better in the community. There were four programmes here that used GPSI—general practitioners with special interests—in epilepsy and in headache; telemedicine for the use of remote epilepsy clinics; community brain injury services; and triaging e-mail referrals, which reduced the number of referrals. They were all there. They were good ideas that were being enacted, but what happened? The programmes stopped, and there was nobody to talk to and nobody to develop this and say, “Let’s take it out. Let’s roll it out.”

You can see that even now we are getting that in this report from the Royal College of Physicians and the Association of British Neurologists. Again, it is packed full of ideas of how you can spend the money better. Of course we feel that we need more neurologists in the long term; compared with the rest of western Europe, there are not enough neurologists—but that is not actually the issue. What you need to be doing is spending the money more effectively. The problem at the moment is that we do

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not know who to talk to and say, “Look. There is a really good headache service run by a GP in South London. Why can’t we emulate that?”

**Steve Ford:** If I can elaborate, the reality of that is that, because it is not a national priority in that sense, it is really difficult to engage local people about those kinds of issue, because people say, “I am not being measured against that. That’s not one of my priorities.” It is really difficult to implement what is actually a very easy and obvious thing to do.

**Q7 Chair:** You are old-style NHS. I would say to you that, in the new world, you have to find mechanisms within the new landscape and framework that give you those outcomes.

**Steve Ford:** An outcomes strategy fits completely within the new landscape.

**Q8 Chair:** You have not been very clear to me. I will go to Fiona, because we run this session for about half an hour and then we go into the main session, but just give me some indication of the sort of outcomes that we would measure. I do not quite know what it means. Come back on that later. Let the others have a go first.

**Steve Ford:** Okay.

**Q9 Fiona Mactaggart:** I agree with your analysis, but I think you are missing out a bit of the picture. I should declare an interest in that I have MS. That is not on my declaration of interests, but it is obviously very relevant to this session.

One thing that is different about neurology is that with most neurological conditions the patient is likely to know much more about their condition than their GP. GPs now have no neurology in their basic training. As I understand the Royal College of Physicians’ report, the majority of people who are admitted to a district general hospital with a neurological condition do not see a neurology specialist. As well as the national direction, framework and leadership that you talk about, that has to be significant, does it not?

**Dr Pollock:** Yes, absolutely. That is one of the reasons why neurology admissions are rising. People are being identified as having neurological conditions, but they are not being dealt with very expeditiously, so they have inordinately long stays and a higher than acceptable rate of readmissions.

I will explain how we have tried to tackle this in East Kent. This document is the Kent and Medway neurosciences partnership strategy, which the old SHA set up in 2007. What we did was get all the key players from across Kent who were involved in multiple sclerosis. We were able to get a lot of evidence to show that MS was not being worked terribly well where there were unstructured services. We demonstrated that if you had MS nurses, as there were in East Kent and in Dartford but not to such a great extent in West Kent, you could reduce admissions and bed days, and you could free up out-patient time. It was a win-win situation.

In order to achieve that, you needed to have a clinical leader to drive the programme along, and you needed support from the PCT and from the local providers, which we were able to get. As a result we were able to define a service which was built not round a

neurologist but around the MS nurse. It was clear—we had good evidence to show this—that where you put MS nurses in, admissions dropped and the number of patients referred to clinic dropped. The MS nurses were doing it much better than we were, so we said, “Right. That’s it. We’ll build our service around the MS nurse.”

Now, whenever a patient in East Kent is diagnosed as MS they are sent into a system where they meet the MS nurse who becomes their navigator. That is their lifelong friend. Now it is slightly different from being a key worker, because a key worker can change, depending on what the problem is. A key worker if you have incontinence would be the continence nurse; if you got a problem with social services, it would be the person with the particular experience there. The navigator—the MS nurse—is able to say, “I can sort your problem, or I know somebody who can.” It has been dramatically successful—it got a national award and we are extremely proud of it—but again I come back to the problem we face, which is: how do you promulgate this? How do you get these ideas out into the wider world? It ran into exactly the same problem as Action on Neurology.

**Q10 Fiona Mactaggart:** Yet the Department of Health says it does not think we have provided enough evidence to say that this is not good value for money.

**Dr Pollock:** I’m sorry, but I don’t agree. Even if you were to take a very simple outcome measure, deaths from epilepsy, that has been rising over the last decade as money has been poured into neurology.

**Steve Ford:** It is quite an indictment of the service that we do not know what value for money is and that the information is not there to tell us.

**Chair:** We will come back to it at the end, but you might think about what outcomes you think we should have.

**Q11 Nick Smith:** Dr Pollock, I am still trying to bend my head around some of your remarks. As I get it, a third of patients referred should not be seeing a neurologist anyway and the majority of patients who have a neurological condition are not seeing a neurologist. There is a complete mismatch between patients and the clinicians who are supposed to be dealing with them. Is that right?

**Dr Pollock:** Well, broadly. I would qualify what you said slightly in that one of the neurologist’s jobs is to decide whether or not there is a neurological problem. In an ideal world if you feel that you have multiple sclerosis or Parkinson’s disease, whether or not you have—if you have just been looking it up on the internet and you think, “Ooh, I’ve got this tremor. I’d like to see a specialist.”—in an ideal world that would be a reasonable action, but the fact of the matter is we have not got the resources to do that except by depriving in-patient neurology and long-term neurology.

There are ways round this. For instance, 20% of out-patient referrals are to do with headache. I think headache could be managed in the community by trained GPs. There is no reason why not; there are good examples; there is published evidence. What they have to have is to be networked into the whole

service, so that if they get out of their depth with the one in a hundred patient who has a headache from a brain tumour or something like that, they can quickly refer to the neurologist. It is a matter of organisation, and right now that is what we are not getting. To exaggerate a little, it is easier to see a neurologist because of a tingling finger than it is to get neurological treatment if you are in a life-threatening illness like status epilepticus.

**Q12 Nick Smith:** Thanks for that. Mr Ford, you talked of the increase in funding from £2.1 billion to £2.9 billion. In the first part of your remarks you talked about it being spent on emergency admissions, or at least some of it being spent on that, but then you said that you did not know where it had gone. Have you got some sort of assessment of where the bulk of this large amount of money went?

**Steve Ford:** The point is that it has not been measured. That is really the issue. There is no monitoring system at all around neurology services, so we can talk about the amount of money that is spent, but it is very difficult to measure the impact around that. There is no target and because of that there is no accountability in the system either for any of that. We do not know. There is a gap in data here.

**Q13 Meg Hillier:** Maybe you can think about it and at the end talk about what targets you would like to see and you think would make a difference. It seems to me the Report shows that there is a poor link-up between health and social care. We have seen this in other areas as well. The stark figures about the increases in emergency admissions suggest that there is a serious problem about social services/community care, as you highlighted. Is this because local authorities provide that, and they are not joined into the national system?

**Steve Ford:** Yes.

**Q14 Meg Hillier:** My worry then, with the NHS proposals and shape of the NHS, is that that fragmentation will get worse. I do not know whether you have any thoughts about that. The value for money, whatever you do now, if it is broken up, will be difficult to keep track of.

**Steve Ford:** To answer that, I think I would go back to the point about what a good target could be, because I think that we are seeing here a 32% increase in emergency admissions, which for someone living with a neurological condition is a disaster. I think it would be great for the service—the joined-up services of social care and the NHS—to have a target, an outcome, which is about reducing emergency admissions.

That means the whole system has to work together in a completely different way. We have to make sure that the kinds of things that Dr Pollock has been talking about, using the work force in different ways, are done. It has to be completely refashioned. If you had that kind of target, the NHS Commissioning Board could set out some good models of good practice, the third sector could really be mobilised to add support to all of this, and we could see some real rapid change, which would have a massive impact on people's lives,

just through having that one measure, so that people—NHS chief executives, clinical commissioning groups, social services directors—knew that they were accountable for that kind of target. It could make a massive difference.

**Q15 Meg Hillier:** Accountability seems to be a very big part of it. In the past I cared for two disabled adults, and at one point I worked out there were 13 different agencies that I was having to engage with on their behalf. The complications of that must be immense if you have a neurological condition, which perhaps leads to other disability. Then there are the carers, as well. What is the target you would like to see? I like this idea—the value for money in having what you called the navigator role. I think they do that with diabetes similarly, and there has been some progress looking at that role. Have you, or has anyone, done an analysis of what that costs? Dr Pollock, you talked about your example in Kent. Have you done a full analysis of the costs of that, taking out the costs of the emergency admissions that are reduced as a result, and the softer costs—the support that family and others have to provide, particularly, for instance, when the person has other disabilities, or is a child?

**Dr Pollock:** No.

**Steve Ford:** There is lots of evidence; the charities have got lots of evidence of where investing in specialist nurses, for example, has reduced admissions and the amount of consultant work load.

**Q16 Meg Hillier:** Which begs the question have the Government looked at that? Clearly it has not worked very well.

**Steve Ford:** There was no mid-point review of the National Service Framework, but we have been doing work on that. Neurological Commissioning Support, a body set up by three of the neurological charities to help the commissioning process, has done a lot of work on that. I was reading this morning of some work they are now doing in Surrey, where they have got the neurological community together and they put a plan together that improves services and reduces costs. That is the kind of focus on neurology that can lead to that win-win situation.

**Q17 Jackie Doyle-Price:** This is very much further to that. Everything you have been saying about outcomes is absolutely spot-on. I think the key is making sure that you have the right people challenging those outcomes. With that in mind, how do you see the health and well-being boards playing that role? Do you think it is currently high enough on their radar for them to realise that they need to be looking at this?

**Steve Ford:** I do not think it is currently. We have no evidence, looking around, that we have seen any areas focusing on neurology, first because it is not part of the general set of priorities and secondly because it is really complex. That is where we can do some work to help people find some of the practical solutions to improve this, and also by putting some accountability in the system. That to me is why having a kind of shared outcome of reducing emergency admissions

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could be a very powerful way of unlocking the system.

**Q18 Jackie Doyle-Price:** On that, certainly in my locality, I find that lots of the local groups representing sectors find it very difficult: when things are dictated from the centre in the health service they have expectations that they are going to get enhanced care; then it does not get delivered, and they do not have a way of challenging that. I think that obviously is a role we expect the health and well-being boards to fulfil. Do you see that as well?

**Steve Ford:** Yes, definitely. That is a really good example. There are lots of local groups that do not just want to challenge; they want to play a really proactive role in designing the solutions. Hopefully the structures can enable that increased level of service-user engagement.

**Jackie Doyle-Price:** In some respects, we have raised their expectations with this strategy and more money, but it has not really been delivered.

**Q19 Meg Hillier:** May I ask one simple question? Do you have a figure, or could you get us a figure—perhaps the NAO could—for the actual cost of an emergency admission? That is quite key. Obviously it is not great for the individual unless there is a real need for it, but what is the actual cost?

**Steve Ford:** The tariff is anywhere between £2,000 and £4,000, depending on precisely—

**Q20 Meg Hillier:** That is different from the cost.

**Steve Ford:** Well, tariff prices ought to equal costs in the health service.

**Q21 Chair:** David, do you want to add to that?

**David Moon:** We could look at doing something on that.

**Chair:** Austin has some questions, and then I will ask you for any final thoughts. I know it is a quick session, but we have the main session with the accounting officers.

**Q22 Austin Mitchell:** The witnesses have given us some powerful evidence that concurs with the very effective Report. Our problem is where we go now to secure value for money. I take it that there is not going to be another pot of money—the first having been squandered—in the present climate. You have had it. So where do we go now? From what you are saying, I get the national clinical director, national priorities and targets on readmissions, but what else?

**Dr Pollock:** The Chair has done me the honour of describing me as an old-style Stalinist, which is a very unusual position for a neurologist. In fact, I am not a Stalinist.

**Austin Mitchell:** That is my job.

**Dr Pollock:** I am very happy for neurological services to be delivered at a local level. I believe that the idea that putting money out of the hospitals and into the community has a lot to commend it. The trick for the Department of Health is to make sure that the new structures they are developing do not treat neurology as simple when it is clear from all of our discussions that there are complications. Therefore, it does need

to be looked at in a way that gives proper guidance and weight to the development of outcomes.

As I said, if we were just to take the simple outcome measure of death rates in epilepsy, we should pack up and go home. They are going up the more money we spend. So what I plead for is more strength and direction within the Department of Health about understanding the problem. That has just not been there. Nobody listens to the submissions because nobody has the grip and the responsibility to do so. How you deliver a particular programme could be left safely to a local commissioning group, provided that it is properly informed and given a clear remit about what is and is not acceptable. Whether you have a geriatrician or a neurologist running a Parkinson's disease programme in the community matters only inasmuch as which is the best service for the particular area.

**Steve Ford:** My closing comment is that we could be here again in three years having exactly the same conversation unless something different happens. We do not see that there is anything currently within the system that is going to change the problems that the NAO so powerfully describes. We will see emergency admissions continue to rise, and there will not be that kind of focus on neurology.

**Q23 Chair:** The things you really want to change are?

**Steve Ford:** The things we want to change are to have this outcomes framework. We want a clear vision, with some targets within it, of how neurology services should be provided, with some leadership, levers to support these emerging clinical commissioning groups to implement all the changes and some accountability in the system. If we were to get that, we would see rapid change.

**Q24 Meg Hillier:** What targets? Who should be accountable? Should it be different people in different areas? Should it be the neurologists? Should it be the community? The diabetes clinicians I have spoken to said that they did not believe how much of a difference it would make giving GPs targets. It has overnight transformed the system.

**Steve Ford:** Exactly. I think it has to be the commissioners who are accountable. When someone is living with a neurological condition, with all of the challenges, with the 22 different health professionals they need to see and all of that, it is up to the commissioners to ensure that they are securing for them a package of care that works and is co-ordinated.

**Q25 Fiona Mactaggart:** One reason we are a little sceptical about that is that we know how varied provision is around the country. I compared spending in my constituency with that of Mr Bacon who normally sits next to me. His gets 50% more than my constituency. That is not in the least uncommon. Local accountability is not delivering equal spending. Fair enough if it had equal standards, but it is not doing that at any level at the moment. Can we do it with a locally accountable system?

**Steve Ford:** That is the system we have and we have to make it work.

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**Q26 Fiona Mactaggart:** Your view is, *faute de mieux*, that we have to.

**Steve Ford:** Part of that, but actually there is a massive appetite for ownership locally. We see that there are lots of neurologists like Dr Pollock who want the opportunity to reshape services, working with local patient groups. The problem is that we have not been able to get on the agenda of commissioning groups to do that kind of work. If we put some impetus behind this, make it a priority, we shall unlock a tremendous amount of creative forces.

**Q27 Chair:** Finally, what is the population profile that you need for a neurological service? I know that is a bit crude, but what would it be?

**Dr Pollock:** At the end of our report from the Association of British Neurologists and the Royal College of Physicians, we made a first attempt to show how commissioning should work for a population of 500,000. We think 500,000 is a good number because it is large enough to avoid single-handed nurse practitioners and so on, and you can get some kind of momentum behind your programme. It allows you to have some direct management of in-patient neurologists, but it is small enough to keep yourself in a local environment.

That would be either working round one acute trust, or maybe two acute trusts coming together to say, "We will provide the in-patients and you can provide the Parkinson's disease programme or the MS programme, because you are better equipped to do it." I think 500,000 is a good number to work with. I am worried that if we are just dealing with clinical commissioning groups of 50,000 we will lose time before they work out that actually they are going to have to coalesce.

**Steve Ford:** Networks are really important.

**Q28 Meg Hillier:** You talked about the stroke model earlier. Do you think that works? I was sold on the stroke model when the benefits to patients were explained to me—and the costs helped, as well. Do you think that model would work? You talked about 500,000; that is about two London boroughs—I am a London MP. That would mean one acute trust would be leading and the other services—

**Dr Pollock:** Yes.

**Chair:** Wouldn't it be through the commissioning? But it is quite useful to have that in terms of how we question the others.

Good. Thank you very much for your clear and helpful evidence.

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### Examination of Witnesses

*Witnesses:* **Sir David Nicholson**, Chief Executive, NHS, **Una O'Brien**, Permanent Secretary, Department of Health, and **Dr Chris Clough**, Chair, National Clinical Advisory Team, gave evidence.

**Q29 Chair:** Welcome. Looking at the present structure, David Nicholson, you are responsible for the past; Una, you will be responsible for the future.

**Una O'Brien:** I think we are jointly responsible for the future, if I may say so.

**Sir David Nicholson:** But only I am responsible for the past.

**Q30 Chair:** This is a difficult area, but it is a very interesting area. I have probably have had more lobbying on this subject than I have had on anything in the times that I have been Chair, so I would really appreciate really specific and direct comments in the answers—no waffle. I will interrupt if I feel that we are not getting anywhere. Is that all right? They are the terms of engagement.

One of the many letters that I had about this inquiry, which was from four of the all-party parliamentary groups—on Parkinson's, MND, MS and ME—said, "Many neurological services are not fit for purpose due, in part, to inefficient and poorly monitored use of public funds". Comment.

**Sir David Nicholson:** There is no doubt that any of the funds that we use in the NHS could be better. We could improve the value for money on almost everything you could possibly imagine. Over the last period, we have seen the attempt to implement a National Service Framework, which—

**Q31 Chair:** This is worse. The cancer strategy people have been praising the stroke strategy. This was another strategy, which on all sorts of indicators

seems to be—we will come to why you had no data and why there has been no monitoring of it later, but it is unusual for me to see in a Report such a clear statement from the NAO around failure to get value for money.

**Sir David Nicholson:** But it was a different kind of National Service Framework. At the time, as you remember, the Government were moving away from the idea of top-down; you identify a national tsar, you give them a bag of money, you give them national targets and you drive change.

**Q32 Chair:** That makes it even scarier.

**Sir David Nicholson:** The Government were moving to a position where they believed that a better model of change would be to drive it from local circumstances, hence the idea that you would set out a set of quality standards for a service, and essentially, with support, let people get on with it.

**Q33 Chair:** I understand all that. It was done under the Government of which I was a member, but the interesting thing about this whole area is that will be the pattern of service provision under the Health and Social Care Bill. So if things have gone so badly wrong here, we've gotta think—which is why I want to be really specific this afternoon—about your analysis of why you didn't perform better, accepting entirely it was a different framework, and what you have learnt from it and what you are going to change as we move forward.

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**Sir David Nicholson:** We have learned quite a lot from it. This is part of the dilemma in terms of the discussion about this kind of issue in the NHS. People take positions very quickly. It is either all top-down and you are accused of being a Stalinist or it's all what you have given up—you give the money out and let people do what they like. But actually when you want to make change, you have to do bits of both. What we have learnt from those circumstances—my take on the neurological long-term position is that we put too much store on the ability of local people suddenly to rise to a challenge that we had had. Of course, in those areas where you had really good clinical leadership and really good people who were engaged, you got good services. In those places where you didn't, you didn't. That is a very powerful lesson that we can learn. So what is very important to us as we go forward is that we make sure that we have the right amount of national and central work on this, as well as the local.

**Q34 Chair:** Are you considering a national clinical director?

**Sir David Nicholson:** Well, at the moment the NHS Commissioning Board is looking at the way it manages itself. As part of that, we are looking at the way we organise ourselves. What we are trying to do is organise ourselves around the major elements of the outcomes framework. So we will have a top-line clinician responsible for the drive on reducing mortality. We will have one who is responsible for driving the quality of life for people with long-term conditions. We will have one responsible for what is described as episodic care, one for patient experience and one for patient safety. That is the way the organisation will be set up. Within that, of course, there will be clinicians who will work with those people. We haven't yet come to a conclusion about how we are going to deploy our resources.

As you know, in terms of quality standards, there are about 150 different conditions that we could have clinical tsars for, so we have to think about that very carefully. But what is clear to me is that—Steve and other people are absolutely right—we need to strengthen the national leadership in order to make the change happen. Leaving it to local will not deliver.

**Q35 Chair:** I want to push you a little on that. I hear that, and I think the problem is that Chris Clough has responsibility for long-term conditions—we will come to him in a minute—and neurology gets sort of ignored in that. From the evidence we had from the two people in the field, what was clear was that a real focus on neurological conditions is what is needed with outcomes around neurological conditions. Very helpfully, we heard about reduced emergency admissions, access to specialist nurses, a clinical director and personalised care plans. Those were the ideas that came out of the evidence we just heard. I don't want those hidden in something for people with long-term conditions, because that appears to me to be where we went wrong under the old strategy.

**Sir David Nicholson:** But I do think the outcomes framework is very powerful in this, in the sense that

it sets out improvements in the quality of life of people with long-term conditions, as an outcome.

**Q36 Chair:** It is very vague.

**Sir David Nicholson:** I don't think it is. It sets out a series of ways in which we are going to measure that, and you can in that measurement identify those people with long-term neurological conditions. For example, part of the way we will measure it is via the GP survey—the survey of more than 2 million patients that we do. In that we will use the questions that have been well researched and evidenced across Europe for how you would measure the quality of life of people with neurological conditions. People will identify the answers and that will be reported both locally and nationally, so we will be able to track that over time. So that is in the outcomes framework.

The other thing—this speaks particularly to the point about variation—is that, as you know, as part of the development of the work that came out of High Quality Care for All, the Ara Darzi work, we would identify quality standards that use all the evidence to identify quality standards. NICE would do that as an evidence-based objective body. It is currently designing three: one for people with motor neurone disease, one for Parkinson's disease and one for multiple sclerosis<sup>1</sup>. Those quality standards will be short documents—15 pages, perhaps. There will be a number of measures within all that on which we will hold clinical commissioning groups to account for delivering improvements over time. So I think there are national things in the system that I think will help and will expose the issues that have been identified very well.

**Q37 Chair:** We heard at the end that you need a population of about half a million to make sense in services for neurological conditions. The commissioning groups are rarely going to be that big, so that leaves you in charge of commissioning with a bit of a problem. How are you going to tackle that?

**Sir David Nicholson:** Every day that goes by, the clinical commissioning groups get slightly larger, I have to say. There are some that are over 500,000, as it happens, but obviously that is not common across the NHS as a whole. What we know from commissioning, with any sort of condition, is that there is no right population for it. Even though half a million was identified as being suitable for neurology, for certain neurological conditions, you can have a smaller population, and for some, you can have one even larger than half a million. The issue for us is, how do we flexibly use the commissioners to do that? Clinical commissioning groups have to go through an authorisation process for us, as a Commissioning Board, to say, "Yes, we think you are capable of commissioning." As part of that, groups have to go through a process of what we describe as collaborative

<sup>1</sup> *Note by Witness:* NICE have been commissioned to develop Quality Standards covering epilepsy services for both adults and children and headache/migraine in young people and adults. Quality Standards for motor neurone disease, Parkinson's disease and multiple sclerosis were part of the recent engagement exercise run by the National Quality Board and NICE on those topics that will initially make up the proposed library of Quality Standards.

commissioning. They have to show how they are working together with other clinical commissioning groups to create a population to deal with some of these conditions. That is part of the process. We will be talking to the kinds of organisations that are represented here today about authorisation, so people can make comments. That is a good process to take things forward.

**Q38 Chair:** If we come back to this in two years' time, having looked at the disaster of the past, what would you want us to measure to show some improvement?

**Sir David Nicholson:** I would want to see many of the things that were identified earlier, which were absolutely right. We would want to see a reduction in the number of emergency admissions across this group and across most groups with long-term conditions. That is part of our strategy going forward. We would want to see progress in terms of the quality standards identified, but more important, in all that, we would want to see demonstrable progress on the quality of life of people with the long-term conditions that we have identified.

**Q39 Chair:** Which you measure how?

**Sir David Nicholson:** We measure it by asking the individuals. There is a mechanism that you can use to get that data.

**Q40 Chair:** Things like specialist nurses and personalised care plans—

**Sir David Nicholson:** Personalised care plans would be an important part of that. Indeed, we do measure that at the—

**Q41 Chair:** Only 22% or something at the moment.

**Sir David Nicholson:** We do a survey of literally millions of patients, which gives a much higher figure than that, but I will not argue with the NAO's figures. Certainly, that is an indicator of where we are.

I think we would draw the line at inputs. That is the issue that we have struggled with before. It is up to local organisations to decide how many staff they will have and how they will deploy them.

**Q42 Chair:** No, but you might say access to a nurse—

**Sir David Nicholson:** Access to a nurse?

**Chair:** Access—and then we will come back again, because there is a great variation. You have to think about variation.

**Q43 Amyas Morse:** Reflecting on what Sir David was saying about measurement, quite a lot of the measures that we have been talking about have a composite feel, therefore you imagine that they get meaningful over time. But one or two things that we heard testimony about are clear signs that things are going badly wrong—if emergency admissions are shooting up, for example. With things like that, you imagine that you would want to be able to react rather more short term. By react, I do not mean necessarily taking over services; I am not thinking that at all. Simply, from what we have heard and what is in our

Report, there seem to be some measures that you take as a bit of a tripwire—you think, if this is going the wrong way, people should be asking some pretty immediate questions. Will there be a means of getting that more short-term measure? When do you need at least to step in and ask some questions?

**Sir David Nicholson:** I understand. First, I want very gently to push back a little on your point about emergency admissions. One of the things about this particular group of patients—we knew it was the case when the Government set up the national service framework—was that people thought that progress would be made through the generic changes that were happening in the service—in particular, access to diagnostics. The figures in your Report dramatically show how more people have access to diagnostics and quicker access to services. What clearly comes out of that is a better identification of people. What you are seeing here is not just an increase in emergency admissions being necessarily a bad thing—but overall it is—you are also seeing a lot more people being identified as having neurological conditions, which slightly overstates it. The other thing is that we want to get more people in who suffer from a TIA or a mini-stroke, so it is slightly more complicated.

Having said that, you are absolutely right about some of the composite indicators. It takes many years to get to that place. The way that we are going to deal with that is we are going to develop, in concert with this, something called the commissioning outcomes framework, which, in a sense, takes these things and looks at what the short-term changes are that will happen and which we will monitor. We are going to hold commissioning groups to account for that, in the short term.

**Q44 Chair:** Give us an example. What does that mean in practice in this area?

**Sir David Nicholson:** In this area, it could be emergency readmissions, for example. We could say to the clinical commissioning groups, "We want to see a demonstrable and significant reduction in readmissions into hospital." You can measure that quarterly. You don't need to measure that every week. We would incentivise the clinical commissioning group to enable them to do that. That is a way in which you could turn a bigger outcome into a particular indicator.

**Q45 Fiona Mactaggart:** I thought that the framework that we are talking about did exactly that, trying to look at the targets that it had. I thought that that was one of them, but, in fact, it has gone the other way. Am I wrong?

**Sir David Nicholson:** I'm sorry?

**Q46 Fiona Mactaggart:** I thought that that was exactly what was planned in the existing framework, and the existing framework has gone in the opposite direction.

**Sir David Nicholson:** What happened in the public service agreements—

**Q47 Fiona Mactaggart:** Reducing emergency bed days by 5% is one of the original targets.

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**Sir David Nicholson:** And we did more than that. We reduced it by significantly more than that.

**Q48 Fiona Mactaggart:** But then there was an increase in readmissions.

**Sir David Nicholson:** And there has been an increase in readmissions, which gives you a flavour of how difficult it is sometimes to select a number that you can focus on and which will deal with everything else. It is absolutely true: we have a rising number of emergency readmissions in the NHS at the moment, which is a big problem, both for the patients and for how we operate.

**Q49 Fiona Mactaggart:** And it is rising faster in neurology than it is in other conditions.

**Sir David Nicholson:** I do not know whether Chris wants to say anything about that, but I would query that. I am not absolutely sure that that is the case. In a sense, it is not relevant, because the number of readmissions is going up and we need to get it down. What we are doing at the moment is examining every single readmission, from every hospital, that is happening in the NHS to assess, first of all, whether we think it is a reasonable and clinically required readmission. We are only paying hospitals for those that we think are clinically required, which is a major incentive and a major driver of change in NHS at the moment.

**Q50 Chair:** But the unintended consequence of that, as we talked about earlier, could be that you get people not being discharged, because you are scared you will not get the money when they are readmitted. There also could be an unintended consequence of social care not meeting its bit of the funding, because the hospital will pick it up and you do not have to pay for it.

**Sir David Nicholson:** You reflect there the dangers of the work and the potential that we get in all of that. That is why you have to do all those things together. You have to have your quality standards, you have to have your outcome framework, you have to have your commissioning outcomes, you have to have the contractual arrangements between hospitals and you need the right people in place. You need all those things lined up to deliver change.

**Q51 Chair:** So you have to be quite Stalinist.

**Sir David Nicholson:** I do not think that you have to be a Stalinist, but you have to be clear about what you need to be clear about. The point that I am trying to make is that if you take the quality standards that are put in the NSF for long-term conditions, we put them out into the service and we let people get on and look at them. We have no mechanism for monitoring them and we have no mechanism for holding people to account.

**Q52 Chair:** Exactly.

**Sir David Nicholson:** We trusted that the system would drive change, but it is not going to work. We have learned that.

**Q53 Fiona Mactaggart:** Do we get as good value for money from this area of the health service's work as we do for our CHD work, for our work on cancer and for our work on stroke?

**Sir David Nicholson:** It is more difficult to measure this one. That has been part of the problem.

**Q54 Fiona Mactaggart:** So that is why you say in paragraph 26, "It is the Department's view that there is insufficient evidence to support a conclusion that current spending on neurological health and social services is not value for money." I have always discovered in politics that when people use double negatives, you should not trust what they are saying.

**Sir David Nicholson:** You should trust what I am saying.

**Chair:** Is it value for money?

**Sir David Nicholson:** I think it is too early to tell.

**Q55 Fiona Mactaggart:** This has existed since 2005.

**Sir David Nicholson:** Yes, but it is a 10-year strategy. That is the point.

**Q56 Chair:** And you cancelled the mid-term review to see whether it was working.

**Sir David Nicholson:** We never said we were going to have one, apparently.

**Chair:** What?

**Sir David Nicholson:** We apparently never said we would have one.

**Fiona Mactaggart:** So the fact that you were accused of cancelling it was made up by someone? I don't think so.

**Sir David Nicholson:** Can I go back to the point that the thing about cancer, coronary heart disease, stroke—all of those things—is that they were the priorities of the Government, and they were the priorities of the Government because they were the big killers. They are the things that kill lots and lots of patients.

**Q57 Austin Mitchell:** Are you saying neurology was not a priority?

**Sir David Nicholson:** It was not a priority. It has not appeared in any of the operating frameworks over the past five years that any of the Governments have produced. That is true. It has not been a national priority in that sense. That is absolutely true.

**Q58 Chair:** Why did you do a national service framework for it? What was behind that?

**Sir David Nicholson:** We have done lots of frameworks. There are lots of them around that have been produced over time. I am not saying that because it is not a priority you should not do anything about it; you should. But if you ask me whether it has been one of the four or five things that the Government have said needs changing, then no, they have not. Part of the reason for that is because the focus has been on saving lives, and that is a relatively straightforward thing to measure. Quality of life, for people with long-term conditions, is quite a difficult one. In a sense, that is why we had some problems doing it, but I think we are getting to a place now where we can do it and where we can focus our attention on taking it forward.

**Q59 Fiona Mactaggart:** Sir David, it seems to me that not only is it not one of the Government's actual priorities, but it is almost the opposite in as far as if you are referred to a hospital with a neurological condition, it is unlikely that you are going to see a specialist. If you compare that with admissions to physician wards in hospitals, nearly everybody else will see a specialist in their condition. They will see a respiratory or a gastroenterology specialist, to take two things which are not in your absolute priorities. Yet, if their condition is neurological, frequently they will not be admitted by a neurology consultant. That is the common experience of people. That sounds to me not only as if it is not a priority; it sounds to me as if it is the opposite of a priority. The number of consultants per population in this country is 1:125,000. The European average is 1:20,000. Not only are we not doing as well as we ought to; we are doing quite frighteningly badly, I would suggest.

**Sir David Nicholson:** I will let Chris have a word about that. Fundamentally, I agree that too many people are being admitted in an unselected way to acute hospitals. It is bad for them and it does not provide great value for money for the NHS. For example, over the past six months, the number of emergency admissions to hospitals in the NHS has gone down by 1.9%, for the first time in many, many years; it has been going up at 3%. That is partly because of the way in which we have tried to manage long-term conditions better in the community—not particularly this particular group, but people across the NHS—because it is vital for us to do that for the quality of service for patients, and also because we simply cannot afford for the rise in emergency admissions to continue.

**Q60 Fiona Mactaggart:** We are a value-for-money Committee, so we want to reduce those emergency admissions. We are with you. The reason why we focused on neurological conditions, rather than on all long-term conditions, is because this is the area where, obviously, we are getting the value for money frighteningly wrong.

**Dr Clough:** I have a number of things to say. Your description of the disaster I just do not recognise. As a front-line clinician, I really do not recognise that. What I have seen in my own practice is actually improving services for neurological patients.

**Q61 Chair:** Hang on. Before you go on, the 2011 study by the Royal College of Physicians—I do not know if you are a member of it—concluded there had been no major improvement; an audit of 11 sites by the neurological commissioning unit found that not one had fully met a single quality requirement; emergency admissions and A and E are up; only two thirds of people with Parkinson's are seen by a specialist within six weeks; one third are not given proper advice and support when they have MS; the Oxford university survey of a number of things showed that only 22% had a personal care plan; and only 5% of NHS and LA budgets are pooled. I could go on and on. None of those indicators is good.

**Dr Clough:** There are good things and bad things. Let's face it. The audit Report you might call a bit of

a curate's egg, because it does report on some good things—

**Q62 Chair:** That is a heck of a lot. Do not come and tell us that it is good.

**Dr Clough:** You obviously do not ask your barber if you need a haircut. In other words, if you ask a group of people with neurological conditions whether the services meet their requirements to 100%, which is what the audit Report did, they are largely going to say, "Well, maybe not."

**Chair:** Can I just stop you there? That is absolutely outrageous.

**Q63 Fiona Mactaggart:** I have had cancer and I have MS, and I have to say that the services that I have had because of my cancer have been excellent and completely wonderful. I would say that they could beat anyone in the world. The treatment that I have had for neurology has, in many cases, not been.

**Dr Clough:** I am very sorry to hear that.

**Q64 Fiona Mactaggart:** That is an anecdote, but I am speaking from the point of view of the patient to whom you referred.

**Dr Clough:** Okay. Let's talk about—

**Q65 Chair:** Can I just say that I think it is hugely important that the NHS puts the patient at the heart of what they do? If the patient's views are that they are not getting what they want, you, as the clinician, should jolly well listen to that. I feel that that is absolutely imperative in all public services, particularly in health.

**Dr Clough:** Yes, but the methodology of using 100% met is not a very good methodology, because nobody will ever say that. It is rather like the bar of chocolate, is it not? You can send it back if it did not meet your—

**Chair:** No, it is not. If people have a good service, they will say so. That is just not true.

**Q66 Mr Bacon:** It is an interesting reflection on your overall philosophy. I know that we are not discussing businesses, but many organisations, in seeking to measure the satisfaction of those who use them, including many private sector organisations, would aspire to 100%, and if they got to 98% or 98.5%—the Chair mentions Marks & Spencer—they would use that as the starting point and then study constantly where they were falling short. Your statement about not asking your barber whether you need a haircut suggests that all the things that the National Audit Office studies produce equally poor reports from those who are using them. That is simply not the case.

**Dr Clough:** Of course, you should take the entirety of the evidence. The audit Report has based a lot of its conclusions about value for money on emergency admissions, and Sir David has already alluded to this and said that the increase in emergency admissions is not what you would want to see. However, what it does is prompt a question. You have to look under the stone and say, "Why did that occur?" The challenge is to understand why emergency admissions have risen within neurology, and it is of course a very complex

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answer. Complex answers are not always what politicians want to hear. The answer is that—

**Q67 Chair:** I think, actually, us politicians just want to hear that people working in the NHS put the patient, not the clinician, at the heart of what they do.

**Dr Clough:** And that is exactly what we are trying to do.

**Chair:** It does not sound like it.

**Q68 Amyas Morse:** Is it not true that people really argued and pleaded that you should put baseline metrics in place at the start of this process? Is that not true? Are you really saying that people did not ask for that? We have evidence that there were a lot of requests from the clinical community that there should be a clear measurement baseline put in place and that those requests were not acceded to.

**Sir David Nicholson:** I can, hopefully, help with all of this. In terms of the national service framework and the way that it was constructed, it was not done by accident. It was done on purpose. People weighed up the kinds of issue that you have described, and they said that we should have a local audit, using a national tool. If you are asking me whether, if we set out to do it again, we would do it like that, we would not. It is essential that you have a baseline, because how on earth can you then measure progress? That has bedevilled this process.

I am not in any way suggesting that the services that we provide are adequate. It is absolutely central to the NHS to continuously improve. If you look at the outcomes framework, the main determinant of our success as an NHS is the quality of life of the people with long-term conditions. That is determined by what they say. That is what is in the outcomes framework, and that is what we want to take forward.

**Q69 Fiona Mactaggart:** I want you to look at figure 7, which compares the different national service frameworks. Sir David, you talked about having a system where you might measure the outcomes in terms of particular aspects of people's experience when they have long-term conditions. I have been pressing the issue about the number of neurologists, and not by accident. I suspect that these particular aspects will be mis-measured in relation to neurological conditions because—I never thought I would argue for more consultant neurologists as I have had such horrible experiences with them—there are insufficient numbers of consultant neurologists or GPs with any form of neurological training. That is the first problem.

So figure 7 tells me that if you have someone like Professor Mike Richards, who is a clinical lead and has some clinical respect in his community, they can guide people into making cost-effective decisions. I remember Mike once saying that one of the things that one of the cancer collaboratives did was pass on referrals by text rather than fax, or something like that, and it saved in that case thousands of pounds and weeks of patient time. So it is not necessarily rocket science, but it requires someone who has the clinical understanding of that field. My absolute terror is that your proposal that we will see how people deal with

this bit of their condition and that bit of their condition will create on a national level the thing that people with neurological conditions face on a local level, which is that you can't find which bit of the system is going to deal with what you need. Why don't you just learn from what you've done well, produce value for money and do it for neurology? Una should perhaps answer this as she is responsible for the future.

**Chair:** Una, do you want to answer that? You have been very silent. Una, only if you want to.

**Una O'Brien:** The first thing to say is that the reform programme, particularly the outcomes framework, is a fundamental and systematic approach to addressing the issues that were raised in the first part of this session and some of the things that we have been talking about now. So there is much more to be brought out about that. We have not had an opportunity to check with you in full on that.

**Q70 Chair:** But there is a specific question that Fiona asked.

**Una O'Brien:** I want to come on to Fiona's question and figure 7. My own experience of observing these frameworks from when I was working in the NHS, and now back in the Department, is that it is the combination of factors that has led to success. I have huge respect for the national clinical directors as great leaders of their respective areas of care. My observation is that it is a combination. It is where the issues have been easy to tackle. It is where we have had a very clear objective and where there has been, as David said, the model that was used—

**Q71 Fiona Mactaggart:** So shouldn't the combination include national clinical leadership?

**Una O'Brien:** Yes. The model that was used in the early part of the decade was very much to pour a lot of money behind these as well. So there was one model that went at those particular illnesses and conditions, which led to improvement in those. The point about the NHS is that we are responsible for everybody. The problem with that model is that by the time you get round to applying this approach to everybody, you are leaving people out and there are rare conditions and other groups that aren't getting that attention. I think that is one of the fundamental reasons why we need systematic reform, rather than working our way through each of these in turn.

**Q72 Chair:** To be absolutely honest, the best is the enemy of the good there. As I read this Report, 10% of people have a neurological condition. That is a heck of a lot. You are spending a heck of a lot of money on it. It's 4.5% of NHS expenditure. It is quite a lot of money. It seems to me that if you've got one in 10 of us lot having to cope with people like Dr Clough at some point, it might help if we had a clinical director, which did work. It has worked. The evidence is there that you know it works. I just can't see the resistance to using that model.

**Una O'Brien:** It will be for the Commissioning Board to determine how they use the clinical advice and clinical networks. I won't be prescribing it one way or the other because I think the key thing—

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**Q73 Fiona Mactaggart:** But this hasn't been prescribed and it has failed. You are saying that you are going to use this model, which we have profound evidence has not worked as well as other models, rather than another model. That seems very odd.

**Una O'Brien:** We are not using this model, no.

**Sir David Nicholson:** It is absolutely not using this model.

**Q74 Austin Mitchell:** I think you are in a hole that is getting deeper, so you should stop digging. I also think, Sir David, that you are a bit devious by putting this on a philosophical plane as part of a transition from Stalinism to localism. I say this as the last surviving Stalinist, I suppose—I have been called in by the shadow Chancellor for remedial economics at 5 o'clock, so I will have to pursue this quickly—but that disguises what was essentially a failure of the Department. It was a failure of the Department not to attach sufficient importance to neurological conditions. All the evidence we have had from the Neurological Alliance and from Pollock and Ford, who appeared earlier, is that there is no clinical director, no clinical drive from the top and no expertise at the top. All the warning signals that came up from the localities are that readmissions and emergency admissions were up twice the rate of other areas. Emergency readmissions, all of them very expensive, were rising substantially, too. All of that was ignored while you blindly handed out the money, which was effectively wasted. So you got no effective control of value for money or knowledge of whether the money was being spent usefully. That is a failure of the centre, not of localism.

**Sir David Nicholson:** Well, I could say a whole series of things, but I will start at the beginning. I think I have already acknowledged that the model of change used to develop the national service framework for people with long-term neurological conditions was not adequate for the changes that we needed to make. That was the policy at the time. It was not done by accident; it was done on purpose, because there was a belief at that time that that was the best way to get the change.

**Q75 Austin Mitchell:** But surely the groups that were advising us were also saying to you, "This will not work unless you do so and so."

**Sir David Nicholson:** Well, I get lots of people telling me that the cancer strategy does not work either. You always get people who will say—

**Q76 Austin Mitchell:** But that's Stalinism that worked!

**Sir David Nicholson:** The cancer strategy is very interesting because what we have been really good at doing is delivering better services for patients—those kinds of treatment services. Where we have struggled is in early diagnosis. Mike Richards himself would say that that is a generic problem in the NHS; it is not a problem specific to cancer. What Mike and the clinical teams are doing now is looking across all of diagnosis, including this kind of diagnosis, to see what are the common things about how we can speed it up. So, for example, access to MRI scanning for general

practitioners. All those sorts of things come out of that generic approach.

I acknowledge absolutely that the model of change was not right, but I think that the changes we brought in as part of high-quality care for all, the Ara Darzi work, and the changes we are making now make a much more coherent model of change that includes a strong centre that sets out what the standards are and gives people local flexibility about how they deliver it. I think this is a better opportunity than what we had in 2005.

**Q77 Austin Mitchell:** But at the start of this strategy the centre was not strong enough, effective enough or knowledgeable enough to see whether we were getting value for money.

**Sir David Nicholson:** The Government's view was that we had to move away from top-down targets. That was a very strongly held view, and it was not just the Government that held that view. Lots of clinicians have argued that, too. My experience of this is that clinicians are very keen on targets about their own service but less keen on others. Nevertheless, that was the case at the time.

**Q78 Austin Mitchell:** There were available targets, and they were flashing red—admissions, readmissions.

**Dr Clough:** Again, you have got to understand emergency admissions, because you have based a lot on emergency admissions. You have to understand that what I see now coming into hospital under my care are patients who are much older and much more complex with multiple morbidity. So the increase in neurological emergency admissions may be part of a demographic of an ageing population, but also, because of the 18-week RTT, we are now diagnosing these people, whereas perhaps before, someone in their 80s who had a mini-stroke or something like that might have been left at home without a diagnosis. Now they are coming into hospital, and that is probably appropriate, because we are now preventing strokes by people coming into hospital. There are a whole variety and a raft of reasons why your emergency admissions are going up.

**Q79 Chair:** There have been shaking heads from our expert witness behind you, as you were saying that. No one knows who is right—whether you are right or our expert witness before was right—so what is important is that we need the evidence base; we need the data which was lacking.

**Sir David Nicholson:** Absolutely.

**Chair:** Was that where you were going, Nick? Go on then.

**Q80 Nick Smith:** That was sort of where I was going.

Miss O'Brien, throughout the Report, there were references to poor data. On this Committee we have placed a lot of emphasis on consumer or patient voice, which is really important for improving outcomes. In his evidence, Mr Nicholson said that the GP survey will mean that the quality of life of people with long-term conditions will be improved. How will the data

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that you get from that GP survey lead to improved outcomes for people with long-term conditions like this?

**Una O'Brien:** The essential thing that we have to do is to establish a baseline from which we can measure progress. If I may go for a moment, if you like, inside the building called the outcomes framework, that is the second of those five major planks referred to by David, which is improving the quality of life for people with long-term conditions.

The plan at the moment contains a number of indicators. We will build those indicators and add to the framework year on year as we gain confidence that there is a relationship between the measure that we are using and the impact that it is having on people's lives. So when it comes to that particular measure that you asked me about—the GP survey—the way it is constructed at the moment is that we ask people to self-report on five themes: their mobility, their support for self-care, their usual activities, pain and discomfort, and anxiety and depression. There is a list on which they can self-define what their condition is; there is quite a long list of conditions, and one of the conditions that people can identify as having is a long-term neurological condition.

This will enable us, when we assemble the data, to do multiple analysis. We will be able to assemble the information nationally but also disaggregate it to locality. One of the things that we want to do is to be able to support local commissioners with this sort of data and with time series. Who knows what the percentage is that you are looking for? Actually, myself, I am aiming for 100%. I do want people to be satisfied as taxpayers—as an accounting officer, that is my goal. I may never reach it, but that is what I am after—to gain high levels of satisfaction with their care. What this will really enable us to do, for the first time, is that I will be able to see that data at the centre but I will also know that the clinical commissioning groups in Birmingham, Kent or wherever will all have that information relevant to them.

**Q81 Nick Smith:** It sounds very good, but it also sounds as if you will be developing it over time, and it will be a long time before patients see the value of it.

**Una O'Brien:** The great value will come over many years, but I believe and, in fact, I know that you will get value very quickly, because you will have your initial data from the first year's survey and then you will have comparator data the following year. We need to remain disciplined, enabling those time series to develop, but we also need to keep learning from feedback from patients as to what things are meaningful.

I know myself from being a patient that you can think you are well at one point in time but your condition can change, so we need to be able to develop these measures in a way that reflects the reality of people's lives. Historically, we have measured inputs and processes. They all have a part to play. But every health system in the world is trying to do this, and I happen to believe that we are as advanced as anybody else. We have the power of a national primary care system that is going to enable us to get at this data

much more readily than other systems. It is in development. I don't want to over-claim for it, but I believe that we are learning the lessons and trying to construct a system of measurement that really reflects the reality of people's lives.

**Q82 Nick Smith:** How would you get the commissioning groups to take notice of the data and to implement actions on the basis of them?

**Una O'Brien:** If I may, I would like to briefly set out the architecture of how that accountability system works. First and foremost, the relationship between the Secretary of State, the Department of Health and the Commissioning Board—

**Nick Smith:** Specifically on the use of this data to improve local services, given the evidence you have. Go straight into it.

**Una O'Brien:** The outcomes framework is centre-stage inside the mandate. It is not the only thing in the mandate, but it is centre-stage, and all that goes with it, in terms of the requirements on the use of information. We want to do this in a way that empowers the Commissioning Board to take that agenda and build on it. This is why we are going to strengthen the relationship between the information centre and the Commissioning Board, so that the Commissioning Board can nationally be as supportive as possible of the clinical commissioning groups.

David may want to say something about how he intends to build that relationship between the headquarters, if you like, of the Commissioning Board and what the clinical commissioning groups actually do and how they are held to account for that.

**Sir David Nicholson:** We will use all the levers at our disposal. The first lever that we have is the setting of the commissioning outcomes framework. We will set out what improvements we expect for each clinical commissioning group in these areas. That could range from continuous improvement, which is, "You have to show a bit of improvement," to, "You have to demonstrate a significant amount of improvement." We will hold them to account through the general management processes you would expect, but also by the allocation of incentive resources to them to make that happen. That is obviously a way of holding them to account.

Secondly, we have the ability to use things such as the quality and outcomes framework for general practice, for individual GPs. We commission primary care directly, so we will be able to identify, through that commissioning process, progress that we would expect general practitioners individually and in partnerships to make.

**Q83 Nick Smith:** How could you hold the GPs to account on that?

**Sir David Nicholson:** The clinical commissioning group holds the general practitioners to account for their commissioning activities, but in terms of their primary care activities, we hold them to account through the payment system that we have with general practice.

**Q84 Chair:** You would withhold payment?

*Sir David Nicholson:* It depends how you look at it. Some people say we give them incentives; some people say we fine them. It's whatever, but it is the way they are paid.

**Q85 Meg Hillier:** Value for money matters to the Committee. I think others have stressed that value for money and patient experience matter, so I was heartened by what you said. But it misses out a large chunk. Social services is not something that the Department of Health controls. There are many, many different therapists who could be involved with somebody with a neurological illness—most are lifelong. If it takes 10 years to get to an improvement, that is a very long time. For some patients, that will be too long. Particularly on the social services point, what are you doing about that? For certain patients, that could be a really big part of their ongoing community care, and you have no control.

*Una O'Brien:* Absolutely. We have touched on some of these matters before, I know, in this Committee. Again, I would stress the significance of the systematic, whole-scale change that is needed in relation to social care.

**Q86 Meg Hillier:** Those are big words. What do you mean?

*Una O'Brien:* For example, the switch that is happening towards personal budgets is, I think, really significant. I have shared with the Committee before some of the evidence that is coming through as we evaluate the personal budget pilots. Interestingly, we have a number of pilots currently under way around personal health budgets. I am expecting the evaluation report to be ready in the autumn.

**Q87 Meg Hillier:** That would mean someone could buy in a therapy.

*Una O'Brien:* Yes. This is particularly relevant for people with motor neurone disease or Parkinson's disease, people who have health and social care needs, who will be able to have self-directed care, to manage their own choices in how their care is organised with the relevant support—if we can make it work, because accountability does matter at that level as much as at the level of millions of pounds.

**Q88 Chair:** You will remember that we looked at that. One of the weaknesses was that you have no statutory powers to require it, and it is going really slowly. I can't remember the figures off the top of my head, but it is going really slowly.

*Una O'Brien:* Yes, and as you know, the Government have said that if they don't see the progress they are expecting, they will take those powers and will see it through. Their expectations of local authorities are clear and we are monitoring that.

**Q89 Chair:** So, remind me when you are expecting them.

*Una O'Brien:* I cannot remember the exact date but our expectation is that there is measurable progress towards the offer of a personal budget for everybody who is judged as eligible for social care. This is a really important piece of progress and I think it is

very empowering for people to have that. That has to happen.

As you know, there is a plan for a social care White Paper later in the spring, where we are going to address some of these fundamental issues about quality and access to services. There is also—obviously, it is very live at the moment—a major debate about funding reform for social care, which puts some big systemic changes behind some of the delivery issues that we have got, which cannot be sorted out on a micro basis; you have to take a macro approach to them.

**Q90 Meg Hillier:** This question is for Sir David and maybe Dr Clough. In other areas, many consultant clinicians have gone out into the community to run clinics, which is massively better for individuals. It takes less time out of their day; it is less of a hassle. I have only just seen the report from the Royal College of Physicians and the Association of British Neurologists, but I am picking up that that does not seem to be happening so much in neurology. Is that true? What can you do about it?

*Dr Clough:* I agree with your point. A lot of neurology could be done within the community, close to patients' homes. There is no reason why neurologists could not be employed by CCGs directly to lead services locally. In a sense, the health reforms do give us that opportunity. Perhaps in the past neurologists have been within their citadel, if you like—within the hospitals. We have just been talking about admissions. Clearly, there is a requirement for access to neurological opinion within hospitals. I digress slightly because it picks up a point that one of you touched on earlier about whether patients get to see neurologists in hospital. Of course, the access is variable, but people are trained in neurological conditions, so it is not as if the person receiving the patient into hospital does not have those skills.

I probably have wandered off the point here, but somebody talked about gastroenterologists and cardiologists; well of course the person you see as you come into hospital may be none of those things. They will be somebody who has the skills to receive you with your generic undiagnosed condition acutely. Those are the skills you have as an acute physician or a general medicine physician. Once the diagnosis is made there is a requirement to get you on the right clinical pathway. The issue there is, when do you access the specialist opinion?

To come back to your point, there is a requirement for neurologists within the acute sector, but I very much support your point. A lot of what neurologists do within long-term conditions should be done in collaboration, in partnership, with our primary care colleagues: GPs and clinicians.

**Q91 Chair:** Do you accept the NAO statement that only two-thirds of people with Parkinson's are seen by a specialist within six weeks? Do you accept that? Normally there is an acceptance of the facts. I am asking David or Una—one of you. It is unusual here to get something where you dispute value for money; I accept that. But are you accepting the fact that one

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in three people with Parkinson's do not see a specialist within six weeks?

**Sir David Nicholson:** I have no reason to believe it is not true.

**Chair:** Thank you.

**Q92 Fiona Mactaggart:** There is a double negative again; he is an expert. Sorry, that was a cheap joke. Forgive me.

**Dr Clough:** The RTT was achieved for neurological conditions for more than 90% of patients.

**Chair:** Say that again.

**Dr Clough:** The 18-week referral-to-treatment target was part of the roll-out of the NSF.

**Q93 Chair:** Yes, we know that because there was an 18-week referral target—I think that was the evidence that we got before—all the energy went into that. It does not mean that people with Parkinson's saw a neurologist.

**Dr Clough:** Well, should people with Parkinson's always see a neurologist? That begs the question. They should see somebody who has the right skills to diagnose them and to ensure that they receive the right treatment. When we listened to patients within the consultation for the NSF, that is what we heard from them. That could be different types of people. There is no reason why geriatricians, for instance, who have skills with Parkinson's disease, should not diagnose Parkinson's disease. Increasingly, of course, our nurse specialists are getting such skills. It is always about whether the person has the right competencies to assess somebody with that particular presentation. I don't think we should get into professional rivalries on this one.

**Q94 Fiona Mactaggart:** Dr Clough, you were implying that I was wrong in the allegations that I made earlier. I was quoting a report of D. E. Bateman, who is the chair of the Royal College of Physicians working party on local adult neurology services for the next decade, in which he says that the general physician with neurology expertise has disappeared. He states that admissions to acute medical unit are normally done by a general person, in the way that you described, followed by triage to the relevant specialist, such as cardiology or respiratory. He says that specialist beds and care is routine for all specialities except neurology, and he says that 10% to 20% of acute admissions are neurological. It is the third most common cause of acute admissions, and yet specialist beds and care is not routine in neurology. Does that not seem like something that you should do something about?

**Dr Clough:** Yes, but the answer to that may be a bit more complicated. People present acutely with problems that are not diagnosed, so you need to get on the right patient pathway. Who is the right person to receive that patient in hospital? In America, they have someone called the hospitalist, who has those generic skills who can actually say, "This looks like a neurological problem; let's get them down the neurological pathway." I think my general physician colleagues and geriatric colleagues would be deeply aggrieved by Dr Bateman's statement, because they

do feel that they are trained to receive acutely ill patients and do have the skills to understand whether they are neurological or not.

**Q95 Chair:** I will just say for the record that the specialists behind you are shaking their heads. You have been very selective in whom you have put before us today.

**Dr Clough:** Well, there are always different views of the world.

**Chair:** That is why we are very pleased that we saw some specialists before you came.

**David Moon:** Is the point not the emphasis on where the care is taking place? If the care is taking place in a specialist hospital or a tertiary centre, it is likely that the patient, if they have a neurological condition, they will end up under the care of a neurologist at some point. If it is in a district general hospital, yes, I take the point that they will probably get admitted under either a general physician—an acute physician or a geriatrician—but then, if they have a neurological condition, it is unlikely that they will be seen in a DGH by a neurologist. Is that not the issue here?

**Dr Clough:** If I can unpick that, it is not entirely the case that if you go to a tertiary centre, you will be admitted into a neurology bed. Some tertiary centres such as Plymouth and Hull take, from the front door, acute neurological patients, but most do not because the tertiary centre has an issue of equity for all the patients in its domain: it worries about the competition between people coming through the front door—local patients—with patients who are at a distance, who do not have the same call on their services. There is a variable picture there.

I think you are absolutely right. The issue is about what the target should be to see a neurologist within a DGH. All our DGHs have visiting neurologists, but the level of cover in DGHs is variable, so not all of them are able to meet a target of seeing a neurological patient within 24 hours. That is something that I would strongly support: every patient with an acute neurological problem who comes into a DGH, diagnosed appropriately and assessed appropriately by the acute physician, should be able to see a neurologist within 24 hours.

**Q96 Amyas Morse:** And the fact they are not all seen means that the provision, taken overall, is not as high as it should be? That is what you are saying, I think.

**Dr Clough:** If you look at the picture of where the neurologists are, London does pretty well and in parts of the country there are fewer neurologists. One of the key points of Dr Pollock's report was that there should be more equitable provision of neurologists throughout the UK.

**Q97 Jackie Doyle-Price:** One objective of the framework was to increase the number of people with their own personal care plans, but this Report has found that only 22% have those plans. Why do you think that is? Why is that figure not higher?

**Sir David Nicholson:** This is significantly different from the information that we have. I cannot explain why there is that discrepancy.

**Q98 Jackie Doyle-Price:** What is your figure?

**Sir David Nicholson:** More than 80% of people with long-term conditions have care plans.

**Q99 Chair:** That is an amazing disparity.

**Sir David Nicholson:** We survey literally millions of patients to get to that figure.

**Chair:** This may be unorthodox, but can we get the specialists at the back?

**Q100 Amyas Morse:** The 22% is your own figure, not ours. We did not go and do some calculations. We were supplied this figure by the Department of Health.

**David Moon:** It is one of the Department's studies.

**Sir David Nicholson:** It is a particular study. Some people—

**Amyas Morse:** We don't make it up.

**Q101 Fiona Mactaggart:** Why did you give the wrong study to the NAO?

**Sir David Nicholson:** It may be that within that 80%-odd almost nobody with a long-term neurological disorder has not got a care plan, but the general point on care plans is that we have been very successful. We have clearly not been as successful as we could have been with this group of patients—

**Q102 Chair:** It has just been pointed out to me that it came from the Oxford University study.

**Sir David Nicholson:** Yes, that was the research that they did at the time. I would argue that our survey is significantly bigger than that one. Having said all that, though, whatever it is, it is not enough. One thing that comes out of all this clearly to me—to all of us, I guess—is that co-ordination of care is at the heart of all this. There is no doubt that, if you look around at the moment, our biggest difficulties in the NHS at the moment are where we have to co-ordinate significant different people involved in the care of individuals, and that is getting greater. If you look at patients' experience of our care, where they have one specialty, one service and one episode of care, it is much higher than people we have heard of who can, literally, have up to 15 or 16 different agencies with perhaps 20 individuals involved in their care. That is a real challenge for a system like ours to deal with, and I have to say we have not solved that problem.

What we have done is look at how you integrate care and what are the most likely ingredients that you need to make that care happen. The first ingredient—I almost do not want to say this—is information about individual patients. If you do not get that right—for example, utilisation of the NHS number across health and social care—that will have a massive impact on our ability to integrate care for patients, because at the moment we cannot track where patients are being treated and what services they have. First, you get that register. The second thing is that you then stratify—they call it risk stratification—which means you identify those patients who require lots of care and those who require less, and you organise your services to deliver individual packages in that way, as opposed to a blanket approach. Then there is a series of other things that you need to do.

The pilots have just reported on this. As you know, the NHS Future Forum has been looking at integration of care. I think we have some really good ways forward now, which will help and improve that position, because at its heart it is a big problem for patients and for us.

**Q103 Jackie Doyle-Price:** Do all the PCTs prioritise this enough, or is application inconsistent? A conclusion from what you said is that one difficulty with your data and ours might reflect the data that you are receiving from the PCTs, which is not consistent. That comes back to the question: why have we not got clear objectives and clear data that they need to report?

**Sir David Nicholson:** Clearly, not all the commissioning organisations in the country are treating this in the same way. That is obvious from the variation that we have, and there is too much variation. Indeed, one downside of the National Service Framework and the way it has been set up is that you are really dependent locally on the enthusiasm and leadership of local people to make your service happen. That is great for those places where you have that leadership, but a real problem where you do not have it. Building that leadership capability, whether through a national clinical tsar like Mike Richards or through some other mechanism, is vital to making this happen.

**Q104 Jackie Doyle-Price:** One of my biggest concerns about the output of this policy is that, having set the strategy and raised expectations, those who represent vulnerable people wanted to take advantage of those expectations. The fact that you have such poor and inconsistent application by PCTs has really left them in a very cynical position. We have a challenge and the new well-being boards give us an opportunity to address that, but I think we are looking for quite a strong steer from the NHS that, "We are going to fix this and we have learned from what has gone wrong." What sort of guidance are you going to give to make sure that all the local health organisations grasp the nettle of this challenge?

**Sir David Nicholson:** In a sense, it is one of the benefits of having a National Audit Office Report of this nature, because this Report will be read throughout the NHS. We are identifying the three quality standards that NICE will produce and we will publish, and the measurement of that will be available to all health and well-being boards and organisations, so you will absolutely be able to tell where you are on that. We will set commissioning guidance that will support the implementation of these quality standards in an organised way. We are not just going to produce quality standards and let people decide whether they want to do it themselves. We are going to say: these are the standards that we expect and we want to see your plans to deliver them, which I think is quite a different way from the National Service Framework as it was originally established.

**Una O'Brien:** If I may just add to that in relation to the Department of Health, during this year we will consult on the first mandate between the Department of Health and the Commissioning Board. That

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mandate will contain priorities or objectives that the Government wish the Commissioning Board to meet. We want to have a wide-open consultation. We want to hear from patients and the public, and we will ourselves be looking at the evidence of where there are opportunities for improvement and where there is underperformance. I am sure that Ministers will want to have a look at all of that in weighing where they want to pitch the mandate. I think that that is going to be a significant first step into the implementation of the new system—setting the mandate for 2013–14, next year—so using the outcomes framework is centre stage.

Going back to Mr Smith's question to me earlier, the real question is, "What is the level of ambition that the Government wish to set for any one of those indicators?" They are not necessarily targets, but there is an ambition to be set for the Commissioning Board to deliver. We are going to hand over this amount of money. What are we going to get in return for it? That is going to be the big question at the centre of the mandate. At national level, that will be our focus this year and we will certainly be taking account of this and other reports that we have had from your Committee. We will be taking account of feedback that we get back ourselves from patient groups from all different arenas of the health and care sector and bringing that evidence together to try to calibrate where we should set the priorities in the mandate.

**Q105 Nick Smith:** Just a little thing. Mr Nicholson, when talking about the importance of building local capacity, you remarked that it might be the responsibility of some sort of national tsar or lead clinician, and I just did not get that. I think that local capacity is best done by local advocacy groups, or people from a particular area.

**Sir David Nicholson:** Sorry, what I meant by that is that if you take cancer, which I think people regard as the gold standard in some ways, one of the things that Mike Richards did very effectively is that he got the local clinicians, the oncologists, the surgeons, the pathologists and the radiologists together and he

worked with them. We gave them education, training, support and help so that they could become local leaders. That is what I meant.

**Nick Smith:** Okay, I understand that.

**Q106 Austin Mitchell:** I am glad to hear that. I was disappointed to hear you say earlier that the politicians were only really interested in statistics when they can prove lives have been saved or whatever, and this is not that sort of area, so you got the impression that politicians were not interested. Well, the politicians were interested enough to give a big dollop of money for the treatment of these frightening, appalling conditions. The way that money was spent, whether it gave value for money and whether it encouraged best practice was your responsibility at the Department. The failure is there. It is not a failure of the politicians. It is a failure of the Department. That augurs badly for the age of localism to come, unless you pull your socks up.

**Sir David Nicholson:** I will obviously pull my socks up. I obviously need to be better. We all need to be. I definitely was not blaming or criticising politicians for any of that. I was just observing on the Government's policy at the time. It was not just the Government; everybody thought that the big killers, cancer and coronary heart disease, were the things, and partly because the way of the time was about national targets, money attached to them and all of that sort of thing. These groups of patients and the conditions that they have do not fit easily into that situation. There were no big national targets that you could apply in that time and in that way. I certainly was not criticising, because you are absolutely right. The NHS has grown by a third over the last 10 years.

**Q107 Chair:** Thank you very much indeed. I hope the National Audit Office can return to this, after 2013–14 but before the end of this Parliament, so that we can then measure, if that is possible, the impact of the lessons learned from this. Thank you very much indeed for your evidence.

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### Written evidence from the Association of British Neurologists

#### RESPONSE OF THE ASSOCIATION OF BRITISH NEUROLOGISTS TO THE NATIONAL AUDIT OFFICE (NAO) REPORT ON THE NATIONAL SERVICE FRAMEWORK FOR LONG TERM NEUROLOGICAL CONDITIONS (NSF LTNC)

##### BACKGROUND

The range of neurological conditions is extensive—they can be acute or chronic and these may be very common or individually quite rare. The NSF LTNC focuses on the structures available to diagnose and manage chronic, progressive disorders, and the support network needed to achieve high quality care for the patient. Consultant neurologists and neurology teams will be responsible for this important group but also for the wider spectrum of neurological patients that enter the health system through both scheduled and unscheduled care. This will occur in community settings, district general hospitals and regional neurosciences units—whichever is most appropriate for the patients. It is crucial that commissioners and NHS managers acknowledge this when planning neurological services.

The Association of British Neurologists (ABN) works closely with the Neurological Alliance and its component charitable organizations to improving the care of patients with neurological illness through achieving equal and appropriate access to high quality care across the UK.

The NHS Modernisation Agency's Report, Action in Neurology which began in 2003 and followed by the NSF LTNC (2005) identified a range of problems faced by people with neurological disorders along the patient pathway:

- fragmentation of and unequal access to services;
- long waiting times for access to a specialist;
- long waiting times for investigations;
- poor-quality and inconsistent information for individuals;
- individuals and/or staff travelling long distances to access services;
- inconsistent referral processes;
- lack of support for carers;
- variable access to, and little integration of, health and social services; and
- poor quality of care in hospital.

These issues re-emerge in the recent NAO report and many had been highlighted by the ABN in its joint report with the Royal College of Physicians (2011).

#### GENERAL COMMENTS

1. The ABN is concerned about the findings of the NAO Report (Report), which highlights a lack of strategy, implementation structure and review process in relation to the NSF LTNC.

2. The Report is based on evaluation of neurological services in England. We assume it will be made available to the devolved Governments in Wales and Northern Ireland. Scotland has produced its own strategy (*NHS Quality Improvement Scotland; Clinical Standards. Neurological Health Services, 2009*) and implementation (*NHS Quality Improvement Scotland; Clinical Standards—Neurological Health Services; Implementation and Improvement Support Plan (2010)* documents).

3. THE NSF LTNC was much needed, with a 10 year plan to improve neurological services. It lacked the levers to make change happen. We have to learn from this. There has been success with the 18 week pathway (in England), but the pressures on delivering targets for new patients and distorted new: follow up ratios compromise good clinical practice and the care of those with long-term conditions.

4. NSFs in other areas have led to significant investment in the development of new services. The lack of investment to back up this NSF, and in particular the lack of investment to allow appropriate access to neurologists and for local neurological leadership was an important factor in the limited impact of the NSF.

#### RECOMMENDATIONS

1. *Creating clinical standards.* Standards for neurological health services need to be developed, and set within a quality framework of safety, effectiveness, patient-centeredness, timeliness, efficiency and being equitable in terms of access and quality to all patients with neurological disorders. Standards can be generic relating to delivery of services and where appropriate be disease specific.

2. *Implementing and auditing clinical standards.* The Department of Health in England, and respective bodies in Wales and Northern Ireland, has to financially support the implementation and improvement of standards, and set in place a mechanism for regular auditing of progress across all service providers.

3. *Commissioning of neurological services.* This has to reflect the spectrum of conditions being treated and there needs to be equality in access to the services developed. A clear link between "specialist" and "local" commissioning is crucial. It is essential the limitations in the "new to follow up" ratio is not used within commissioning, often with punitive contractual consequences if exceeded, as seems to be increasingly the case. This has a major detrimental impact on the management of long term conditions.

4. *Investment in neurological services.* The access to specialist neurological opinion remains very restricted. The number of neurologists per capita in the UK remains significantly lower than the rest of the developed world. Patients with long term neurological disease need and deserve good access to specialists with an interest and expertise in their condition.

5. *Engagement of front line users.* NHS staff, patients, carers, patient support groups and social care workers know what is working well and what is failing—they all need to be involved with setting the standards and in commissioning services. There needs to be a network where clinical staff and managers can share information, build on good practice and learn from mistakes.

6. *A National Director for Neurology.* Clinical leadership is needed to monitor progress and push through continued improvement.

### Written evidence from M.A.C Partnership LLP

The Moore Adamson Craig Partnership LLP is a specialist engagement consultancy which led the work with the MND Association on the creation of the MND Year of Care pathway commissioning tool and its transformation (along with pathways for Parkinson's and Multiple Sclerosis) to a web-based "ready reckoner" format for commissioners to access via "Neuro Navigator".

This memorandum to the Public Accounts Committee for its session on 18 January 2012, reflects MAC's views on the shortcomings around neurological commissioning and integration of services for people with neurological long term conditions which have given rise to the failures so strongly identified in the National Audit Office report *Services for People with Neurological Conditions* (December 2011).

"FIVE YEARS AFTER THIS NSF WAS PUBLISHED, NOT A SINGLE AUDITED SITE COULD MEET A SINGLE QUALITY REQUIREMENT"

That is the damning conclusion of the *LTNC NSF half way review*. As far as we can see, there has been no outcry about this national failure—as there certainly would have been were the subject cancer or heart disease or diabetes as opposed to neurological conditions.

According to the evidence submitted by Neurological Commissioning Support to the Health Committee enquiry on commissioning:

*Neurological Commissioning Support has discovered that there are insufficient numbers of health and social care staff with specialist training and understanding in neurology who are competent to manage the needs of the eight million people living with a neurological condition in England (and 10 million in the UK). The lack of understanding of the needs of these people has led to excessive and costly length of stays in hospital or inappropriate emergency admission where preventative treatment would have been more cost effective as well as enhancing the individual's quality of life.*

#### THE ORPHAN NSF

Parkinson's UK says the government has abandoned the LTNC NSF. It recently told the Health Select Committee:

*.... the foundations for neurological commissioning are too weak to see health and social care services through the transitional period. The Coalition Government have abandoned the National Service Framework for long term neurological conditions without putting in place anything to replace it. Even with the National Service Framework in place, neurological services were often not meeting the quality requirements. Without it, we worry that the services that are in place will not continue to be commissioned by GP consortia. In two or three years time, neurological services could have fallen away with little impetus to replace them.*

#### AN OPPORTUNITY LOST, MAYBE FOREVER

MAC's view from working in the field is that "Long Term Conditions" as a concept is not understood by most clinicians or commissioners to include neurological conditions. This NSF was mis-named from the start. That makes the LTNC NSF very much a "lost NSF" and the carers for people with LTNC are often "lost carers" whose needs are not even looked for, much less met.

There was never any alignment between the LTNC NSF, the commissioning guidance for LTNC of April 2007, the NSF neurological care metrics that the Healthcare Commission was developing (but never used) and the "10 Quick Wins" for local implementation. The potential synergy between these was so obvious, but was squandered and lost. Why did this happen? Because no one was in charge.

#### CUSTODIANS OF WHAT?

In 2008, the third sector neuro organisations were told bluntly by Government, "you are now the custodians of the NSF". Despite the sterling work of those who created this NSF, Ministers didn't own it, there was never enough sustained national level leadership and—crucially—no resources were put to achieving the "quality requirements" and metrics in it, unlike the CHD NSF.

#### THE DRIVE FOR INTEGRATED SERVICES

Integrated services reflecting individual needs and marshalling skills and resources across the health and care sectors for the right people in the right place at the right time. That's what we should have now after 60+ years of a nationally funded health service. But we don't have it and in some places things are becoming more fragmented as clinical networks break up in the post-PCT confusion of emerging clinical commissioning groups.

A recent case in point is the National Audit Office's damning inquiry into services for people with neurological conditions like MND, Parkinson's and MS identifying persistent disconnects and *failings around emergency admissions* despite massive investment. More money doesn't automatically mean better outcomes.

#### “IMPROVING OUTCOMES BY WORKING TOGETHER”

That’s one reason why the joint *Kings Fund/Nuffield Trust recommendations* to the Future Forum and the DH on integrated commissioning are worth attention. What they are talking about is integration of services around the needs of individuals (elderly people, children) with complex needs and many others with long term needs, including end of life care. That is all to the good but not new. It should have happened a long time ago of course. There is already a guide to this, the *National Voices Principles of Integrated Care*.

#### SOCIAL CARE ELEPHANT IN THE ROOM

There is a big policy elephant in the room: the vexed social care resourcing issue. The report merely identifies this as a “barrier” to integration. That it certainly is. But by far the biggest barrier to integration is the acute-focused clinical culture of most of the NHS and the local authority protectiveness of much of social care. These are like oil and water and, frankly, they need nuking. Our view is that without organisational integration, common pots of money and buckets of inspirational and innovative leadership in the professions and councils, the “pace and scale” of change which the report says is vital is unlikely to happen. There are too many vested interests conspiring against it.

#### PATIENT AND CARER POWER AND PARTNERSHIPS?

Could patients and carers not charge the barricades and demand integrated services? Individual budgets may be one way to tunnel underneath the obstructions. But it is not sufficient to talk only about personal health budgets. That is only part of the picture: we need integrated health AND care budgets for individuals—as realistic levels—as anyone with a long term condition will tell you who uses services across the sectors.

Patients and carers could leverage more power in the system in their role as budget holders. But they need brokers and guides to act as agents and facilitators with service providers if they are to maximise their purchasing power and not to get ripped off. Here is a big partnership opportunity for 3rd sector bodies and for specialist clinicians like neurological nurses—will they rise to it?

#### MORE RADICAL THINKING NEEDED

Blockages to integration are not just about resources. It is about more subtle things, including professional leadership and personal fulfilment. Dr Peter Carter, CEO of the RCN, made this plain before the Health Committee recently: the impulse of good practice like integrated services has to be “*encrypted into the culture*”. Florence Nightingale might have said it differently, but not any better.

Until we develop more capacity in primary and community health care to deal with demand outside of hospitals, too many elderly, frail people and others with complex and long term conditions of all ages are going to end up there by default as the NAO report on neurological services shows. This is bad for them and bad for the institutions that have to receive them.

The reality of NHS provision—and it does not have to be bricks and mortar, there can be “virtual wards” in the community—has not matched the political rhetoric about this goal. All governments share the blame here and a few glib targets will not turn the situation around quickly. Just look at who is occupying a high proportion of acute beds to see what the problem is when people cannot be cared for at home or in intermediate settings which are better and safer for them. Better yet, we need to prevent a much higher proportion of unplanned admissions in the first place.

Health and care are a continuum. We must break down the funding and cultural barriers between the health and care sectors and the rivalries and turf wars between professions. To achieve integrated services, professionals must do this in partnership with patient leaders.

#### OUTCOMES ARE THE NEW TARGETS

Coalition health policy is clear: targets are on the way out and outcomes are coming in as the new focus. There is nothing essentially wrong with that, so long as they are the right outcomes and that there are consensus standards to refer to in order to keep the new commissioners and their providers on the straight and narrow where good neurological practice is concerned. Third Sector neurological organisations are excellently placed to make sure that the Government understands the work already going forward on MND, PD and MS YOC commissioning pathways in particular and that the outputs of this work are incorporated into the new government’s thinking about pathway tariffs and quality of outcomes.

#### COSTINGS TOO LOW?

Our concern is that bodies sponsoring this work could suddenly find that centrally taken decisions about what is “affordable” will downplay quality and focus only on costs, and those costs will be lower—possibly very much lower—than the real costs being revealed by YOC work in long term neurological conditions. Centrally fashioned “commissioning packs” may have no user-led content in them and may not reflect the breadth and depth of health and social care inputs which appropriate year of care pathways must have.

As the pre-diagnosis 18 week pathways targets are also being removed, people with possible LTNC could face a double whammy: not getting a timely diagnosis and commencement of treatment and also not getting an appropriate care pathway in place which delivers quality outcomes that are affordable, deliverable and acceptable.

#### WHICH WAY NOW?

In the current climate of reduced resources, things could go forwards through QIPP or they could start to go backwards through removing key posts like specialist neurological nurses. One thing is clear to us: everyone concerned with long term neurological conditions needs to make sure that their voice is heard—loudly and often—and their investments in quality and effectiveness are not wasted.

Removal of performance management raises the clear danger of slipping/driftng back into long waiting lists and unresponsiveness, despite the Government's stated intention that this should not happen. The new clinical commissioners must hold providers to account for good outcomes. Many PCTs were not very good at this in the past, so why should their successors suddenly get better?

#### SETTING A CLEAR COURSE

To address all of this, we need leadership from neurological leaders across the clinical, social care and user-led sectors, which is based on setting a clear course for commissioning at consortium level and the role of the National Commissioning Board in terms of the division of long term neurological conditions between them. Some will be "specialised" and some won't be—and should not be. Some will have "specialised" elements in their intervention possibilities and then there is always the question of new drugs appearing on the market to consider. Cancer drugs are getting all the running about this, but there are plenty of other conditions to consider in terms of NICE approvals and their cost benefits.

#### SAFE HAVEN NEEDED FOR NEUROLOGICAL COMMISSIONING

We think all of this is going to be troublesome because there is no consensus about what goes where for neurological commissioning. GPs historically do not have a strong affinity with neurological conditions and there will be temptations to let this drop off the commissioning table. What proactive line will the neurological 3rd sector community take to overcome this? "Nothing about me without me" must be owned by people with LTNC in order to switch on the power of the patient and carer voice.

As the half-way evaluation of the Long Term Neurological Conditions NSF showed, and the NAO report underscored, wherever users of neurological services are, they are certainly *not* "at the heart of neurology commissioning" as they ought to be. Until they are at the heart of *everything* that concerns them, we will not escape the chaotic situation articulated by the recent NAO report.

18 January 2012

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### Written evidence from the Royal College of Physicians

#### ABOUT THE ROYAL COLLEGE OF PHYSICIANS

The Royal College of Physicians (RCP) has been at the forefront of improving healthcare and public health since its formation in 1518. The RCP plays a leading role in the delivery of high quality patient care by setting standards of medical practice and promoting clinical excellence. As an independent body representing over 25,000 fellows and members worldwide, we advise and work with government, the public, patients and other professions to improve health and healthcare. The Royal College of Physicians is responsible for standards of education and training in neurology, one of its 30 specialties.

#### RCP EVIDENCE ON NEUROLOGY SERVICES

The Royal College of Physicians would like to submit evidence to the Public Accounts Committee, based on the report "*Adult Neurology Services*", produced by the *Royal College of Physicians* and the *Association of British Neurologists*, the two major medical organisations involved in providing and maintaining standards for neurology services. The report, which is evidence based and has the backing of neurological charities including the Neurological Alliance, makes recommendations for improvement in quality and value of neurology services, in a practical way that the National Service Framework for long term conditions (2005) did not achieve. The failure of the NSF to define a budget, emphasise clinical leadership or provide strategic direction meant it was unlikely to succeed. Subsequent evidence, including outcome measures (admission and readmission rates, epilepsy mortality) demonstrated that the NSF was neither widely nor effectively implemented despite the disproportionate rise in expenditure highlighted in the NAO report.

The NSF failed to address the more than three to one inequity in the UK distribution of neurologists. The majority of neurology expertise is concentrated in large neurology centres in the major cities, whereas the majority of the patients are elsewhere. We must address this by providing more and better access to neurology

services locally, while also addressing the shortage of neurological expertise in the UK compared with the USA and Europe.

The recommendations of the RCP/ABN report demonstrate how existing resources can be used more effectively to provide better outcomes in unscheduled care, (acute neurology admissions), scheduled care, (out-patients) and community management of neurological long term conditions.

The recommendations are for changes in process. Recent evidence has shown how important simple changes in process, like those proposed, such as getting neurologists into the front line at the right place at the right time, can produce big improvements in care and better value for money.

The RCP and ABN are especially concerned that those responsible for neurology within the Department of Health have not fully recognised the serious shortcomings in acute neurology care in most District General Hospitals, particularly following the recent changes in the organisation in the process of acute medical care in the UK. General physicians who used to deal with emergencies in all specialties are increasingly being replaced by specialist teams eg cardiology, respiratory medicine, gastroenterology. However, although neurological emergencies are the third most common cause of acute medical admission, the lack of structured local neurological services and availability of neurologists in the DGH make it unlikely that neurology patients will receive the same level of organised care provided by other disciplines.

Admitted neurology patients often have a new potentially serious neurology disorder eg fits, meningitis, encephalitis, sub-arachnoid haemorrhage, which need prompt accurate diagnosis. Most are admitted to the local DGH where they are rarely seen by or managed by a neurologist in contrast to patients with other medical disorders who are mainly now looked after by the appropriate specialist. The recent national audit measuring the care of people with epileptic seizures admitted to hospital (National Audit of Seizure Management in Hospitals, <http://www.nashstudy.org.uk/Default.aspx>) showed that not a single admitted patient was under the care of a neurologist, despite epilepsy being a very common disorder with a rising mortality.

Correct diagnosis and management is fundamental to a good outcome. For example, evidence given to the RCP working party from Northern Ireland showed that a new or altered diagnosis was made in 43% of admitted patients when seen by the neurologist with a change in management in 80% of epilepsy patients. Length of stay was halved producing considerable savings and better value for money.

Comparing the services for neurology patients with those for stroke patients highlights the current deficiencies and inequity of care. As a direct result of a strong enforced initiative by the DH Stroke Strategy, patients are normally immediately admitted under a stroke physician, and are managed both in the acute ward and the community through a defined clinical pathway for which the specialist is accountable. There is considerable overlap between stroke and other neurological emergencies with opportunities for joint working, and the same model should be progressively introduced for all neurological patients.

The RCP/ABN report drew attention to the disproportionate use of scarce neurological resources in out-patients. This not only reduces neurological input into acute care but also deprives long term condition management of the clinical direction and expertise it requires to function effectively.

Several members of the public accounts committee suggested that strong clinical leadership was necessary to effect these changes. We agree that this is essential, and that whatever structures are put in place to commission and provide care for neurology patients take account of the need for a strong leadership culture in addition to commissioning against specific outcomes as outlined above.

These must address the three basic ways in which patients access services:

- Acute neurology care must be commissioned to be provided locally by neurologists.
- Scheduled care has to be modernised to achieve value for money and shorter waiting times.
- Local care for long term conditions has to be properly coordinated and planned by a local commissioning board.

The RCP recommends that the new clinical commissioning groups be required to commission against national standards of care for neurology patients. These could include care pathways for specific conditions, and recommend best practice in the processes required and the necessary competencies of health professionals to provide the neurology services as suggested by the RCP/ABN report. We believe that outcomes specific to neurology are more likely to ensure good commissioning with better value for money than generalised outcomes. It is vital that these outcome measures are established as soon as possible ready for when the new structures are in place, and are subject to review. The secondary care clinicians on clinical commissioning groups could be a focus for this process.

The NAO report, the hearing of the public accounts committee and the RCP report provide very strong arguments for a reconsideration of neurology services, which need to improve greatly to meet the needs of neurology patients. The Department of Health should lead this process in consultation with patient and professional bodies. Patients deserve better.

**Written evidence from the National Audit Office**

NOTE TO COMMITTEE OF PUBLIC ACCOUNTS:  
COST OF NEUROLOGICAL EMERGENCY ADMISSIONS

At the recent hearing on *Services for people with neurological conditions* the Committee asked the NAO to provide further evidence on the cost of neurological emergency admissions to hospital.

Table 1 provides the average (mean) spending by PCTs to acute trusts across neurological conditions and examples of average spending for two specific conditions.

**Table 1**

AVERAGE SPENDING BY PCTs TO ACUTE TRUSTS PER NEUROLOGICAL EMERGENCY  
ADMISSION (2010–11)

	<i>Average (mean) spending by PCTs per admission (£)</i>
Neurological conditions	1,477
Motor neurone disease	3,960
Epilepsy	1,170

*Source:* Neurology: NHS Comparators

*Note:* Data are derived by dividing total spending by PCTs by total admissions.

Multiplying the average spending for neurological conditions (£1,477) by the total number of emergency admissions for neurological conditions (308,000 in 2010–11, excluding pain) the estimated total payment by PCTs to acute trusts for neurological emergency admissions was £455 million in 2010–11.

National Audit Office

6 February 2012

**APPENDIX**

TECHNICAL NOTES

1. The neurology category (Table 1) is taken from the neurological programme budget category in NHS Comparator. This category excludes neurological pain. This is consistent with the definition of neurological conditions (excluding pain) used in the NAO report. For details see:

<https://www.nhscomparators.nhs.uk/NHSComparators/CommissionerResults.aspx>

2. Emergency admission: Hospital Episode Statistics define an emergency admission as a completed spell. A spell covers the entire length of stay for a single admission. A single spell can be made up of more than one Finished Consultant Episode (FCE). An FCE is an episode of care under a single consultant during an admission. Between 80–90% of all admitted patients have a single episode of care, the rest may have two or more episode of care under different consultants. There are a number of different admission methods for an emergency admission including:

- via accident and emergency;
- via GP;
- via bed bureau; and
- via consultant outpatient clinic.

3. The spending shown in Table 1 exclude any activity not covered by mandatory tariffs so may understate the actual amount paid by PCTs to acute trusts for the treatment of an emergency admission.

**Written evidence from the Department of Health**

PAC HEARING 18 JANUARY 2012—NEUROLOGICAL LONG-TERM CONDITIONS

I am writing to follow up on a number of issues you raised during the recent evidence session with DH officials.

First, I thought it would be useful to provide further clarity on the current and future approach the Government is taking to improve outcomes for people with long-term neurological conditions. The key content of the National Service Framework for Long-Term Neurological Conditions (March 2005) was a set of good practice standards for services developed through widespread consultation. These still hold true today and the Government intends to use new mechanisms within the system and the reforms to embed delivery, improve

the integration of health and care services, make commissioning and service provision more responsive and to incentivise delivery based on achieving better outcomes.

#### ACCOUNTABILITY IN THE NEW SYSTEM

Improving quality and delivering better health outcomes for patients is the primary purpose of the NHS. Accountability throughout the system needs to be focussed on the outcomes of care, rather than the process of care. This focus on outcomes will start at a national level with the NHS Outcomes Framework (first published December 2010) that, for the first time, defines and will enable measurement of the key outcomes that matter to patients. Its purpose is threefold:

- to provide a national overview of how well the NHS is performing, wherever possible in an international context;
- to provide an accountability mechanism between the Secretary of State for Health and the proposed NHS Commissioning Board; and
- to act as a catalyst for driving quality improvement and outcome measurement throughout the NHS by encouraging a change in culture and behaviour, including a renewed focus on tackling inequalities in outcomes.

All five domains within the NHS Outcomes Framework have relevance for people living with a neurological condition. For example:

- Domain 1—preventing people from dying prematurely—the overarching indicator is about mortality from causes considered amenable to health care. Epilepsy is one of the conditions where, as we heard from Dr Pollock during the evidence session, there is still room for considerable progress.
- Domain 3—helping people to recover from episodes of ill health or following injury—will capture information on patients’ journeys through the system.
- Domain 4—positive experiences of health care—will measure such things as patients’ experiences of primary care.
- Domain 5—treating and caring for people in a safe environment and protecting them from avoidable harm—where some of the indicators can support better medicines management, which is important for people with Parkinson’s disease.

Domain 2, enhancing the quality of life for people with long-term conditions as a whole, is the most immediately relevant to people with neurological conditions. This reflects the fact that increasing numbers of people have multiple long-term conditions, and it is not necessarily helpful to see their care from the perspective of a single clinical pathway.

This domain seeks to capture how successfully the NHS is supporting people with long-term conditions to live as normal a life as possible and will be measured using three outcomes:

- Feeling supported to manage their condition—this measures how well the NHS as a whole is doing in supporting people to look after themselves and handle the consequences of their conditions;
- Functional ability—this measures how well the person is able to live as normal a life as possible, and by looking at employment ties in well with the Department for Work and Pensions and the Government’s wider policies about getting people back to work; and
- Reduced time spent in hospital—this measures how successfully the NHS manages the condition(s) by looking at unnecessary hospital admissions and excessive length of stay.

Through the Mandate, Ministers will retain the freedom to set specific objectives for the Board to focus on. This provides clear accountability: the Board must seek to achieve any objectives in the Mandate, and both the Board and Department must report annually on its performance against the Mandate. The Department could also set legally binding requirements on commissioners through “standing rules” regulations—which could be enshrined as patient rights in the NHS Constitution.

It will be the responsibility of the NHS Commissioning Board to determine how to deliver the outcomes in the NHS Outcomes Framework. The Board will use the Outcomes Framework and NICE Quality Standards to develop a Commissioning Outcomes Framework and together these will be the basis for clinical commissioning groups to be held to account. The Board will also support commissioning by developing detailed commissioning guidance and tools such as standard contracts and, working with Monitor, tariffs.

The NHS Outcomes Framework covers the majority of treatment activity the NHS is responsible for delivering but is also aligned with similar accountability mechanisms for adult social care and public health. For adult social care, this is through the Quality Outcomes Data set, and for public health, this will be through the Public Health Outcomes Framework. Where outcomes depend on integration and alignment, the frameworks use indicators replicated across sectors, or complementary indicators.

#### COMMISSIONING FOR NEUROLOGICAL CONDITIONS

Commissioning for long term neurological conditions is complex due to the nature of the conditions and the sheer number of episodes of common symptoms that can have no physical origin. The umbrella term “long

term neurological conditions” covers a broad range of conditions ranging from very common disorders to some very rare conditions that health professionals will encounter only once in a career.

Under the provisions of the Health and Social Care Bill, the NHS Commissioning Board will directly commission those specialised services, which are currently provided at both a national and regional level. Included within those services are those specialised services for people with neurological conditions. No final decisions have yet been taken on the final list of services that the Commissioning Board will commission from April 2013. Decisions are expected later this year.

The creation of the Board provides a unique opportunity to bring together the planning and funding of all specialised services by commissioning these services once, nationally. The new structure for specialised commissioning will embody the principles of quality, consistency, equity and value whilst supporting patient choice. It means that these highly specialised services will need to be visible in the new commissioning arrangements so that the NHS continues to ensure that it discharges its responsibilities for people who have the rarest conditions.

Whilst specialised services will be commissioned within a national framework, the thrust of the Government’s health reforms is to devolve commissioning as close to clinical decision making as possible, so clinical commissioning groups (CCGs) will commission the majority of NHS services for people with neurological conditions. These will include the care provided through multi-disciplinary community teams, led by professionals with specialist expertise, including specialist nurses and professionals allied to medicine.

There are, however, a number of services where a collaborative approach may be needed, and CCGs will be able to commission collaboratively across larger populations if this makes sense for them.

#### QIPP

The quality, innovation, productivity and prevention challenge (QIPP) is an opportunity to prepare the NHS to deliver high quality care in a tighter economic climate.

At a regional and local level, strategic health authorities have been developing integrated QIPP plans that address the quality and productivity challenge. These are supported by national QIPP workstreams, which are producing tools and programmes to help local change leaders in successful implementation.

The QIPP Right Care workstream has developed the NHS Atlas of Variation, which offers clinicians and commissioners the opportunity to identify variation and take action to reduce unwarranted variation. The Atlas includes 71 maps, which highlight the amount each PCT spends on clinical services and link to the health outcomes experienced by patients. While variation occurs naturally in the NHS and is encouraged where NHS services are tailored to meet local needs, the Atlas aims to support commissioners to expose unwarranted variation and help the NHS provide consistently high quality care for patients. The 2011 Atlas includes data on drugs prescribed for Parkinson’s disease and emergency admission rates for children with epilepsy.

The QIPP Long-Term Conditions (LTC) workstream, led by Sir John Oldham, initially focussed on identifying and creating a proof of concept for an evidence-based system for managing people with long-term conditions, including neurological conditions. This comprised of three drivers: risk profiling the long-term conditions population; creating neighbourhood integrated care teams (including social care, primary care, community services—including specialist nurses—and allied health professionals), who pro-actively assist those patients in a much more coordinated way, and lastly, systematising the empowerment of patients to maximise the support for those who can co-manage or self-care. The guiding principle is the patients’ collective voice: “I want you to treat the whole of me and act as one team”.

Since June, the QIPP LTC team has entered its scale phase. It has engaged CCGs and their stakeholders around the country to implement the drivers in a locally sensitive way. The population coverage is now 30 million, with London to be included shortly. It is intended that this phase will be completed by the end of the year and will be further embedded by CCGs and their clusters.

The QIPP LTC team are also leading work to develop a Year of Care tariff based on levels of need. This is scheduled to be available for CCGs by April 2013. In this way, it is intended that changes to the financial model will reinforce the care model, and both should provide patients with a more co-ordinated and enhanced control of the services they receive.

#### HEALTH AND SOCIAL CARE INTEGRATION

People with neurological conditions may have a complex mixture of health and social care needs, and the new arrangements will provide a strong foundation for improved integration of health and social care. The NHS Commissioning Board, CCGs, Health and Wellbeing Boards, Monitor and CQC will all have enhanced duties to encourage integration and to work across health and social care to help us achieve better outcomes and better value for money.

Health and Wellbeing Boards will have a stronger role in direct commissioning and promoting locally integrated provision. The local authority and clinical commissioning Board will be required to undertake a Joint Strategic Needs Assessment (JSNA) through the Health and Wellbeing Board, leading to a Health and

Wellbeing Strategy. This will provide an objective analysis of local current and future needs for adults and children spanning the NHS, social care and public health, and potentially wider issues such as housing or education.

#### LONG-TERM CONDITIONS OUTCOMES STRATEGY—FORTHCOMING IN 2012

Integrated services will also be a key theme of the long-term conditions outcomes strategy, which will build on the existing generic long-term conditions model by looking beyond health to how other sectors, such as housing, education and transport, can work together to improve quality of life and independence for all people with long-term conditions. The strategy, which will be published later in 2012, will not focus on specific conditions, but will be generic, given that many of the issues faced by people with longterm conditions are shared across conditions.

We are committed to involving all partners in the development of this strategy. We will be working with the third sector, patient and carer groups, the NHS, social services and others to ensure that the strategy takes account of their views, and is a meaningful, relevant document. Third sector neurological organisations have been invited to engagement events surrounding the strategy, and officials working on the strategy will meet with the Neurological Leadership Group, and the Neurological Alliance.

#### CARE PLANNING FOR PEOPLE WITH NEUROLOGICAL CONDITIONS

A number of members also questioned the discrepancy between the proportion of people with a long-term neurological condition having a care plan (22%), as outlined in the NAG's report, compared to information on care planning the Department derives from the GP survey. Whilst we cannot explain this discrepancy, I think it would be helpful to provide the Committee with some additional information.

The most up to date information the Department has on care planning (January-March 2011) shows that of nearly two million respondents with a long-term condition, 83% reported they have had a care planning discussion, and 96% reported an improvement in their care as a result of care planning process. The NAG's figure of 22% was taken from a study by the University of Oxford to assess experiences of health and social care services for patients with Motor Neurone Disease, Multiple Sclerosis and Parkinson's disease and their carers. This study was one of a number set up by the Department of Health's Policy Research Programme in 2006 to assist implementation of the National Service Framework for Long-Term Neurological Conditions.

In the Oxford University study, of 2,563 patient respondents, 22% **were aware** of having a formal care plan. However, of those who were aware of having a care plan, three quarters felt that their care plan was kept up to date. The research report acknowledges that:

“although there may be ambiguities as to what constitutes a care plan and varying levels of awareness of the existence of coordinated plans, it is clear that there is a major challenge to move toward all individuals being fully aware of a care plan in which they have been actively involved”.

I hope that this letter provides additional clarity on these important areas and look forward to receiving your report which I believe will be a valuable contribution to our thinking on how we can better support people with long-term neurological conditions and improve their outcomes.

6 February 2012

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