National Assembly for Wales
Health, Wellbeing and Local Government Committee

Report of Inquiry into Stroke Services in Wales

March 2010

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The Health, Wellbeing and Local Government Committee is appointed by the National Assembly for Wales to consider and report on issues affecting health, local government and public service delivery in Wales. In particular, as set out in Standing Order 12, the Committee may examine the expenditure, administration and policy of the Welsh government and associated public bodies.

Powers

The Committee was established on 26 June 2007 as one of the Assembly's scrutiny committees. Its powers are set out in the National Assembly for Wales' Standing Orders, particularly SO 12. These are available at www.assemblywales.org

Committee membership

Committee Member	*Party*	*Constituency or Region*
Darren Millar (Chair)	Welsh Conservative Party	Clwyd West
Lorraine Barrett	Labour	Cardiff South and Penarth
Peter Black	Welsh Liberal Democrats	South Wales West
Andrew R T Davies	Welsh Conservative Party	South Wales Central
Irene James	Labour	Islwyn
Ann Jones	Labour	Vale of Clwyd
Helen Mary Jones	Plaid Cymru	Llanelli
Dai Lloyd	Plaid Cymru	South Wales West
Val Lloyd	Labour	Swansea East

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Chair's foreword

An estimated 10,000 to 11,000 people in Wales suffer a stroke each year. Of those, a third will die from the severity of the stroke; a third will be left permanently disabled; and the final third will recover with proper rehabilitation and support.

The effects of stroke can be both devastating and life-changing. A stroke can affect a person's ability to communicate, restrict their mobility and take away their independence - in short, their quality of life changes.

We should also remember the wider impact that a stroke can have on the family members and carers of survivors. It is for these reasons that it is so important that the people of Wales have access to a first-class stroke service.

Stroke services in Wales have received a lot of publicity during recent years. Audits conducted by the Royal College of Physicians found that the service in Wales was lagging behind the rest of the UK. As a result of these audits, there have been many improvements to the service, and the Committee received evidence of this. However, evidence also suggests that there is still a long way to go to provide the people of Wales with the service they deserve.

I hope that the recommendations contained within the Committee's report will be a catalyst for further and sustained improvements in the service.

On behalf of the Committee, I should like to express my gratitude to all those who gave evidence to the inquiry and those who helped to compile this report. I commend it to the Minister for Health and Social Services and to the National Assembly for Wales.

Darren Millar AM

Chair, Health, Wellbeing and Local Government Committee

March 2010

The Committee's Recommendations

The Committee's recommendations to the Welsh Government are listed below, in the order that they appear in this Report. Please refer to the relevant pages of the report to see the supporting evidence and conclusions:

Recommendation 1. We recommend that the Minister draws together all stroke policy documents and develops an all-Wales stroke strategy that includes targets, deadlines and standards. Page 21

Recommendation 2. We recommend that the Minister should introduce formal systems for monitoring the targets and timelines of stroke service provision, and that the results of the monitoring should be published regularly. Page 23

Recommendation 3. We recommend that the Minister should establish a national register of patients in Wales with stroke to monitor the incidence and patient outcomes. Page 24

Recommendation 4. We recommend that the Minister draws up a clear structure for stroke leadership comprising the NHS and Government, with, for example, stroke champions or team leaders, and regional and/or national overarching multi-disciplinary bodies reporting to NHS/Government with a mandate to ensure compliance if necessary. Page 26

Recommendation 5. We recommend that the Minister should keep under review the allocation of funding for stroke services in Wales, and identify more clearly resources that contribute to stroke services to ensure that levels of funding are commensurate with those of other UK countries. Page 28

Recommendation 6. The Minister should include, as part of any stroke strategy, the aspiration that all patients should have access to a dedicated stroke unit as clearly defined by the NHS and her Government. This definition should include details of the multi-disciplinary clinical and therapy teams expected to support the unit. Page 33

Recommendation 7. We recommend that the term 'stroke unit' should be clearly defined and that this definition should be applied

uniformly throughout the NHS and in government strategic documents. Page 34

Recommendation 8. We recommend that all stroke patients should be admitted directly to defined beds and that the practice of admitting them to general wards be phased out as a matter of urgency. Page 36

Recommendation 9. We recommend that the Minister introduces mechanisms to monitor the following of national guidelines regarding direct admission of stroke patients to defined beds in the acute stage. Page 36

Recommendation 10. We recommend that Health Boards look at innovative ways of restructuring stroke care to maximise existing resources, by considering examples of good practice. Page 37

Recommendation 11. We acknowledge the Minister will be mounting a campaign to raise awareness of the connection between high blood pressure and stroke, but would recommend that a planned series of high profile campaigns for professionals and the public be incorporated into strategic documents. Page 41

Recommendation 12. As part of the plan suggested in the recommendation above (Recommendation 11), a campaign to alert the public and professionals to Transient Ischaemic Attacks (TIAs/mini strokes) as a possible forewarning of major strokes should be given priority. Page 41

Recommendation 13. We recommend that the priority categorisation of 999 calls for stroke should be changed so that a fully crewed ambulance is dispatched against a Category A response time. Page 43

Recommendation 14. We recommend that the Welsh Ambulance Services NHS Trust should explore opportunities to ensure that the most appropriate method of transportation is used for transporting suspected stroke cases. This applies particularly in rural areas as set out in the Rural Health Plan, where transportation to a hospital where appropriate assessment and treatment, including thrombolysis if necessary, can be undertaken. Page 44

Recommendation 15. Priorities for stroke services are currently focused on the acute and secondary care stages of the patient

pathway. We recommend that the Minister should increase the emphasis on community and longer-term rehabilitation and support. Page 53

Recommendation 16. We recommend as a matter of urgency that attention is now given to the needs of those living with the after effects of stroke. This should be done through Social Services with appropriate access to housing; adaptations; benefits; social support; and through adequately resourced multi-disciplinary therapy services. Page 53

Recommendation 17. We recommend that the Minister improve services for stroke survivors with communication difficulties to a standard that addresses unmet needs in this area. This should be done by making available additional funding to enable Health Boards to recruit the number of speech and language therapists they previously requested, and to meet the Stroke Unit Trialists Collaboration recommendations. Page 53

Recommendation 18. We recommend that each Health Board has a minimum of one clinical psychologist or psychotherapist with responsibility for stroke. Page 58

Recommendation 19. There are insufficient training courses in Wales available across the board to professionals engaged in stroke services. We recommend that, as a starting point, this situation is addressed by ensuring that good examples of training that have been developed should be consolidated and rolled out with a core module applicable to all professions. Page 58

Recommendation 20. We further recommend that the Minister ensures sufficient money is made available to pay trainers and deputising members of staff, and that she seeks to ensure that NHS employers fully recognise the importance of training by utilising their training budgets and giving staff the necessary study leave. Page 58

Recommendation 21. We recommend that the Minister ensures that Wales has a framework in place with properly funded academic posts that allow academic and clinical research to be undertaken with the aim of attracting high quality health and allied professionals. Page 60

Recommendation 22. We recommend that the needs of younger stroke survivors are addressed in stroke policy documents and that all

stroke patients, regardless of their age or severity of their stroke, receive rehabilitation appropriate to their needs. Page 63

Recommendation 23. We recommend that Health Board stroke plans must reflect fully the aspirations of the Rural Health Plan by providing in those areas the same access to stroke services and resources that are available elsewhere in Wales. We are specifically concerned that issues relating to Emergency Care and access to thrombolysis, and to the need stroke patients might have to communicate through the Welsh Language, are addressed. Page 63

Recommendation 24. We recommend that policy initiatives to raise awareness of stroke risk among certain black and minority ethnic groups who are at a higher risk than other population groups, are incorporated into strategic documents. Page 63

Recommendation 25. We recommend that Government documents and Health Boards include plans to manage issues of first language reversion in those whose first spoken language is Welsh or other non-English language, and for deaf people who use sign language. Page 63

Where appropriate, we expect the Welsh Government to report on progress in implementing our recommendations within 12 months of their initial response to this report.

1. Introduction

> "Stroke is a devastating disease. It is the third commonest cause of death and the most important cause of severe acquired disability. It affects people of all ages including children but is predominantly a disease of older people. It has a major impact not just on the patient but their carers and society as a whole."[1]

1. The Committee agreed to conduct an inquiry into Stroke Services in Wales following a series of negative reports from the Royal College of Physicians (RCP) Sentinel Stroke Audits of 2004 and 2006.

2. The 2006 report raised serious concerns about the quality of stroke services in Wales, which were apparently poorer than services in England and Northern Ireland (audits in Scotland are carried out by RCP Scotland).

3. While the Welsh Government has responded to these issues, concerns have been raised that progress in raising the standards of stroke care in Wales was not being made quickly enough. Concerns were also raised that, although work was being undertaken, there was little communication from the Government to Assembly Members, practitioners and the general public.

4. Major advances in the management of stroke in recent years have resulted in highly effective interventions for the treatment, rehabilitation and management of longer term disability. However, in order to deliver these improvements it is necessary to reorganise radically the way in which healthcare is provided for stroke patients.

5. Given that there is evidence that specific service improvements can decrease mortality and disability among stroke patients,[2] aid recovery and wellbeing, and improve the quality of life for both patients and carers, we felt it was important to hold this inquiry.

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[1] Written evidence, HWLG(3)-14-09 Paper 3,

[2] Written evidence, HWLG(3)-19-09 Paper 09 (Tables from Southend experience Paul Guyler unpublished. Information on the stroke trial available from Essex and Hertfordshire Comprehensive Local Research Network)

Terms of reference

6. We agreed the terms of reference at the committee meeting held on 11 June 2009. They state:

> "To examine the current provision of services for stroke victims in Wales and the effectiveness of Welsh government policies in addressing any weaknesses in these services, including:
>
> - availability of specialist stroke units in hospitals across Wales and geographical variation in these services;
> - the resources devoted to stroke services in Wales;
> - availability of specialist staff in acute settings, recruitment and training;
> - availability of specialist equipment, such as scanners to determine type of stroke;
> - availability of aftercare and rehabilitation services, including speech and language therapy, physiotherapy, occupational therapy and other community based services
> - good practice in the treatment and management of stroke in Wales, the UK and other countries and ways in which such practice can be disseminated;
> - programmes for the prevention of stroke and the promotion of lifestyles that minimise the risk of stroke;
> - the effectiveness of indicators and performance measures applied to stroke services;
> - the impact of NHS restructuring on stroke services in Wales; and
> - equality issues relating to the provision of stroke services, including those for BME groups."

Methods

7. The inquiry was held between June and November 2009 with a call for evidence issued on 12 June 2009. Thirty-nine written submissions were received from 22 individuals, including health professionals, survivors and carers, 10 professional bodies and special interest groups, and 7 voluntary organisations. A link is provided (here) to the Inquiry web-pages where written submissions can be accessed.

8. Fourteen sets of witnesses were invited to give evidence during six Committee meetings. A list of dates; details of the witnesses who appeared; written papers provided to the committee; and links to transcripts are provided at Annex B.

9. Agendas, papers and transcripts for each meeting are available in full on the Committee's pages on the National Assembly for Wales' website, which can be accessed here.

10. Members of the Committee also undertook a visit to the stroke facilities at Cardiff Royal Infirmary.

2. Background information

> "By 2006 the standard of stroke services in Wales had begun to lag significantly behind those in the rest of the UK. It was recognised by the Welsh Assembly Government in the Welsh Health Circulars 058 and 082 published in 2007 that this trend had to be reversed.[3]"

11. A series of audits co-ordinated and published by the Royal College of Physicians (RCP) in London and Scotland highlighted the gap in service provision between Wales and the rest of the UK.[4]

12. The RCP's Clinical Effectiveness and Evaluation Unit (CEEU) have conducted the rounds of the National Sentinel Stroke Audit (NSSA), which began in 1998. The rounds in 2004 and 2006 marked out the negative comparisons of service provision in Wales with England and Northern Ireland.

13. The Audit is based on evidence-based standards for the organisation of services and process of care agreed by the representatives of the Colleges and professional organisations of the disciplines involved in the management of stroke.

14. The Stroke Unit Trialists Collaboration (SUTC) developed the indicators used to measure service provision. They include percentages of stroke units, staffing, and access to therapies and rehabilitation programmes.

15. Audit work is carried out internally by NHS Trusts and the data submitted to the CEEU at the RCP England. The CEEU carries out the analysis and publishes the reports that compare data for Wales, England and Northern Ireland.

Wales

16. In 2006, the Welsh Government published the *National Service Framework (NSF) for Older People in Wales*[5], which contains an overarching Standard for stroke. It states:

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[3] NLIAH *All Wales Stroke Services Improvement Collaborative: End of Year Report 2008/09*

[4] The information for Scotland is published separately from England, Wales and N. Ireland, and the work carried out by RCP Scotland as opposed to RCP London.

> "The NHS, working in partnership with other agencies where appropriate, take action to prevent strokes, and to ensure that those who do suffer a stroke have access to diagnostic services, are treated appropriately by a specialist stroke service, and subsequently, with their carers, participate in a multi-disciplinary programme of secondary prevention and rehabilitation and appropriate longer term care."

17. In 2007, the Minister for Health and Social Services published the two Welsh Health Circulars, *Implementation of National Standards for Stroke Services in Wales - action for Commissioners and Providers by March 2008*[6] and *Improving Stroke Services – a Programme of Work*[7] . In addition, the NHS Wales Annual Operating Framework (AOF) 2008-2009 contained National Target 9 stating:

> "Each patient suspected of, or confirmed as having had a stroke must be admitted to dedicated and co-located acute stroke beds staffed by a specialist multi-disciplinary medical and acute rehabilitation stroke team.
>
> NB: As a milestone towards delivering this target, the co-location of beds must be delivered from May 2008."

18. In December 2007, the Minister established the Welsh Adult Neurosciences Expert Review, which completed its report in September 2008. The review states that "the current Welsh plan for stroke services should continue to be developed in conjunction with the neurological and rehabilitation services".[8] In October 2009, two further documents arose from the Review: a North Wales review document, and a Mid and South Wales implementation Plan.[9] The documents make clear the intentions of the Welsh Government to include stroke services within neurosciences policy.

19. During September 2008, the Minister launched the All Wales Stroke Services Improvement Collaborative (AWSSIC). The initial task of AWSSIC was to bring together clinicians and managers from acute hospitals across Wales to improve the reliability of the care stroke

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[5] Welsh Assembly Government, *National Service Framework for Older People in Wales*, March 2006
[6] Welsh Government, Welsh Health Circular (2007) 058, 1 August 2007
[7] Welsh Government, Welsh Health Circular (2007) 082, 11 December 2007.
[8] Welsh Government, Cabinet Statement, *Independent Adult Neurosciences Expert Review* , 30 September 2008
[9] Welsh Government, *Implementation of the Welsh Neuroscience Review* , October 2009

patients receive in the acute stage (the first seven days following a stroke). An AWSSIC end-of-year report for 2008-09 has been published by the National Leadership and Innovation Agency (NLIAH).[10]

20. Targets for stroke services have been included in the Annual Operating Frameworks for 2009-10 and 2010-11.

21. In the 2009-10 AOF, National Target AOF21 was:

> "To implement the organisational delivery plans for 2009/2010 in support of the delivery of the Stroke Programme."

22. The 2010-11 AOF, National Target AOF22 states that:

> "A major focus for 2010-2011 will be to implement the intelligent targets programme around TIA/mini stroke, acute stroke and early recovering and rehabilitation".

23. On 10 November 2009, the Minister for Health and Social Services published a Decision Report, *Stroke Service Improvement Project - Professional Specific Audit*,[11] in which she stated that she was currently considering a report produced by the SSIP Project on the findings of the audit.

England

24. In England, the NSF for Older People was published in March 2001 with a key action that "every general hospital which cares for people with stroke will have plans to introduce a specialist stroke unit by 2004".[12]

25. This was followed by the *Stroke Strategy*, published on 5 December 2007[13]. In the foreword, Alan Johnson MP, the then Secretary of State for Health wrote:

> "Significant improvements have been made over the last decade through the widespread development of stroke units and the growth of dedicated, specialised, multi-disciplinary stroke teams."

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[10] NLIAH, All Wales Stroke Services Improvement Collaborative, *End of Year Report, 2008/09*.
[11] Welsh Government, Decision Report, *Stroke Service Improvement Project - Professional Specific Audit*, 5 November 2009
[12] Department of Health, *National Service Framework for Older People*, March 2001
[13] Department of Health, *Stroke Strategy*, 5 December 2007

Northern Ireland

26. Northern Ireland, the other Sentinel Audit comparator country, has also produced a stroke strategy which states: [14]

> "By 31 March 2011, 80% of stroke patients will be admitted directly to a specialist stroke unit [at least Level 2, as defined by British Association of Stroke Physicians Service Specification][15] with the expectation that by 31March 2012 this should be available to all patients."

[14]Department of Health, Social Services and Public Safety, *Improving Stroke Services in Northern Ireland*, July 2008

[15]British Association of Stroke Physicians, Service Development and Quality Committee, *Stroke Service Specification*, 2005

3. Strategic Direction

Introduction

27. Wales, unlike other UK countries, does not have a dedicated stroke strategy to provide a focus for strategic direction. Instead, a number of documents provide the elements of a strategy. This raises a number of issues:

Identifying and finding key and associated documents and websites

28. Key documents include:

- The Older People's National Service Framework (NSF);
- the two Health Circulars: *Implementation of National Standards for Stroke Service in Wales* and *Improving Stroke Services: A Programme of Work,* which underpin the NSF;
- the NHS Annual Operating Frameworks (AOFs) for 2009/10[16] and 2010/11[17];
- the Stroke Service Improvement Programme (SSIP);[18]
- Health Board plans;
- Rural Health Plan;[19]
- the Neuroscience Review;[20] and
- the All Wales Stroke Services Improvement Collaborative (AWSSIC).[21]

Identifying targets

29. At the time of the inquiry, there were no definitive targets but, for 2010/11, the AOF contains sets of intelligent targets for Transient Ischaemic Attack (TIA) management, Acute stroke care and early recovery and rehabilitation. *NB: Details of these targets are contained in unpublished Annex B of the AOF.*

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[16]Welsh Government, Ministerial Letter 029/08 *NHS Wales: Annual Operating Framework 2009/2010,*
[17]Welsh Government, Ministerial Letter *NHS Wales: Annual Operating Framework, 2010/2011*,
[18]National Public Health Service for Wales, SSIP web-pages, accessed 11.03.10
[19] Welsh Government, *Rural Health Plan for Wales*, December 2009
[20] Welsh Government, Neuroscience Review web-pages, accessed 11.03.10
[21] National Public Health Service for Wales, SSIP web-pages, accessed 11.03.10

Monitoring:

30. To date, statistical information has been collected by the former NHS Trusts through an internal audit system and incorporated into the Royal College of Physicians (RCP) National Sentinel Stroke Audits.

Lack of patient outcomes

31. There is no Welsh stroke register and, as a result, there is no way of evaluating the effectiveness of service improvements.

Lack of milestones

32. While the Minister for Health and Social Services has indicated that all improvements should be in place by 2015, the only milestones have been in the SSIP and most have now passed.

Stroke Services Strategy

33. A number of health and allied professionals referred to the fact that Wales does not have a dedicated stroke strategy. They felt that without a strategy the improvement programme might be difficult to drive forward. The Stroke Association said that:

> "We all know that stroke services are a top priority for the Welsh Assembly (sic) and I think that we need to have a dedicated stroke strategy to focus the mind of the NHS and all the players for stroke services that will have dedicated stroke information, targets, deadlines, and formal monitoring." [22]

34. In written evidence, Dr Dewar, Consultant Stroke Physician, Royal Glamorgan Hospital, recommended the development and implementation of a "Stroke Strategy for Wales which has strong leadership, clear goals and target dates with appropriate funding and outcomes."[23]

35. The Welsh Stroke Alliance said there was an urgent need for an All Wales Stroke Strategy that built on and complemented the work already being done. They said:

[22] Oral evidence, 18.06.09
[23] Written evidence, HWLG(3)-15-09 Paper 2

> "We have done a lot of the basic infrastructure work so far and now we need to take that forward on the basis of a longer term plan" [24]

36. The College of Occupational Therapists felt that there was a need for a clear and dedicated stroke strategy:

> "Strong leadership and the development of consultant occupational therapy posts are critical to drive up the quality of services across Wales. We believe that only with a clear stroke strategy with measurable outcomes to which Local Health Boards are held to account will this be achieved." [25]

37. Questions were also raised about the appropriateness of the Older People's NSF as the key document, as the number of younger patients is increasing. In response to a question about whether or not it was appropriate to include stroke services in the Older People's NSF, Dr Dewar said he was supportive of a stroke-specific strategy:

> "It has to cover the whole population. Our service has always been free of any age barriers. We have seen patients ranging from a girl aged 15 to a lady of 101 years of age, who was in our stroke unit a few months ago. Therefore, we run a seamless ageless service."[26]

38.In commenting on the appropriateness of including stroke in the Older People's NSF, and whether this would encompass the broad age range of people who suffer from stroke and their needs, the Minister said:

> "… the national service framework for older people sets standards for stroke care, which are the standards in respect of all people who require stroke care."

39. In her oral evidence to the Inquiry, the Minister said:

> "I have set a clear policy direction by publishing the formal programme of work to improve stroke services; I have set a target for acute care, and have set a deadline of 2015 for meeting all published national standards for stroke care."[27]

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[24] Oral evidence, 23.09.09
[25] Written evidence, HWLG(3)-20-09-paper 25,
[26] Oral evidence, 18.6.09
[27] Oral evidence, 4.11.09

Our View

40. The Committee felt that the evidence in support of a dedicated stroke strategy was compelling. It felt that this could be a mechanism for improvement in stroke services in the longer term.

Recommendation

We recommend that the Minister draws together all stroke policy documents and develops an all-Wales stroke strategy that includes targets, deadlines and standards. (Recommendation 1)

Monitoring and information provision

41. The progress of the Stroke Service Improvement Programme (SSIP) and the publication of the intelligent targets now require a monitoring framework with milestones that can be used as a tool to assess both the service improvements and their impact on patient outcomes.

42. The Stroke Association described monitoring as "a bit hit and miss" because it has not been formalised.[28] In reference to the documents which contain guidelines for stroke, they said:

> "None of them has any definitive targets or timescales attached and none are formally monitored."

43. In written evidence, the Stroke Association referred to the importance of effective indicators and performance measures and said that:

> "There is a problem in that that there is no accurate and up to date stroke register in Wales, therefore the number of people suffering a stroke is actually an estimate. In terms of data relating to stroke units in Wales and audits of services, we have concerns that this may not be accurate."[29]

44. Dr Dewar, commenting on the Older People's NSF, said:

> "It has not had teeth; people have missed the targets and nothing has happened. A strategy in which you set key goals that are linked to the Annual Operating Framework and

[28] Oral Evidence, 18.6.09
[29] Written evidence, HWLG(3)-15-09 Paper 1

everything else, means that Trusts cannot just miss their targets and forget about them."[30]

45. Dr Rudd said that, in England, setting targets had been very effective:

> "In England, under the National Service Framework in 2001, the setting of a target—which we are not allowed to do any more—that every hospital should have a stroke unit by 2004, was incredibly powerful in ensuring that that happened, and it did happen in virtually all of our hospitals."[31]

46. On the issue of performance monitoring and targets, the Minister said that she was in the process of developing intelligent targets for inclusion in the 2010-11 Annual Operating Framework. Her official added that:

> "We have, obviously, concentrated on the acute interventions, and we might want to talk about that in terms of our progress. However, we are looking through from the whole issue of public health into prevention and planning. These intelligent targets will tell us much more about the outcomes and quality of care rather than just numbers. Numbers are important—we need to have co-located beds; a simple target—and we need to look at the quality of the outcomes and work with the clinicians through intelligent targets, so that we look at what we are doing about making sure that we have effective intervention by speech therapists, for example. It is a very subtle approach underneath some very clear targets, particularly around the co-location of stroke units themselves."[32]

Our View

47. The Committee welcomed the comments of the Minister and her official on the development of intelligent targets. The Committee feels that effective monitoring systems need to be introduced to ensure progress towards those targets is being achieved. The inclusion of milestones within the monitoring framework is important as these can be used as a tool to assess both the service improvements and their impact on patient outcomes. The Committee feels that the results of

[30] Oral Evidence, 18.6.09
[31] Oral Evidence, 11.6.09
[32] Oral Evidence, 4.11.09

the monitoring should be published regularly to ensure that improvement continues and stakeholders can see that progress.

Recommendation

We recommend that the Minister should introduce formal systems for monitoring the targets and timelines of stroke service provision, and that the results of the monitoring should be published regularly. (Recommendation 2)

Stroke Register

48. Evidence suggested that figures for people who had suffered a stroke could only be estimated because the number of people suffering a stroke in Wales was not recorded. The Stroke Association said that:

> "There is a problem in that that there is no accurate and up to date stroke register in Wales, therefore the number of people suffering a stroke is actually an estimate."[33].

49. The Swedish national register, the Rik-stroke Register, is an example of how effective a register can be. It is an invaluable tool for monitoring services and outcomes and informing research. Professors Apslund and Norrving said:[34]

> "The data are closely monitored today by different stakeholders, and are regarded with very much interest from different points of view. An advantage is that we have these different points of view monitored in the Riks-Stroke register. You get the patient perspective, the hospital structures, the availability of stroke units, and the patients' opinions of the quality of care that they have received."

50. The Professors told the Committee that the primary aim of the register was to improve the quality of stroke care in all hospitals in Sweden. Both processes and outcomes were measured and a special emphasis was put on patient-reported outcome measurements (PROMs).

[33] Oral Evidence, 18.6.09
[34] Oral Evidence, 21.10.09

51. They also said that, though research was a secondary goal, the Riks-Stroke Register was being used increasingly for this purpose because, with around 300,000 registered stroke patients, it had become a valuable source of information.

52. When asked about the possibility of establishing a stroke register in Wales, the Minister said:

> "I have asked the chief medical officer to consider whether there is a need for a stroke register on the basis of clinical judgment. He will report back to me, and I will then advise the committee."[35]

Our View

53. The Committee feels that a stroke register could provide a clearer picture of the number of people in Wales who have suffered from stroke. The Committee also feels that the information contained within the register could help drive up standards and improve service provision. Such a register could also provide data for research and could feed into the Minister's intelligent targets.

Recommendation

We recommend that the Minister should establish a national register of patients in Wales with stroke to monitor the incidence and patient outcomes. (Recommendation 3)

Leadership

54. A lack of leadership was an issue for some healthcare professionals and the Stroke Association. While suggestions for a model of effective leadership differed among the professions, the evidence for a need to provide clear structures was convincing.

55. The Stroke Association said that:

> "First, leadership has to come from the political side, and then from the NHS. You could argue that both of them run together. In Wales, from the political side of things, I would say that there is leadership on stroke. The Minister for health, two years ago, indicated that the NHS had to treat stroke as a high priority. Is

[35] Oral Evidence, 4.11.09

> it being treated as a priority by the NHS on the ground? It is difficult to say. In some areas, it is, while in others, it probably is not."[36]

56. Dr Rudd emphasised the importance of "stroke champions" in driving improvements on the ground:

> "You have some clinicians and others who are providing a leadership role within Wales, but that needs to be more widespread. The first thing is to ensure that every area has a clinical stroke champion, who will be arguing for the whole range of clinical services locally."[37]

57. In written evidence, Dr Rudd recommended that teams of people need to be identified, to include a clinician, manager, patient, commissioner etc, who were "able to provide inspirational leadership to help develop and implement a strategy for stroke improvement in Wales."[38]

58. When asked about the suitability of this leadership model, Dr Rudd said that it was still important to have someone who brought everyone together at a higher level:

> "It is not necessarily a question of bringing them all under the same leadership—it is a question of having a leader who can bring everyone together. We do not need to be in the same place organisationally."

59. The evidence indicated that there were a number of groups involved in leading stroke services in Wales, e.g. the Stroke Partnership, the Welsh Stroke Alliance, the Stroke Collaborative, and a number of specific clinical and allied professions networks. While these may be on different levels, there was no clearly defined structure of leadership with powers to ensure compliance with strategic goals. There was no evidence of a multi-disciplinary group providing high level leadership.

60. In relation to stroke champions, the Minister said that

[36] Oral Evidence, 18 .6.09
[37] Oral Evidence, 11.6.09
[38] Written evidence, HWLG(3)-14-09 Paper 03

> "The executive and clinical champions have been put in place in each local health board to lead on stroke services"[39].

61. She added that a director for strategy and planning; a director of operations; and a medical director were also in place – "They provide the national leadership on stroke".[40]

Our View

62. The Committee acknowledges that executive and clinical champions have been put in place, but feels that the structure for stroke leadership needs to be clearer. Such a structure could form part of an all-Wales stroke strategy and should include stroke champions; stroke networks and other organisations.

Recommendation

We recommend that the Minister draws up a clear structure for stroke leadership comprising the NHS and Government, with, for example, stroke champions or team leaders, and regional and/or national overarching multi-disciplinary bodies reporting to NHS/Government with a mandate to ensure compliance if necessary. (Recommendation 4)

Funding

63. Evidence from the College of Occupational Therapists compared the 2008-09 £2.5 million allocated by the Welsh Government to allocations in the three other UK countries. However, it is not possible to make direct comparisons because the money has been allocated for different purposes and over different periods of time.

64. In Wales, the £2.5 million announced by the Minister has been used for very specific purposes, i.e. the Welsh Stroke Alliance and specialist staff. The amount does not take into account other spending on stroke services, for example, the purchasing of scanning equipment and thrombolysis services being piloted in south Wales, which have not been clearly identified as stroke-associated spend.

65. The £77 million allocated in England over three years has been earmarked for wide-ranging services along the whole pathway

[39] Oral Evidence, 4.11.09
[40] Ibid.

including both hospital services and community and support services for survivors living with the aftermath of stroke, and ring-fenced funding for local authorities.

66. Scotland has provided £40 million over three years, but this is to be spent on coronary heart disease as well as stroke, while in N. Ireland, £14 million has been allocated over three years followed by £9 million recurrent funding in Year 4.

67. In his supporting paper, Dr Dewar said:

> "There has been some initial funding made available targeted at the development of Acute Stroke Services. This has been insufficient to develop comprehensive acute stroke teams."[41]

68. He went on:

> "This has been compounded by the withdrawal of the initially agreed non-recurrent money for the necessary training and equipment to safely introduce the Acute Stroke Service."[42]

69. In answering a question about the costs of consolidating and making stroke services sustainable, Dr Rudd agreed with an estimate of around £5-6 million.[43]

70. The Royal College of Speech and Language therapists recognised that an additional £2.275 million had been allocated to stroke services for 2008-09, but their written evidence showed that bids for a number of posts had been unsuccessful.[44] This evidence said that there was a shortfall of over £0.5 million in allocation compared to bids.

71. In response to the question of funding, the Minister said:

> "I have put considerable additional funding into this agenda: £2.5 million in 2008-09 in terms of services and £2.275 million of that has gone directly into front-line services. I have also funded national initiatives to raise awareness and to support the NHS in achieving improvements, which it is starting to achieve."[45]

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[41] Written evidence – HWLG(3)-15-09-Paper 2
[42] ibid
[43] Oral evidence, 11.06.09
[44] Written evidence – HWLG(3)-16-09-Paper 2
[45] Oral evidence, 4.11.09

72. The Minister added:

> "I have invested in a number of stroke-related interventions, but, for the most part, I have allowed local services to decide the best way of spending the funding. Some areas needed capital funding for scanning equipment, some have used it to increase therapy time and others have appointed additional consultants across the piece."[46]

73. In response to queries about the strategic allocation of funding, the Minister said:

> "Our service workforce and financial strategic framework has focused on a whole load of issues and the expert panel has given advice on what to do. I have also supported campaigns with the Stroke Association Cymru and others. When you look at the investments that have gone into CT and MRI scanning across the piece, you will see that we are talking about millions of pounds-worth of investment that will aid stroke services."[47]

Our View

74. Whilst the Committee acknowledges that the Minister has allocated significant funding to stroke services and has made additional allocations, we remain concerned that the funding does not match the levels of funding allocated to stroke services in other parts of the United Kingdom.

Recommendation

We recommend that the Minister should keep under review the allocation of funding for stroke services in Wales, and identify more clearly resources that contribute to stroke services to ensure that levels of funding are commensurate with those of other UK countries. (Recommendation 5)

[46].Oral Evidence, 04.11.09
[47] ibid

4. Stroke Units

Introduction

75. While the number of 'stroke units' in Wales has risen since the published audit of 2006 and unpublished audit of 2009, Wales still lags behind England and N. Ireland.

76. While England and N. Ireland both have targets aiming to put stroke units in place, in Wales, the aim is to develop wards in district general hospitals that have co-located beds, rather than dedicated stroke units.

77. The AOF 2009-2010 states:

> "By March 2009, organisations must have achieved:
>
> - The co-location of stroke beds;
> - Services that ensure that each patient suspected of, or confirmed as, having had a stroke are admitted to dedicated and co-located acute stroke beds staffed by a specialist multi-disciplinary medical and acute rehabilitation stroke team; and
> - The 2008/09 requirements contained with the Improving Stroke Services – a Programme of Work."

78. Professional bodies advocate that all people who suffer from stroke should be admitted to and treated on a dedicated stroke unit. This enables access to appropriate and timely expertise and treatment. This is backed by evidence from studies showing the positive impact unit care has on survival rates, independence and continuing social inclusion of stroke survivors. Stroke units are also seen as a driver to developing services, expertise and knowledge.

79. Issues raised in relation to Stroke Units were:

- Although the Sentinel Audit showed that the majority of acute hospitals in Wales have stroke units, these were sometimes seen as being in name only;
- Lack of clarity around the use and definition of "stroke unit" to describe the arrangements for stroke patients admitted to hospital;

- There are established rehabilitation units in Wales that are sometimes described as stroke units but it is not clear the extent to which these meet the criteria set out by the Stroke Unit Trialists' Collaboration (SUTC);
- In some areas, patients experience difficulties in accessing a stroke unit;
- The location and accommodation of units can be inappropriate

Stroke Unit Policy

80. Many of those who gave evidence felt that there was a need for specialist stroke units, which they saw as a catalyst for developing high quality acute stroke services. Evidence in favour of organised stroke unit care included studies showing benefits both to the health service and patients.[48]

81. The Committee heard evidence from Dr Rudd and Dr Shetty that patients not managed in specialist stroke units tend to stay in hospital longer, cost more and have worse outcomes than those who are admitted to such units.

82. Dr Rudd said:

> "Probably the biggest change that we are seeing is in the number of stroke units that are opening in Wales. I regard those as being absolutely central to delivering a stroke service. If you have a stroke unit, the pre-hospital care tends to be better, because GPs know that they are sending patients somewhere that will actually do something. We also know that, after they are discharged, people tend to have a better quality of care if they have been through a specialist service."[49]

83. Dr Shetty referred to a Cochrane review of organised patient care undertaken by SUTC. The review concluded:

> "Stroke patients who receive organised inpatient care in a stroke unit are more likely to be alive, independent, and living at home one year after the stroke. The benefits were most

[48]BMJ. *Collaborative systematic review of the randomised trials of organised inpatient (stroke unit) care after stroke.* 1997 April 19; 314(7088): 1151–1159.
[49] Oral Evidence, 11.6.09

apparent in units based in a discrete ward. No systematic increase was observed in the length of inpatient stay."[50]

84. In written evidence to the Committee, Dr Shetty said:

> "Managing stroke patients in a specialised multi-disciplinary stroke unit has been shown to reduce death and dependency. This is the only intervention used to manage stroke patients that has been shown to be associated with a reduction in mortality. The number needed to treat to prevent one death/dependency is 23. Assuming that 44 poor outcomes (death/dependency) can be avoided per 1000 patients treated, if all stroke patients in Wales (around 5000 per year) are managed in a specialized stroke unit, we can expect to prevent 220 poor outcomes per year"[51].

85. Professors Norrving and Asplund said that the development of stroke units in Sweden has driven up service standards, quality of treatment and improved patient outcomes. They said:

> "There is no doubt that you need to have stroke units as ambassador sites for good stroke care. If you have an effective stroke unit, it can work with pre-hospital stroke care and also with secondary prevention and the long-term follow-up. It is essential to have the stroke units in place. With good leaders, they have spreading rings around what is happening in the stroke units. It is not only that the patients come in and go out; stroke units have a much broader importance than that."[52]

86. According to the research undertaken by SUTC, for every 100 patients, 26 fewer bed days would be used when treated in a stroke unit rather than in a general medical ward. At an average cost of £125 per bed day, a reduction of 660,000 bed days would be achieved, resulting in £82 million savings to NHS in the UK.[53].

87. Dr Pickersgill suggested a different model to the stroke unit, the Acute Brain Unit. He explained:

> "I would like to compare this idea to that of what are commonly called coronary care units, or CCUs. They are present in the

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[50]Cochrane Database of Systematic Reviews, *Organised inpatient (stroke unit) care for stroke*, Issue 4, 2009,
[51] Written evidence, HWLG(3)-16-09 Paper 1
[52] Oral Evidence, 21.10.09
[53] ibid

vast majority of, if not every single, acute admitting hospital in Wales and the UK and probably the world, but they do not just deal with people who have got a blockage in a coronary artery causing chest pain and angina or heart attack; they deal with people who have heart failure, who are short of breath from an unknown cause, who have heart valve problems, structural heart problems, congenital heart problems, and who have become acutely ill. So, in fact, they are not named correctly. They are heart units, not coronary care units. I think that stroke units could easily develop or become brain units."[54]

88. He went on:

> "I think that it is worth exploring the idea of developing a unit specialising in a range of conditions where the nursing, physiotherapy, bed management and medical expertise can be concentrated but also developed with experience. Patients who have acute neurological problems should be dealt with by an acute neurological team, if you like, not just neurologists… Stroke units would be a place where that could start to mature."[55]

89. When asked whether NHS Wales should be aspiring to have stroke units rather than co-located beds, the Chief Executive of NHS Wales said:

> "Co-location stroke units are a combination of facilities, including beds, diagnostics and therapeutic facilities. In some places it is possible to have them under one roof and in others it is possible to have them next door to each other." [56]

90. On the issue of stroke units, the Minister said:

> "The establishment of a multi-disciplinary team and co-located beds is a fundamental requirement of a stroke unit. There are also other issues that impact on the units far more, such as timely access to decision making, CT scanning and a dedicated stroke team. That is what makes up the unit; it is not necessarily four beds in a walled unit where you can say, 'that's the stroke unit'. It is about how the services combine and come together. As we develop this and give a continuing priority to

[54] Oral Evidence, 23.9.09
[55] ibid
[56] Oral evidence, 04.11.09

stroke units, we will get to grips with some of the wider issues that you have raised."[57]

Our View

91. The Committee was persuaded by the evidence that stroke units are central to improvements in stroke services. We acknowledge the view that recent improvements are as a result of stroke units being established in Welsh hospitals. The Committee feels that the benefits of stroke units are many and they should play a central role in the Minister's stroke strategy.

Recommendation

The Minister should include, as part of any stroke strategy, the aspiration that all patients should have access to a dedicated stroke unit as clearly defined by the NHS and her Government. This definition should include details of the multi-disciplinary clinical and therapy teams expected to support the unit. (Recommendation 6)

Number of Stroke Units

92. In relation to the number of stroke units, the Stroke Association said that:

> "The provision of stroke units in Wales is a key concern. Over 90% of hospitals in England have stroke units compared to half of Welsh hospitals."

93. They went on to say:

> "It is not strictly necessary for every hospital to have a stroke unit, but patients must be within reasonable travelling distance of a facility. These units must be on a par with high quality stroke care in the rest of the UK and not stroke units in 'name only'. For example, over the past two years no Welsh stroke unit has reached the British Association of Stroke Physicians Level 1 standard, which is the NSF minimum."

[57] Oral Evidence, 04.11.09

94. Dr Trevor Pickersgill, giving evidence on behalf of the British Medical Association (BMA) said that only 15 per cent of Welsh hospitals have acute stroke units compared with 59 per cent in England.[58]

95. Dr Shetty drew the Committee's attention to a Welsh Stroke Services Survey conducted in 2006 by the Wales Stroke Interest Group, which showed that only 78 per cent of Welsh hospitals, compared with 99 per cent in England, have a stroke unit, of which less than half (44 per cent) have acute stroke units. Only 28 per cent of the acute stroke units meet all the criteria set by the Royal College of Physicians.[59]

96. Dr Dewar, said that patients admitted to his hospital with acute stroke are "defined" to the care of his medical team and cared for on one of three designated wards. However, although patients are managed by himself as a Consultant Physician specialising in Stroke medicine, they are not on a Stroke Unit and the nurses and therapists who assess and care for them are not specialists.

97. The Welsh Stroke Nurse Alliance said that there are already long-standing rehabilitation units in Wales that have multi-disciplinary teams who are interested in, and knowledgeable about, stroke. However, as with all stroke services, there are geographical variations of availability.[60]

Definition of Stroke Unit

98. We found that the term 'stroke unit' is used to describe a variety of arrangements, including wards of co-located beds, acute units and rehabilitation units. We also found variances in the numbers of stroke units provided in evidence. To improve clarity, we feel that the term 'stroke unit' should be clearly defined.

Recommendation

We recommend that the term 'stroke unit' should be clearly defined and that this definition should be applied uniformly throughout the NHS and in government strategic documents. (Recommendation 7)

[58]Written evidence, HWLG(3)-19-09 Paper 2
[59]Written evidence, HWLG(3)-16-09 Paper 1
[60] Oral evidence, 23.09.09

Access to defined beds

99. In his paper to the committee, Dr Pickersgill stated:

> "The National Sentinel Audit for Stroke (2006) reported that less than half of Welsh hospitals (45%) currently have a stroke unit – compared to over 90% in both England and N Ireland – many are not large enough to accommodate all stroke patients, with the majority finding themselves admitted to general hospital wards."

100. Dr Rudd said:

> "From the clinical data that were submitted last year, from April 2008 until June, we know that there is still a relatively small proportion of your patients that are getting into a stroke unit. Even fewer of those get in quickly and very few actually stay for the majority of their stay."

101. Professor Norrving said that "the strongest recommendation of Swedish stroke units from the beginning" was that:

> "It is preferable to have direct admission to a stroke unit without starting with an observation unit and then making a secondary transfer to a stroke unit."

102. On the issue of stroke patients being located in general wards, the Chartered Society of Physiotherapists (CSP) said that

> "General wards cannot get appropriate seating equipment or all the bits and pieces that an appropriate setting would offer. You cannot trawl a proper treatment plinth all the way through the hospital, and you cannot carry out stroke treatments at the side of a bed. So, there are many issues such as those to do with the equipment. Most stroke units have the basic, bog-standard physiotherapy and mobility equipment, such as the high and low plinths, and the tilt tables. The problem is when they have to be used in inappropriate places." [61]

103. The Welsh Stroke Nurse Alliance said in written evidence that national guidelines were not being followed in Wales regarding direct admission of stroke patients to defined beds in the acute stage:

[61] Oral Evidence, 18.6.09

> "From the Welsh perspective, there are discrepancies with concordance to National Guidelines regarding direct admission of stroke patients to these defined beds in the acute stage. The favoured model is still for patients to go to a general admission unit. The problem with this model of care is that care tends to be delivered by generalist nurses as opposed to the philosophy of "enhanced care" provided by a dedicated stroke unit."[62]

Our View

104. The Committee acknowledges that National Guidelines are in place in relation to the direct admission of patients to dedicated beds, and believes that this should take place in the acute stage.

Recommendations

We recommend that all stroke patients should be admitted directly to defined beds and that the practice of admitting them to general wards be phased out as a matter of urgency . (Recommendation 8)

We recommend that the Minister introduces mechanisms to monitor the following of national guidelines regarding direct admission of stroke patients to defined beds in the acute stage. (Recommendation 9)

Location of Stroke Units

105. Dr Shetty said that many stroke units are housed in unsuitable accommodation. On the location of his own unit, he said:

> "It is completely unsuitable for managing stroke patients. When we are planning future hospitals and services, this is something that we need to look into. We have an opportunity to improve the situation for our patients."

106. In answer to a question about whether it was preferable for patients to be cared for in smaller units locally or whether there was scope for larger specialist units, Dr Shetty said:

> "The important thing is that patients are managed in a geographically localised area by specialists. Whether the set-up is big or small does not matter. What matters is that patients are looked after by the right kind of staff."

[62] Written evidence, HWLG(3)-19-09 Paper 4

107. In a written submission, Gwent Healthcare NHS Trust described how the Trust had organised and staffed their stroke services using existing facilities. The Trust is now the Aneurin Bevan Health Board and appears to have produced a model of a comprehensive integrated service for stroke with multi-disciplinary teams, acute beds and local rehabilitation units. In addition, there are regular clinics for transient ischaemic attacks (TIAs)[63]

108. The Minister said that location of stroke units was an issue which could be looked at in the longer term:

> "When you look at a new build in the future or when you undertake alterations to buildings and so on, you might decide to look at this and at how you would review your definition of your stroke unit in its location."

Recommendation

We recommend that Health Boards look at innovative ways of restructuring stroke care to maximise existing resources, by considering examples of good practice. (Recommendation 10)

[63] Transient Ischaemic Attacks (TIAs) are mini strokes. People recover from them quickly without effects, but they can sometimes the precursor of a major attack.

5. Access to Treatment

Introduction

109. It is important that people with suspected stroke are triaged, assessed and treated appropriately without delay. This is because thrombolysis, clot-busting drugs, administered swiftly to patients who suffer an ischaemic stroke can lessen considerably the effects of physical and emotional damage. It is vital that before someone with suspected stroke is thrombolysed, a diagnosis using scanning equipment and other tests is carried out. Using thrombolysis on a patient who has suffered a stroke as a result of bleeding rather than a blood clot can have very serious consequences for the patient.

110. The evidence highlighted a number of issues related to timely assessment and treatment:

- The importance of raising awareness of the symptoms of stroke among the general population and among health professionals;
- The need to raise awareness generally of prevention measures and causes of stroke; and
- The importance of responding urgently to a potential stroke, and how this might be done more effectively.

111. A further issue raised was the necessity for transient ischaemic attacks (TIAs),or mini-strokes, to not only be recognised more frequently but to be treated. TIAs are often a pre-cursor to a major attack, and it is important that they are recognised and treated because doing so can prevent or minimise the damage of a further attack.

Raising Awareness

112. A number of patients highlighted their own lack of awareness and a lack of awareness on the part of professionals of stroke symptoms, appropriate treatment and accommodation. Examples included patients being turned away by hospitals and general practitioners, and delays in being admitted to hospital and diagnosed. Once they had been admitted to hospital and/or diagnosed some had experienced a lack of treatment and had been placed in inappropriate

wards. Although most of these patients had suffered strokes a number of years ago, others were more recent

113. Stroke Association Cymru drew attention to the three-year, £12 million Act FAST[64] advertising campaign, run by the UK Department of Health and which was designed to inform the public about the symptoms of stroke:

> "…I understand that 92 per cent of people in England have seen the advert and can remember it when asked."

114. The Stroke Association Cymru also referred to their campaign in Wales:

> "We ran the Act FAST campaign in April last year, and it ran for two weeks on the radio. It ran for seven days on Real Radio, and we had 52 spots, which, according to Real Radio's research, means that 309,000 people will have heard it. As for the rest of the media, we placed an Act FAST advertisement in 20 weekly newspapers across Wales for two weeks. We carried out an evaluation of people's awareness of the symptoms of stroke, and that showed a threefold increase, albeit from a very low base."

115. The Minister said she provided funding in 2008 and 2009 to the Stroke Association Cymru and others to support campaigns to promote awareness of stroke, its symptoms and risk factors. She also said she would be running a campaign in 2010 to alert the public to the link between high blood pressure and stroke.

116. The BMA praised the FAST campaign but said it needed to be built on:

> "A national public awareness campaign is needed to highlight the prevalence and severity of stroke, how to recognise the symptoms, and that it requires a 999 response. The FAST campaign did some good work in relation to this but needs to be built on – for example, the ways to recognise transient ischaemic attacks (TIA), the risk factors such as high blood pressure and diabetes, high cholesterol, smoking, excess alcohol intake and recreational drug use should also be

[64] FAST stands for **F**acial weakness, **A**rm and leg weakness, **S**peech problems, **T**ime to call 999.

highlighted. Many people still do not realise that strokes are preventable, do not know the symptoms or risk factors, or how to manage them." [65]

117. Dr Pickersgill informed us of an online British Medical Journal (BMJ) learning module designed for GPs on neurology, which includes updates on stroke recognition, prevention and treatment. These are available for GPs to take if they wish, as is the programme of Postgraduate training courses. GPs could be encouraged to undertake such courses through their annual appraisals:

> "The system that GPs use to keep themselves up to date, namely continuing professional development, could be fine-tuned to major on those things that need developing, and stroke might be one of those. I was talking to a colleague yesterday who has recently completed an online BMJ learning module on neurology, including updates on stroke recognition, prevention and treatment. So, there is a variety of ways in which current GPs and the GPs of the future are trained and can be trained in this."[66]

118. Dr Mushtaq Wani, Vice Chair of the Wales Stroke Alliance and Welsh Association of Stroke physicians, also highlighted the need to raise awareness of TIAs.

119. Dr Wani also highlighted the connection between smoking and the risk of stroke. He informed us of the high rates of smoking he had found among Welsh stroke patients (45 per cent) in his own small stroke thrombolysis project in Swansea compared with those in UK (22 per cent) and Europe (20 per cent).

120. Written evidence concerning the risks of smoking was also submitted by Action for Smoking and Health (ASH) Wales who said:

> "The number of adult deaths from Cerebrovascular Disease caused by smoking was 52,523 in 2000 in both Wales and England (Peto et al., 2006). The total estimated NHS costs of Cerebrovascular Disease attributable to smoking has been estimated by Allender (2009) using the WHO Global Burden of

[65] Written Evidence, HWLG(3)-19-09 Paper 2
[66] Oral Evidence, 23.9.09

Disease Project Figures to be £113.6m in Wales in 2005-2006. The total cost of stroke being £516.5m."[67]

121. In his evidence, Dr Amer Jafar, Gwent Healthcare NHS Trust said:

> "I would like to see more active collaboration between the primary care doctors and the secondary care medical professionals regarding preventing cardiovascular diseases in general and stroke in particular. This will raise the issue of having general practitioners with special interest in stroke medicine in Wales."[68]

Our View

122. The Committee feels that awareness-raising campaigns in relation to stroke are vital and can have a significant effect. We acknowledge that work has been done in this area and that the Minister intends to introduce more awareness-raising campaigns. We feel that there is a need for regular communication campaigns targeted not only at the public but also at healthcare professionals and that such campaigns should form part of an overall stroke strategy.

Recommendations

We acknowledge the Minister will be mounting a campaign to raise awareness of the connection between high blood pressure and stroke, but would recommend that a planned series of high profile campaigns for professionals and the public be incorporated into strategic documents. (Recommendation 11)

As part of the plan suggested in the recommendation above (Recommendation 11), a campaign to alert the public and professionals to Transient Ischaemic Attacks (TIAs/mini strokes) as a possible forewarning of major strokes should be given priority. (Recommendation 12)

Emergency Response

123. In response to a question, Mr Jenkins of the Welsh Ambulance Service NHS Trust (WAST) agreed that there were issues in relation to telephone triaging when a call handler answers a 999 call. He said:

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[67] Written evidence, HWLG(3)-20-09 Paper 19
[68] Written evidence, HWLG(3)-23-09-Paper 1

> "The predominant issue is that it is very difficult for the emergency call takers to pattern-match a group of symptoms into a working clinical impression to make sure that the adequate response is apportioned to the presenting complaint."[69]

124. He added that the WAST was developing a triaging protocol where stroke is suspected.

125. It was encouraging, however, to hear from Mr Jenkins that training of paramedics and other ambulance staff to recognise and prioritise stroke using Act FAST and national guidance had been rolled out.

126. On the categorisation of responses to suspected stroke cases, Mr Jenkins said:

> "…what has been agreed now is that, on receipt of a 999 call presenting some high-level signs and symptoms aligned to a transient ischaemic attack or a stroke, it is afforded a category B response. The benefit of that is that you get a fully kitted ambulance with a paramedic on board and so the next point of the phase kicks in, which is the transport system. In the Joint Royal Colleges Ambulance Liaison Committee guidelines, the college of paramedics guidelines and the National Institute for Health and Clinical Excellence guidelines, they are very much for us to give treatment on the go, en route."[70]

127. He went on:

> "You have a category A eight-minute response and that will be either an ambulance or a rapid response single-operator paramedic within the eight minute timeframe. Or you have the category B then, with urban, rural and remote at 14, 18 and 21 respectively, where an ambulance is sent as a result of a 999 call. The discussion with the working group was around the fact that if we send it as a category A and you have a single operator response, you are still delaying the transport. What you need is a category A land ambulance to push the transport, and that is what we are going to work to, but as an interim measure we have a category B, with some very pertinent determinants and suffixes. It is almost like having a diagnostic

[69] Oral evidence, 21.10.09
[70] ibid.

tool online: if you have these symptoms or signs, then that is a cerebrovascular accident, and that is your response."[71]

128. In response to a question on whether an RRV could be sent to triage the patient, quickly followed by a fully crewed and kitted ambulance if necessary, Mr Jenkins said:

> "That is what we need to be working towards and what we are working towards"[72]

Minister's Evidence

129. The Minister said:

> "We have a national protocol and quality requirements for the thrombolysis service, and the Welsh ambulance trust has confirmed that the rapid response is in place. It is part of its service improvement project."[73]

130. The Minister's official added that:

> "The trust has a specific protocol where suspected stroke is involved, and the other aspect of this is rapid and direct admission through accident and emergency units at district general hospitals. That is another area where there has been good progress; we just need to finalise work on that."[74]

Our View

131. The Committee was concerned that suspected stroke calls are classified as Category B calls. Though we recognise the rationale for this - so that a fully kitted two-person crew ambulance is dispatched in the first instance, we remain unconvinced that this is appropriate handling for a call where a swift response can be vital, especially since the Category B call targets are no longer included in the AOF.

Recommendation

We recommend that the priority categorisation of 999 calls for stroke should be changed so that a fully crewed ambulance is

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[71] Oral Evidence, 21.10.09
[72] ibid.
[73] Oral Evidence, 4.11.09
[74] ibid.

dispatched against a Category A response time. (Recommendation 13)

Air Ambulance Service

132. The Committee heard how the use of air ambulances in remote areas in Sweden contributed to higher rates of thrombolysis than were apparent in some urban areas.

133. The Committee was told that the Welsh Stroke Alliance was looking at the pathway with the WAST in order to provide appropriate access. This work would be completed in the first part of 2010.

134. Members heard that the work of the Wales Air Ambulance is developing and may be used to transport stroke patients to a hospital where there are appropriate facilities.

135. On this issue, the Minister's official said

> "The use of the air ambulance is part of the overall protocol with the ambulance service trust. Deployment is agreed between those two organisations. I agree that it has a key role to play."[75]

Our View

136. We feel that the Welsh Ambulance Services NHS Trust should continue to explore the most effective methods of transporting stroke patients, particularly in relation to the location of the patient and proximity to services.

Recommendation

We recommend that the Welsh Ambulance Services NHS Trust should explore opportunities to ensure that the most appropriate method of transportation is used for transporting suspected stroke cases. This applies particularly in rural areas as set out in the Rural Health Plan, where transportation to a hospital where appropriate assessment and treatment, including thrombolysis if necessary, can be undertaken. (Recommendation 14)

[75] Oral evidence, 4.11.09

A & E Handover and Direct Access

137. We heard from Mr Jenkins (WAST) that a protocol had been devised between NHS Trusts and the WAST to facilitate a rapid handover and direct access at Accident and Emergency (A&E) entrances for suspected stroke cases.

138. We also heard that while some NHS Trusts had developed good practice in this respect, there were still problems within a minority of Trusts, particularly in West Wales. This was confirmed by the Minister.

139. Mr Jenkins said that electronic patient clinical records could make the process more effective:

> "I should mention electronic paperwork. We have a patient clinical record at the moment with a very small narrative—there is a tick box on pulse, respiratory rate and so on, and you put your figures in, and there is a small narrative box. That is the key box as regards an opportunity for you to expand on your clinical impression. If that was electronic and dynamic on scene and was telemetrised across the hospital, with the cardiac services and door-to-balloon time considerations, it would speed up the process, as evidence suggests."[76]

Diagnosis and Thrombolysis

140. Thrombolysis is one treatment that can significantly mitigate the impact of the stroke on a patient. However, it cannot be undertaken until a diagnosis is made and this requires, among other tests, a CT or preferably, an MRI scan. It is important that this diagnosis has been made as treating a non-acute ischaemic attack could have a serious adverse impact on the patient. Thrombolysis must also be delivered within three hours of the commencement of the attack.

141. Currently, access to thrombolysis is available at only three sites in Wales and only during normal working hours, five days a week.

142. The Committee heard from the Minister that there had been recent investment in scanners, and that plans for organisational

[76] Oral Evidence, 21.10.09

change to provide better access to thrombolysis on a 24/7 basis were progressing.[77]

143. Dr Hughes, Consultant Neurologist, University Hospital Wales, pointed out that thrombolysis cannot be undertaken unless there are sufficient radiology and radiography services.

> "A plain CT of the head must be performed in all patients presenting with symptoms suggestive of an acute ischaemic stroke and this must be done immediately, or as soon as possible after presentation. This is a considerable challenge for stroke services and requires resident radiographers, a CT scanner, and a system which allows radiologists to interpret the images, either on site or on-line." [78]

144. In his written evidence, Dr Neil McKenzie said that, at Llandudno Hospital, diagnosis was unaided by NMR[79]. This leaves doubt about whether a stroke is due to bleeding or clot, which is a serious problem.

145. We had expected to hear from Sweden that telemedicine was a major factor in the high rates of thrombolysis in rural areas, but Professors Apslund and Norrving felt they were due more to the use of the air ambulance for transportation. Nevertheless, telemedicine is being used in Scotland in relation to stroke and may be a way forward in Wales.

146. Dr Mushtaq Wani provided some results from a European research study site in Kent where the effects of thrombolysis were being monitored. The Stroke Association estimates that around 45 per cent of people who suffer a stroke have an acute ischaemic attack which, if diagnosed and treated promptly, can make a significant difference to a patient's recovery and outcome. However, diagnosis requires the continuous availability of a CT or, preferably, MRI scanner together with staff to operate and interpret results.

147. Dr Hughes, on behalf of the Welsh Stroke Alliance, suggested that organising responses for stroke could be based on the Healthcare for London programme where a standard had been set that every patient within Greater London should be within 30 minutes by ambulance of a centre that can carry out a scan. The centre must also

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[77] Oral Evidence, 4.11.09
[78] Written evidence, HWLG(3)-19-09 Paper 13
[79] Nuclear magnetic resonance spectroscopy

be able to get the clinical opinion and come to a conclusion about the clinical and radiological aspects within 30 minutes.

148. This had been achieved using 10 centres in the whole of Greater London. In Wales, it would be possible to designate certain centres to offer that sort of immediate assessment, particularly out of hours and at weekends. The M4 corridor in South Wales and the A55 in the North offers this opportunity without staffing all centres every weekend.

149. On the issue of thrombolysis, the Minister said:

> "We are also running some trial work on thrombolysis with Edinburgh University, and I would be happy to update you on that when all of this is completed."

6. Treatment, Care and Support

Introduction

150. This section contains evidence relating to hospital treatment and therapy interventions and community and longer term rehabilitation and support. The evidence has been presented separately for the two levels of care but we would point out that ideally there should be a seamless transition between acute secondary and community care.

151. A project of the Stroke Service Improvement Programme (SSIP) is to develop a whole patient pathway, but, to date, resources and development work has focused on the acute sector. [80] A recent Health Inspectorate Wales (HIW) review of the Older People's National Service Framework has highlighted the need to develop the stroke pathway to provide support and early intervention in community as well as hospital settings.[81]

Hospital Treatment and Therapy Interventions

152. Re-organising acute and other secondary care services takes time and results may not be immediately forthcoming. However, while figures provided by Dr Rudd show that although there have been improvements in the delivery of some interventions monitored by the Sentinel Audit, those improvements do not appear to have been significant, and performance remains below that of England and N. Ireland.

153. The Minister has set a date of 2015 for the completion of the Stroke Services Improvement Programme, and as work in Wales started in 2007 this means that health bodies will have been given an eight year period to develop services. England, N. Ireland and Sweden all appear to have made greater progress in a shorter time span.

154. Levels of, and access to, hospital treatment and care for stroke remain variable throughout Wales. While the Committee received submissions from former patients praising the care they had received, we also received a number of submissions giving examples of poor levels of treatment and care.

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[80] NHS Wales, All Wales Stroke Services Improvement Collaborative, *End of Year Report, 2008/09*

[81] Health Inspectorate Wales, *Review of the Older People's Framework*, October 2009,

155. Chris Franks, regional AM for South Wales and a member of the Assembly's Cross Party Group on Stroke, said in written evidence that he had visited stroke wards in his region and while being impressed by the commitment of Welsh NHS staff, he was concerned by the lack of necessary specialist equipment and time available for stroke patients.[82]

156. Gaps in stroke services are to some extent due to the fact that they are still developing. There are a range of issues such as stroke units, staffing, training and research, that are interdependent with treatment and care, and these are dealt with elsewhere in this report.

157. Dr Rudd pointed out the particular concern that a number of rehabilitation stroke units exclude patients on the basis that they have no rehabilitation potential. He said that very few stroke patients do not benefit in some way from the expertise of a stroke unit, and even those who are likely to require institutional care may benefit from intervention that may improve their longer term quality of life.

Community and Longer Term Rehabilitation and Support

Early supported discharge (ESD) schemes

158. We were advised that early supported discharge teams reduce the length of stay and improve quality of life for patients and carers. They are important for patients' recovery and can help services by freeing up beds. These schemes are becoming widespread in England, but in Wales, schemes appear to be only operating in Cardiff and Wrexham. A particular benefit noted by the Chartered Society of Physiotherapists of ESD is that fewer people are being admitted to general wards as there are more beds available.[83]

159. The College of Occupational Therapists provided information on the Stroke Outreach Service based at the Regional Stroke Unit (RSU) in West Wing, CRI. It is a pilot project that comprises an Occupational Therapist, a Physiotherapist, and Stroke Association Family Support Organiser. The Outreach Service assists in the discharge of patients from RSU, focuses on their individual aims and goals at home, and provides patients with ongoing interventions and support.

[82] Written evidence, HWLG(3)-20-09 Paper 10

[83] Oral evidence, 18.06.09

Rehabilitation and community support

160. The Chartered Society of Physiotherapists was concerned that only the acute end of the stroke pathway had been prioritised so far, and they were eager to see the part of the Minister's Programme of Work '*Maximising Post Stroke Living and Quality of Life*' implemented.[84]

161. We were informed that rehabilitation in the community and support for people with strokes is thinly spread across Wales, with people in many areas having little or no access to the type of therapy that they require. Age Concern, Ceredigion highlighted a number of areas where services were lacking.[85]

162. This is particularly the case with regard to speech and language therapy and psychological counselling. Mrs. Moore, who submitted written evidence, said she was pleased with the care her husband had received in hospital, but that the support stopped when he was discharged, even though the stroke had affected his speech.[86]

163. We also received evidence from people caring for partners who had suffered stroke that they had to pay for physiotherapy and speech and language therapy because those services were not available in their respective areas.

164. On the issue of rehabilitation, the Chartered Society of Physiotherapists explained that, in Cardiff:

> "We only follow up patients that have been in our rehabilitation in-patient unit, which is a big limitation to our service because in Cardiff, all those patients that go to the Heath hospital and are discharged directly home from there—which is quite a number of patients—do not get the follow-up service, because they have not come through the rehabilitation unit. So, there is a big gap in the service provision."[87]

165. Dr Dewar referred to therapy staffing levels and said:

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[84]WAG, Welsh Health Circular, (2007) 082, *Improving Stroke Services: A Programme of Work*, 11 December 2007
[85] Written evidence, HWLG(3)-22-09 Paper 08
[86] Written evidence, HWLG(3)-20-09 Paper 15
[87] Oral evidence, 18.6.09

> "…Therapy Staffing levels have not risen in line with patient numbers and thus Specialist stroke therapy input into out-patient and community services has had to been reduced and waiting lists and prioritization for in-patients has sometimes been necessary. Many of the therapy staff on the stroke unit have become highly skilled and are contributing greatly to the Welsh Stroke Alliance."

166. The College of Occupational Therapists said that a longer-term holistic approach to the rehabilitation of stroke patients that included leisure activities was needed. They also pointed out that there was inconsistent funding of such services across Wales.[88]

167. Another area that caused concern for carers was the lack of respite care.

Voluntary sector support

168. Evidence we received made it clear that the voluntary sector provides a valuable source of support for many patients and carers. However, Joyce Watson, Regional AM for Mid and West Wales and chair of the Assembly's Cross Party Group on Stroke said in her written evidence:

> "I have discovered there is a disparity within Wales with regard to community care for stroke patients."[89]

169. She went on to say:

> "In recent months Powys Local Health Board has agreed to fund the Family and Carer Support Service…I met with staff from the shadow Hywel Dda Trust in May to discuss the issue of Ceredigion and Pembrokeshire lacking services whilst Carmarthenshire had both services. I was told there was simply not enough money."

170. Joyce Watson pointed out in her submission that Family Care Support is recommended in the Older People's NSF and the Royal College of Physicians' National Clinical Guidelines for Stroke.

171. The Stroke Association stated in their oral evidence that they have 18 family and carer support servicegroups and 18

[88] Written evidence, HWLG(3)-22-09 Paper 2
[89] Written evidence, HWLG(3)-20-09 Paper 14

communication support groups in Wales. Where multi-disciplinary teams exist, family and carer support co-ordinators are a part of them, and as such provide continuity between the hospital and the community.

172. Mrs Turley wrote to say that, at the age of 71, she cares for her husband, who was severely affected by a stroke, largely on her own. Due to the level of charges for home care, she says they cannot afford to use carers very often. Of the support they do have, she said:

> "There has been a small weekly group run by the hospital's speech and language department, constantly struggling for funding. There is also a Stroke Club, which meets once a week; I do not know how this is funded. I take my husband to both of these groups."[90]

173. Stroke clubs are one means by which survivors and carers can receive social support. Mr Robinson, a stroke survivor, submitted written evidence to the inquiry after hearing about it from his stroke club.[91]

174. The Stroke Association wrote strongly in their paper about the necessity for family support:

> "Stroke has a serious impact on the family of stroke survivors and the needs of those family members (who will often be the future carer of the stroke survivor) and must not be ignored. Voluntary sector family and carer support services are vital here. There needs to be more joined up working and closer working partnerships between everybody involved in stroke care."

175. We were not provided with evidence of the type of joined up or closer partnership working that the Stroke Association describes. However, there was some indication of other voluntary groups that might wish to be involved in providing community support. Changing Faces is a national organisation with a Welsh base in Swansea who wrote saying they have the necessary interest and expertise to assist with the psychological needs of people who have disabilities as a result of stroke.[92] The Royal National Institute for Blind People also

[90] Written evidence, HWLG(3)-20-09 Paper 11
[91] Written evidence, HWLG(3)-19-09 Paper 06
[92] Written evidence, HWLG(3)-20-09 Paper 23

demonstrated in the written evidence the depth of their knowledge of the consequences that can arise when a person's vision is affected by stroke.[93]

Recommendations

Priorities for stroke services are currently focused on the acute and secondary care stages of the patient pathway. We recommend that the Minister should increase the emphasis on community and longer-term rehabilitation and support. (Recommendation 15)

We recommend as a matter of urgency that attention is now given to the needs of those living with the after effects of stroke. This should be done through Social Services with appropriate access to housing; adaptations; benefits; social support; and through adequately resourced multi-disciplinary therapy services. (Recommendation 16)

We recommend that the Minister improve services for stroke survivors with communication difficulties to a standard that addresses unmet needs in this area. This should be done by making available additional funding to enable Health Boards to recruit the number of speech and language therapists they previously requested, and to meet the Stroke Unit Trialists Collaboration recommendations. (Recommendation 17)

[93] Written evidence, HWLG(3)-20-09 Paper 24

7. Staffing: Recruitment, Retention and Training

Introduction

176. Evidence suggests that there have been difficulties in recruiting staff at all levels and of all types, and the Minister has cited this as a factor affecting the implementation of co-located beds in some hospitals and Trusts.[94] Issues for staffing stroke services have parallels with NHS services staffing in general.

177. We heard from clinicians and others that difficulties in recruitment are complex and are related to other problems. They include a lack of funding and prioritisation for staff posts and training; a lack of developmental and research opportunities, which leads to difficulties recruiting and retaining expertise, and difficulties in recruiting in rural areas.

178. Wales has traditionally appeared to find it difficult to recruit health professionals in many geographical areas due to a lack of access to academic departments, which are clustered around Cardiff, Swansea and to an extent, Bangor.

179. A lack of prioritisation and commitment in terms of providing trainers and mentors appears to be another key issue.

Clinical staff and GPs

180. We were told by clinicians that there was not one full-time stroke specialist in Wales. Clinicians managing stroke patients are often geriatricians or physicians by training who work with stroke patients for a few sessions a week because they have developed an interest in stroke medicine. Dr Shetty said:

> "So, to start with, we do not have specialist stroke physicians, which is an important point, because the people who work in stroke are severely stretched given their other clinical commitments. The issue therefore needs to be addressed. We need to have sufficient sessions to do justice to the job."

181. In addition to this, only one registrar training post in Wales was identified by witnesses and there is, therefore, a lack of junior doctors to support clinicians, and the small number of sessions per week

[94] Oral evidence, 04.11.09

spent by clinicians on stroke medicine means there is an absence of trainers or mentors.

182. We heard from Dr Pickersgill (BMA) that there are around 22 neurologists in Wales, many of whom would be interested in managing stroke patients. He said that this could be done with some reconfiguration of the work people do and that it could be done without the requirement for additional resources.

183. In reference to the retention of staff, Dr Pickersgill said:

> "…you can retain doctors or specialists in Wales or GPs in Wales only if there are jobs for them to go into once they have finished their training."

Nurses

184. The Sentinel Stroke Audit shows that there have been improvements made in working towards achieving recommended ratios of nursing and therapy staff to patients, but Wales still lags behind England and N. Ireland.

185. The Welsh Stroke Nurse Alliance has pointed out that most Trusts now have Clinical Nurse Specialists/Stroke Co-ordinators. Their roles are often involved in developing and running the stroke services together with the physician, so it is important to recognise the need for additional nursing staff to undertake practical nursing duties. The Nurse Alliance has also said that one of the biggest issues for nurses is training. Factors which impact on this issue were that trusts are "being prudent with training budgets"; a lack of training specialism in Wales; and training having to be bought in from England.

186. However, the Open College Network has accredited a Living with Stroke Module, which has been running in one area, and the Nurse Alliance said there is a need to disseminate this more widely.

Therapists

187. There are Physiotherapists, Occupational Therapists and Speech and Language Therapists available to stroke patients in Wales, although they are not always specialised in stroke care or available in the recommended ratios to patients. There are, however, few if any of the other Stroke Unit Trialists' Collaboration (SUTC) recommended therapy and practitioner professionals that in an ideal world should

make up a multi-disciplinary team. These include professionals providing podiatry, orthotics and psychology support.

188. The All Wales Podiatrist Stroke Group suggested there were few, if any, Podiatry staffing levels in stroke service provision, and that there was a need for more use of Podiatry and Orthotics interventions at both the acute and rehabilitation phases in the stroke pathway. They pointed out in their written evidence that stroke survivors may experience many complex foot disorders that will impact on their health and well being. An example of what they can offer is:

> "A potential reduction in an extrinsic risk factor identified in falling i.e. footwear/slippers. The podiatrist will offer ongoing advice on appropriate footwear together with orthotic devices. In addition, reductions in foot pain/problems that may put them at further risk of falls."[95]

189. The mental health impact of stroke, which can cause behavioural and cognitive changes that are often the most distressing consequences of stroke for carers, is not being addressed in Wales. In their written submission, Clinical Psychologists wrote about stroke survivors:

> "One in three have significant intellectual impairments, 30% suffer from depression and a significant minority experience personality change and behavioural problems. Research shows that abnormal mood and cognitive difficulties impede rehabilitation and prolong the adjustment process. This increases the costs of rehabilitation and impact on long-term outcomes such as relationship breakdown, return to employment and childcare issues."[96]

190. Optometry Wales and the Royal National Institute for Blind People also told us about the importance of eye and vision care since strokes can cause irreparable damage meaning that patients have considerable difficulties in seeing, reading and negotiating obstacles around the home and when outside.[97]

191. The Royal College of Speech and Language Therapists (RCSLT) has identified from the unpublished Profession Specific Audit carried

[95] Written evidence, HWLG(3)-19-09 Paper 14
[96] Written evidence, HWLG(3)-19-09 Paper 21
[97] Written evidence, HWLG(3)-20-09 Paper 20

out in Wales in 2008 that the workforce in Wales is "very small".[98] The ability to communicate is vital and more than a third (30-43 per cent) of people who have strokes remain severely affected with communication disabilities in the long term. A Welsh survey conducted with survivors by the RCSLT in 2008/09 showed that 9 out of 10 people responding to the survey said their lives were strongly affected by the communication problems arising from their stroke.

192. RCSLT submitted a list of the bids that had been submitted to the Welsh Government for extra staffing throughout Wales. Although around 10 whole time equivalent (WTE) staff were sought, only 3.5 WTE staff were allocated.

193. The Chartered Society of Physiotherapy (CSP) in Wales reported that around 120 extra physiotherapists and support staff were needed to meet the requirements for physiotherapy set out in a Welsh Health Circular.[99] They also reported that training budgets remained small or frozen.

194. The College of Occupational Therapists said that not enough posts were being created to fulfill needs. They did not envisage any difficulty in filling posts if they were created, and there were issues over grading, often due to insufficient funding being allocated.[100]

195. They also said that training needs were not being met because there was insufficient funding and study leave for therapists to undertake postgraduate and higher education training, which meant that they could usually only attend short courses. The College also said that the lack of clinician sessions in Wales impacted on the ability of occupational therapists to take on research projects and, as a consequence, there were no research occupational therapists active in Wales.

196. The College provided examples of good practice in Wales, including the fact that the Welsh Stroke Alliance education sub group had created an "excellent" network to support stroke education, forging new links with the National Leadership and Innovation Agency for Healthcare and the Open College Network. The Alliance was seeking accreditation for a national stroke competence training

[98] Written evidence, HWLG(3)-16-09 Paper 02
[99] WAG. Welsh Health Circular (2007) 082 cited in HWLG(3)-15-09 Paper 3
[100] Oral evidence, 21.10.09,

programme, although they said there were issues with funding to pay trainers and backfilling staff time.

Recommendations

We recommend that each Health Board has a minimum of one clinical psychologist or psychotherapist with responsibility for stroke. (Recommendation 18)

There are insufficient training courses in Wales available across the board to professionals engaged in stroke services. We recommend that, as a starting point, this situation is addressed by ensuring that good examples of training that have been developed should be consolidated and rolled out with a core module applicable to all professions. (Recommendation 19)

We further recommend that the Minister ensures sufficient money is made available to pay trainers and deputising members of staff, and that she seeks to ensure that NHS employers fully recognise the importance of training by utilising their training budgets and giving staff the necessary study leave. (Recommendation 20)

8. Research

197. Stakeholders suggested in their evidence that not enough research was being undertaken because there were too few practitioners with too few NHS sessions.

198. Similar issues apply to training in that the low numbers of clinicians and practitioners are not conducive to individuals being able to take time off to pursue research.

199. While there were some small research projects being undertaken by individuals, there was no clinical academic post or a body of research that could potentially attract good quality medical professionals to Wales. This, it was suggested, was one of the key issues for the development of specialist multi-disciplinary teams and attracting staff.

200. While we were told that little research was being undertaken, we were made aware by individuals of the thrombolysis projects being undertaken in Swansea and Cardiff, evidence of which was also provided by the Minister.

201. We were also made aware of the Older People and Ageing Research and Development Network (OPAN) Wales Stroke Research Interest Group, which had received funding from the Welsh Government's Department of Health and Social Care's Wales Office of Research and Development (WORD). The aims of the group include providing leadership and developing a critical mass of researchers with an interest in stroke research.[101]

202. Dr Dewar said that clinicians had had discussions with the Welsh Government's Wales Office of Research and Development (WORD) for Health and Social Care to try to set up a Wales equivalent of the regional network in England, but were told there was no funding for it. Clinicians had been told by WORD that there would be some "tagging on" of research initiatives to the OPAN programme and they were sharing the co-ordinator appointed to help people at grass roots level to undertake research.

[101] Written evidence, HWLG(3)-19-09 Paper 20

Recommendation

We recommend that the Minister ensures that Wales has a framework in place with properly funded academic posts that allow academic and clinical research to be undertaken with the aim of attracting high quality health and allied professionals. (Recommendation 21)

9. Inequalities

203. This section focuses on inequalities related to age, access, Welsh and minority languages and stroke prevalence in black and minority ethnic (BME) people, which are apparent in the provision of services for stroke.

204. It has been mentioned earlier in the report that more younger people are presenting with stroke, and that the service is currently failing to respond adequately to their needs. Younger stroke patients may have to make massive changes to their lives, which can take a long time to come to terms with. The youngest patient seen by Dr Dewar was 15 years of age. The College of Occupation Therapists said there are hardly any services for younger stroke survivors and that this group in particular need focused occupational therapy, vocational rehabilitation and community follow-up to enable them to achieve life goals.

205. At the same time, carers and stroke survivors have expressed fears that older people and those with severe stroke are not given the same level of therapy and interventions that they perceive are given to younger patients and those whose strokes have had less impact.

206. Inequality of access, which affects many services in the NHS, is apparent in rural areas and more specifically, Pembrokeshire, Powys, and NW Wales. Age Concern Cymru also highlighted unequal access to transport and hospitals in rural areas in their submission:

> "Transport and accessibility of services such as rehabilitation and outpatient services are also a significant issue for older people who have suffered a stroke. The reorganisation of the NHS and development of related strategies such as the rural health plan need to tackle problems accessing specialist services such as these in rural areas of Wales."[102]

207. Attention has also been drawn elsewhere in this report to the fact that people who are admitted to general wards as opposed to wards where there are specific stroke therapies and rehabilitation do not always get continuing therapy once they leave hospital.

[102] Written evidence, HWLG(3)-20-09 Paper 26

208. It has been suggested that those who have more severe strokes may not get the same levels of therapy as those who have more minor strokes even though therapy might improve their quality of life.

209. No information was given about the incidence of stroke in the black and minority ethnic (BME) population. However, in their written submission, ASH Wales provided us with a link to their website and this included a factsheet which stated:

> "Although Black Caribbean people have a lower risk of coronary heart disease they have a higher risk of stroke. The 2004 Health Survey for England found that among respondents aged 55 and over Black Caribbean men had the highest prevalence (11.5%) of stroke while among women aged 55 and over the highest prevalence was among Bangladeshi (11.9%) and Pakistani (10.1%) respondents.[103]"

210. No specific information was provided on issues relating to treatment or therapy being unavailable in Welsh or any of the languages that are spoken in minority ethnic communities in Wales, but we are aware that levels of Welsh-speaking NHS staff and those with languages other than English and Welsh are low.

211. We felt this was particularly important given that it is a known fact that stroke survivors who speak English as a second language often revert to their first language as a consequence of a stroke. We were told that communication with people from ethnic communities often has to be done through family members and this is not the most satisfactory way of communicating.

212. We did not find out during the inquiry what impact a stroke might have for deaf people who use sign language, but it is known that there is a body of research on this. Although we, unfortunately, did not discover how the Speech and Language Therapy service responds to this need, and to the needs of deaf people who do not sign, we would wish to raise this in the report.

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[103]Action on Smoking and Health, Factsheet No.26 *Tobacco and Ethnic Minorities*, August 2006.

Recommendations

We recommend that the needs of younger stroke survivors are addressed in stroke policy documents and that all stroke patients, regardless of their age or severity of their stroke, receive rehabilitation appropriate to their needs. (Recommendation 22)

We recommend that Health Board stroke plans must reflect fully the aspirations of the Rural Health Plan by providing in those areas the same access to stroke services and resources that are available elsewhere in Wales. We are specifically concerned that issues relating to Emergency Care and access to thrombolysis,[104] and to the need stroke patients might have to communicate through the Welsh Language,[105] are addressed. (Recommendation 23)

We recommend that policy initiatives to raise awareness of stroke risk among certain black and minority ethnic groups who are at a higher risk than other population groups, are incorporated into strategic documents. (Recommendation 24)

We recommend that Government documents and Health Boards include plans to manage issues of first language reversion in those whose first spoken language is Welsh or other non-English language, and for deaf people who use sign language.[106] (Recommendation 25)

[104] Welsh Government, *Rural Health Plan*, 14.12.09, p.27, para. 2.4.1.6.
[105] Ibid., p.45, paras 3.5.7. - 3.5.9
[106] ESRC Deafness, Cognition and Language Research Centre, http://www.dcal.ucl.ac.uk/Research/Handedness_deaf_stroke.html

Annex A - Witnesses

The following witnesses provided oral evidence to the Committee on the dates noted below. Transcripts of all oral evidence sessions can be viewed in full at http://www.assemblywales.org/bus-home/bus-committees/bus-committees-scrutiny-committees/bus-committees-third-hwlg-home.htm

11 June 2009

Dr Anthony Rudd	Consultant Physician in Stroke Medicine

18 June 2009

Wendy Davies	The Stroke Association
Leighton Veale	The Stroke Association
Dr Richard Dewar	Consultant Stroke Physician
Philippa Ford	Chartered Society of Physiotherapy
Tudor Smith	Chartered Society of Physiotherapy
Maggie Webster	Chartered Society of Physiotherapy

25 June 2009

Dr Hamsaraj Shetty	Regional Stroke Unit Cardiff
Dr Alison Stroud	Royal College of Speech and Language Therapists
Natalie Elliott	Royal College of Speech and Language Therapists
Howard Bale	Royal College of Speech and Language Therapists

23 September 2009

Dr Anne Freeman	Chair, Welsh Stroke Alliance
Dr Tom Hughes	Welsh Stroke Alliance

Dr Mushtaq Wani	Welsh Stroke Alliance
Dr Trevor Pickersgill	British Medical Association, Wales
Lisa Turnbull	Policy Advisor, Royal College of Nursing
Lynne Darcy	Royal College of Nursing
Michelle Graham	Acting Chair, Welsh Stroke Nurses Alliance
Kylie Crook	Welsh Stroke Nurses Alliance
21 October 2009	
Kjell Asplund	Riks Stroke Register
Bo Norrving	Riks Stroke Register
Janet Ivey	College of Occupational Therapy
Ruth Crowder	College of Occupational Therapy
Deborah Pawsey	College of Occupational Therapy
Andrew Jenkins	Consultant Paramedic, Welsh Ambulance Service Trust
4 November 2009	
Edwina Hart AM	Minister for Health and Social Services
Paul Williams	Director General, Health and Social Services
Simon Dean	Director, Strategy and Planning, Health and Social Services

Annex B - Written evidence

The following people and organisations provided written evidence to the Committee in support of oral evidence. All written evidence can be viewed in full at http://www.assemblywales.org/bus-home/bus-committees/bus-committees-scrutiny-committees/bus-committees-third-hwlg-home.htm

Name	*Organisation*	*Reference*
Committee Service	National Assembly for Wales	HWLG(3)-14-09 : Paper 1
Dr Anthony Rudd	Consultant Physician in Stroke Medicine	HWLG(3)-14-09 : Paper 3
Wendy Davies	The Stroke Association	HWLG(3)-15-09 : Paper 1
Leighton Veale	The Stroke Association	HWLG(3)-15-09 : Paper 1
Dr Richard Dewar	Royal Glamorgan Hospital	HWLG(3)-15-09 : Paper 2
Philippa Ford	Chartered Society of Physiotherapy	HWLG(3)-15-09 : Paper 3
Tudor Smith	Chartered Society of Physiotherapy	HWLG(3)-15-09 : Paper 3
Maggie Webster	Chartered Society of Physiotherapy	HWLG(3)-15-09 : Paper 3
Dr Hamsaraj Shetty	Regional Stroke Unit Cardiff	HWLG(3)-16-09 : Paper 1
Dr Alison Stroud	Royal College of Speech and Language Therapists	HWLG(3)-16-09 : Paper 2
Natalie Elliott	Royal College of Speech and Language Therapists	HWLG(3)-16-09 : Paper 2

Howard Bale	Royal College of Speech and Language Therapists	HWLG(3)-16-09 : Paper 2
Dr Anne Freeman	Chair, Welsh Stroke Alliance	HWLG(3)-19-09 : Paper 01
Dr Tom Hughes	Welsh Stroke Alliance	HWLG(3)-19-09 : Paper 01
Dr Mushtaq Wani	Welsh Stroke Alliance	HWLG(3)-19-09 : Paper 01
Dr Trevor Pickersgill	British Medical Association, Wales	HWLG(3)-19-09 : Paper 02
Lisa Turnbull	Policy Advisor, Royal College of Nursing	HWLG(3)-19-09 : Paper 03
Lynne Darcy	Royal College of Nursing	HWLG(3)-19-09 : Paper 03
Michelle Graham	Acting Chair, Welsh Stroke Nurses Alliance	HWLG(3)-19-09 : Paper 04
Kylie Crook	Welsh Stroke Nurses Alliance	HWLG(3)-19-09 : Paper 04
Philippa Ford	Chartered Society of Physiotherapy	HWLG(3)-19-09 : Paper 22
Kjell Asplund	Riks Stroke Register	HWLG(3)-22-09 : Paper 01
Bo Norrving	Riks Stroke Register	HWLG(3)-22-09 : Paper 01
Janet Ivey	College of Occupational Therapy	HWLG(3)-22-09 : Paper 02
Ruth Crowder	College of Occupational Therapy	HWLG(3)-22-09 : Paper 02
Deborah Pawsey	College of Occupational Therapy	HWLG(3)-22-09 : Paper 02

Andrew Jenkins	Consultant Paramedic, Welsh Ambulance Service Trust	HWLG(3)-22-09 : Paper 03
Edwina Hart AM	Minister for Health and Social Services	HWLG(3)-23-09 : Paper 1
Paul Williams	Director General, Health and Social Services	HWLG(3)-23-09 : Paper 1
Simon Dean	Director, Strategy and Planning, Health and Social Services	HWLG(3)-23-09 : Paper 1
	Committee Service	HWLG(3)-01-10 : Paper 4 (Private Paper)
	Committee Service	HWLG(3)-03-10 : Paper 4 (Private Paper)
	Committee Service	HWLG(3)-03-10 : Paper 5 (Private Paper)
	Committee Service	HWLG(3)-04-10 : Paper 1 (Private Paper)
	Committee Service	HWLG(3)-04-10 : Paper 2 (Private Paper)

Annex C - Consultation Responses

The following people and organisations provided written evidence to the Committee as part of its public consultation. All consultation responses can be viewed in full at:

http://www.assemblywales.org/bus-home/bus-committees/bus-committees-scrutiny-committees/bus-committees-third-hwlg-home/business-hwlg-inquiries/hwlg_stroke_services/hwlg_3_stroke_services-call_for_evidence/hwlg_3_-stroke.htm

Name	*Organisation*	*Reference*
Dave Bowles		HWLG(3)-SSW-001
Andrew Misell	Diabetes UK Cymru	HWLG(3)-SSW-002
Mike Brain		HWLG(3)-SSW-003
Glynn Robinson		HWLG(3)-SSW-004
Dr Mushtaq Wani		HWLG(3)-SSW-005
Dave Pitman		HWLG(3)-SSW-006
Mrs G L Probert		HWLG(3)-SSW-007
Ronald Smith		HWLG(3)-SSW-008
Dr T A T Hughes		HWLG(3)-SSW-009
	All Wales Podiatrists Stroke	HWLG(3)-SSW-

	Group	010
E F Gardner		HWLG(3)-SSW-011
	All-Wales Podiatrists and Orthotists Stroke Action Group	HWLG(3)-SSW-012
Andrea Grace		HWLG(3)-SSW-013
Dr Ailsa Dunn		HWLG(3)-SSW-014
Martyn Pengilley	Crossroads Care	HWLG(3)-SSW-015
Older People and Ageing Research and Development Network (OPAN Wales)	OPAN Stroke Research Interest Group	HWLG(3)-SSW-016
Dr Julie Wilcox and Dr Tanya Edmonds	Consultant Clinical Psychologists	HWLG(3)-SSW-017
Mrs Turley		HWLG(3)-SSW-018
M.W. Payne		HWLG(3)-SSW-019
Elaine Morgan		HWLG(3)-SSW-020
Joyce Watson AM		HWLG(3)-SSW-021
Marlene Moore		HWLG(3)-SSW-022
	British Society of	HWLG(3)-SSW-

	Gerodontology, British Society for Disability and oral Health and the All Wales Special Interest Group for Special; Oral Health Care	023
Dr Amer Jafar		HWLG(3)-SSW-024
Rona Howells		HWLG(3)-SSW-025
	ASH Wales	HWLG(3)-SSW-026
	British Geriatrics Society Cymru Wales	HWLG(3)-SSW-027
	Optometry Wales	HWLG(3)-SSW-028
	Gwent Healthcare NHS Trust	HWLG(3)-SSW-029
	Changing Faces	HWLG(3)-SSW-030
	RNIB Cymru	HWLG(3)-SSW-031
	The College of Occupational Therapists	HWLG(3)-SSW-032
	Age Concern Cymru and Help the Aged in Wales	HWLG(3)-SSW-033
	British Dietetic Association	HWLG(3)-SSW-034
Chris Franks AM		HWLG(3)-SSW-035
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Age Concern Ceredigion	HWLG(3)-SSW-038
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