Y Pwyllgor Iechyd a Gofal Cymdeithasol
Helath and Social Care Committee

Cynulliad Cenedlaethol Cymru
National Assembly for Wales

Mark Drakeford AM
Minister for Health and Social Services

9 January 2014

Dear Minister,

You will be aware of the Health and Social Care Committee's stated intention to return to the inquiries it has undertaken during the course of the Fourth Assembly to assess the progress made in implementing the Committee's recommendations and to identify any further steps necessary to ensure their delivery.

The first inquiry in this programme of follow-up work relates to stroke risk reduction. The Committee reported on this subject in December 2011, focussing on the provision of stroke risk reduction services and the implementation of the Welsh Government's Stroke Risk Reduction Action Plan. Key issues identified during the Committee's 2011 inquiry included:

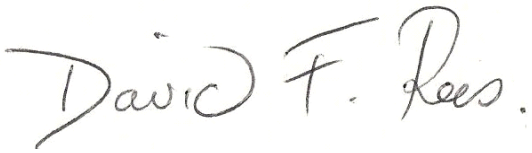
- concerns around the implementation, leadership, management and monitoring of the Stroke Risk Reduction Action Plan;
- a need for an improved emphasis on preventing strokes following a transient ischaemic attack (TIA) or initial stroke;
- a clear need for improvements in the identification and treatment of atrial fibrillation; and
- a greater need for professional and public awareness of stroke and its causes.

The Committee made five recommendations in its report and noted its intention to return to the subject within two years. To this end, during summer 2013, the Committee invited all those who gave evidence to the original inquiry to provide an update on progress, and held an oral evidence session on 23 October. We are grateful to you and your officials for your contribution to this session.

In light of the follow-up evidence received, we have identified a number of key areas in which we believe further work is necessary. Further detail about these areas is provided in the annex to this letter. In undertaking our follow up work on inquiries, we do not intend to publish supplementary reports and a series of additional recommendations; rather, it is our intention to ensure that our original recommendations are implemented where accepted and that the Welsh Government is held to account for progress – or lack thereof – in the subject areas considered by the Committee.

To this end, we wish to make one clear recommendation following our follow-up session on the stroke risk reduction inquiry: given the lack of clear progress in some areas, the Committee recommends that the Welsh Government publish a timetable within 6 weeks of receipt of this letter clearly setting out when it expects to fully deliver the Committee's recommendations, all of which it accepted – at least in principle – in December 2011. Following the publication of the recommended timetable, and the provision of the additional information requested in the annex to this letter, the Committee will return to this subject to ensure that progress continues to be made in relation to stroke risk reduction.

Yours sincerely,



David Rees AM
Chair, Health and Social Care Committee

ANNEX: Key issues arising from the 2013 follow-up inquiry on stroke risk reduction

Introduction

The Health and Social Care Committee reported on its stroke risk reduction inquiry in December 2011.[1] The focus of the inquiry was to examine the provision of stroke risk reduction services, specifically the implementation of the Welsh Government's Stroke Risk Reduction Action Plan. In its report, the Committee noted its intention to return to the subject within two years to examine the progress made in implementing its recommendations.

The Welsh Government's response to the Committee's report was published in January 2012.[2] In December 2012, the Welsh Government published its Stroke Delivery Plan for the NHS up to 2016.[3]

This annex does not seek to rehearse every issue that arose during the Committee's 2011 inquiry into stroke risk reduction. Rather, its purpose is to highlight the areas in which the Committee believes further work is still needed, two years on from its original inquiry. These are issues that were drawn to the Committee's attention during the follow-up evidence session on 23 October 2013, a full record of which can be found **here**. All written evidence submitted to the follow up inquiry can be accessed **here**.

1. Leadership and the role of a national clinical network

A clear theme emerging in evidence submitted to the Committee's follow up inquiry was concern about an alleged lack of national leadership and accountability to ensure implementation of the Welsh Government's Stroke Delivery Plan. There was strong support in written and oral evidence for the establishment of a national clinical network for stroke to drive improvements in stroke services.

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[1] More information about the Committee's original inquiry can be found at: **http://www.senedd.assemblywales.org/mgIssueHistoryHome.aspx?IId=1531** [accessed 2 December 2013]

[2] Welsh Government, ***Response to the HSC Committee's inquiry on Stroke Risk Reduction***, 1 February 2012 [accessed 2 December 2013]

[3] Ibid, ***Together for Health: Stroke Delivery Plan for the NHS up to 2016***, [accessed 2 December 2013]

Dr Anne Freeman of the Welsh Stroke Alliance (WSA) pointed out that cancer, cardiac disease and stroke are the biggest killers in the UK and the world, and whilst Wales has such a network for cancer and cardiac disease, there is no similar network to support stroke service development. Dr Freeman suggested that the WSA itself, with appropriate resourcing, could form an almost 'ready-made' network. The Stroke Association supported this suggestion.

> "… the Welsh Stroke Alliance as a clinical advisory group has, I think, a very strong base to be able to develop into a network. What we would have to really work on […] is bringing the missing partners to the table."[4]

Witnesses from Health Boards and Public Health Wales (PHW) agreed that there was a need for a more coordinated approach to stroke service improvement, and that a national clinical network could have a role to play here:

> "… such a network could be very good at co-ordinating our efforts and helping us to develop a national infrastructure for some of the things that do not necessarily need a lot of money but which could assist us. If we are talking about public awareness campaigns, it would be great to integrate and co-ordinate things, so that anything going on nationally is supported locally and vice versa and so that you get the momentum there."[5]

Nigel Monaghan (PHW) questioned whether, as stroke could be regarded as a cardiovascular event, the cardiac network should be supporting stroke out of existing resources:

> "The rest of us seem to have to do more with less. Asking the cardiac network to support the stroke network would be one way of addressing this."[6]

The Committee requested further information from Health Board and PHW witnesses on the costs associated with running a managed, clinical network (such as the cancer/cardiac networks). Information subsequently provided by Aneurin Bevan Health Board set out the following costs:

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[4] National Assembly for Wales, Health and Social Care Committee, ***Record of Proceedings [para 31]***, 23 October 2013 [accessed 2 December 2013]
[5] Ibid ***[para 179]***
[6] Ibid ***[para 182]***

"Cardiac Network Funding

The annual funding for the South Wales Cardiac Network, agreed in 2011/12 by the Welsh Assembly Government, is £326,226 pa.

The annual funding for the North Wales Cardiac Network, agreed in 2011/12 by the Welsh Assembly Government, is £157,311 pa.

This funding covers the employment and functioning of the Network core team of employed staff and clinical leads, together with non-staff Network costs. There is no specific funding for service developments or improvement initiatives. Since reorganisation in July 2011 the funding for the South Wales Network has been included within Aneurin Bevan Health Board budget.

Cancer Network Funding

The core annual funding for the South Wales Cancer Network, agreed in 2011/12 by the Welsh Assembly Government, is £368,000 pa.

The annual funding for the North Wales Cancer Network, agreed by the Welsh Assembly Government, is £125,000 pa.

This funding covers the employment and functioning of the Networks core teams of employed staff and clinical leads, together with non-staff Network costs. There is no specific funding for service developments or improvement initiatives which is sought through business case or bidding processes to number sources. Since reorganisation in 2011 the funding for the South Wales Network has been included within the Abertawe Bro Morgannwg University Health Board budget."[7]

Additional information provided by the WSA stated "We do not necessarily think that a link with a cardiac or neurosciences network would service the needs of our stroke patients. However, linking with a proposed vascular (surgery) network could work extremely well." It also suggested how a stroke network should be structured:

> "The Network Core Team would lead, co-ordinate and facilitate the activities of the Network, and will consist of:
>
> i) A National Clinical Lead for Stroke / Chair (p/t)

[7] National Assembly for Wales, Health and Social Care Committee, ***Additional information submitted following the oral evidence session on 23 October***, 21 November 2013 [accessed 2 December 2013]

ii) A National Nursing Lead for Stroke (p/t))

iii) A National Therapy Lead for Stroke (p/t)

iv) A National Primary Care Lead for Stroke (GP p/t)

v) A National Stroke Network Manager (f/t)

vi) A Network Support Officer (f/t)

vii) Other clinicians (e.g. National Vascular lead) may be co-opted to undertake specific pieces of work as appropriate.

This team will provide the core support to the Network in delivering against its priorities. It will be supplemented by other skills and resources required to deliver the Network agenda through the flexible use of co-opted expertise. This may include analytical skills, audit support, training and education, or external clinical advice."[8]

The Minister for Health and Social Services indicated that he would give consideration to the need for a national clinical network for stroke, but referred to work underway to examine the effectiveness of the current pattern of networks:

> "I am certainly not saying that we are not going to do it, but if we do it, I want it to be done against a landscape where the advice and the way in which these networks work is clearer, simpler and therefore more effective than is sometimes the case, I believe, at the moment."[9]

The Committee's view: There is clearly strong support for a national clinical network for stroke to be established, and a consensus amongst witnesses that the Welsh Stroke Alliance could form such a network if resourced appropriately. Whilst welcoming the Minister's intention to consider a stroke network in the context of work underway to examine the pattern and effectiveness of networks more generally, the Committee would urge the Government to undertake this examination with pace so that concerns regarding a lack of leadership and accountability in this area are addressed quickly. The Committee asks that the Minister includes a timetable for the completion of the work on clinical networks within the wider timetable requested in our letter above.

[8] National Assembly for Wales, Health and Social Care Committee, ***Additional information submitted following the oral evidence session on 23 October***, 21 November 2013 [accessed 2 December 2013]

[9] Ibid, ***Record of Proceedings [para 280]***, 23 October 2013 [accessed 2 December 2013]

2. Data collection – a stroke register for Wales?

Evidence highlighted a lack of reliable data on stroke patients and care, and some witnesses suggested the need for a 'stroke register' as exists in other parts of the UK. The Stroke Association told the Committee:

> "We are not really working in the full light – our eyes are half-closed, and we are guessing. The data that are coming out, even from the Welsh Government, are not necessarily that robust. So, we need to do some work on a very basic level to be able to understand where we are at and start measuring against the aspirations that each of these plans has had."[10]

Dr Amer Jafar, representing BMA Cymru Wales, emphasised the need for a stroke register:

> "On data collection, we need a stroke register in Wales. We do not have one. England has a very good and comprehensive one. Scotland has a very good and comprehensive one. We need a stroke register – a database or software to catch every single TIA and stroke patient in Wales."[11]

In response, the Welsh Government's Deputy Chief Medical Officer, Dr Chris Jones, stated that – in developing the Stroke Delivery Plan – the need for a stroke register was not raised. He went on to note that this might be a consideration for the Plan's multi-agency implementation group, chaired by Adam Cairns, Chief Executive of Cardiff and Vale University Health Board.[12]

In relation to TIA services, Dr Freeman (WSA) suggested that, at the moment, there is no way of monitoring whether all TIA patients are seen within the target timescales. She did note that, next year, the Royal College of Physicians is planning to run spotlight audits for TIA services. Witnesses described the TIA care bundle approach (part of 1000 Lives Plus) which is used locally by Health Boards as an improvement tool. Some data is therefore available locally, but is not submitted to the Delivery and Support Unit in the way that information relating to acute stroke would be. Dr Jafar (BMA) highlighted the need for an audit of TIA services:

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[10] National Assembly for Wales, Health and Social Care Committee, ***Record of Proceedings [para 45]***, 23 October 2013 [accessed 2 December 2013]
[11] Ibid ***[para 230]***
[12] Ibid ***[para 256]***

> "… we are far away from 7/7 provision [of a TIA service]. As to how we can achieve it […] there should be a group to supervise and study this problem based on numbers and figures. You need statistics to support your conclusion, then you attack the problem, and sort it out."[13]

Other data issues identified included that Welsh participation in the clinical audit relating to carotid surgery remains low, and that an audit tool (part of the 1000 Lives plus primary care programme for atrial fibrillation) is available to GP practices in Wales but use of this is not mandatory.

The Committee's view: It is clear from our inquiry and the follow-up work undertaken that data on stroke patients and their care is inadequate. This data is needed to inform service developments. Participation in clinical audits is too low to provide an accurate picture of performance and, although some data may be held locally (e.g. about transient ischaemic attack and atrial fibrillation), it appears that it is not routinely reported or shared. The issues of inadequate data collection/sharing – and lower than desirable participation in clinical audit – are not unique to this inquiry. The Committee recommends that work is undertaken with pace to improve data collection, facilitate the sharing of data, and increase participation in clinical audits as part of the roll out of the Stroke Delivery Plan. Furthermore, we recommend that consideration is given to the development of a stroke register for Wales.

3. Stroke workforce

Concerns were raised in evidence as to whether there are adequate numbers of appropriately trained, specialist staff to deliver the required improvements in stroke services.

Witnesses explained how the majority of stroke physicians in Wales are geriatricians who have a special interest in stroke. Dr Hamsaraj Shetty of the WSA described the need for stroke specialists:

> "The important thing to recognise is that there has been a tremendous amount of research and developments that have happened in the last 15 years in the field of stroke. Now, it is a truly specialist subject. If stroke and TIA patients are seen by a general physician, we have seen

[13] National Assembly for Wales, Health and Social Care Committee, ***Record of Proceedings [para 218]***, 23 October 2013 [accessed 2 December 2013]

> in our own practice that 60% of the time the diagnosis is wrong or the GP is dealing with something else that is not stroke. Stroke and TIA have great mimics. It is difficult for a non-specialist to pick up TIA, in particular, and that is a valuable opportunity to prevent a catastrophic disease."[14]

Evidence from the WSA highlighted difficulties in recruiting stroke specialists to work in Wales. It was noted, however, that four new stroke speciality training posts have now been created here. The Committee was told that no such posts were available prior to 2012, and it was hoped that this would address some of the recruitment issues by training clinicians in Wales that are more likely to stay in Wales.[15]

Dr Freeman (WSA) referred to work carried out by the British Association of Stroke Physicians (BASP) which, she stated, shows that Wales needs 18 full-time stroke physicians to deliver a quality service along the whole care pathway. Some witnesses described a shortfall in the number of stroke physicians in Wales, though it was not clear in evidence heard by the Committee exactly what this shortfall is.

Dr Amer Jafar, representing the BMA, suggested that a greater number of specialist registrars could be trained in stroke medicine.

> "We have a very good number of speciality and associated specialist doctors in geriatrics. Associated specialist doctors are very well trained; they are doctors with high degrees and qualifications. We need to use their skills in stroke medicine as well. So, that is the Welsh conclusion and our solution to the problem of having a low number of stroke physicians."[16]

Witnesses from the RCN highlighted that there are no consultant nurses for stroke in Wales, and that there is a need for specialist nurses at this strategic level.[17]

Dr Shetty (WSA) highlighted that stroke and TIA should be part of on-going training for all relevant health professionals, and that this would, for example, lessen the likelihood of missing a diagnosis.

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[14] National Assembly for Wales, Health and Social Care Committee, ***Record of Proceedings [para 22]***, 23 October 2013 [accessed 2 December 2013]
[15] Ibid ***[para 38]***
[16] Ibid ***[para 208]***
[17] Ibid ***[para 198]***

In written evidence, the WSA called for a workforce analysis to be carried out – including all key staff involved in stroke care – to identify areas where there are shortfalls, and for plans to address those gaps to be put in place.

Responding to witnesses' concerns about a lack of stroke specialists in Wales, the Minister referred to Professor David Greenaway's Shape of Training[18] review. One of the key messages in the final report, published on 29 October 2013, is the need for more doctors who are capable of providing general care in broad specialties across a range of different settings. This is being driven by a growing number of people with multiple co-morbidities, an ageing population, health inequalities and increasing patient expectations:

> "A move towards a medical workforce with a broader approach to patient care will mean more doctors will be capable of working in rural and isolated areas. With a bigger recruitment pool, these areas should be able to attract more doctors."[19]

The Minister also referred to evidence showing that between 20 and 70 per cent of work done by clinicians could actually be done by advanced practitioner nurses, with the appropriate training and experience.

> "I think that there is a wider pattern of workforce reform that we may need in this area to deliver the service that we need to deliver."[20]

The Committee's view: The Committee notes that one of the key themes of the Greenaway review of medical training is a shift in balance away from specialism towards a more generalist approach. The Committee would welcome further information from the Minister on how he intends to consider the stroke workforce within this context, and what specific action he is taking to ensure there are sufficient numbers of adequately-trained clinicians to deliver quality stroke services in the short, medium and long-term.

[18] ***Securing the future of excellent patient care: Final report of the independent review Led by Professor David Greenaway***, 29 October 2013 [accessed 2 December 2013]
[19] Ibid, p27
[20] National Assembly for Wales, Health and Social Care Committee, ***Record of Proceedings [para 254]***, 23 October 2013 [accessed 2 December 2013]

4. Access to TIA services

The Committee heard that the majority of Health Boards are able to operate Monday to Friday TIA clinics, and provide access to a medical assessment unit for TIA patients at weekends. Dr Freeman (WSA) stated that Betsi Cadwaladr University Health Board (BCUHB) is not currently able to meet this requirement. Dr Jafar (BMA) agreed that there were particular difficulties in the BCUHB area:

> "In north Wales, we even have a problem providing a five-day-a-week TIA service. Sometimes, we do not have a TIA clinic in certain hospitals."[21]

The Minister stated that access to TIA services had improved in Wales:

> "We are reasonably confident that, across Wales, although not in every site, because we cannot possibly do it on that basis, but, in every LHB, there is a service that allows the people who are the urgent end of TIA to be seen on a seven-day-a-week basis, and the low-risk people to be seen on a five-day-a-week basis."[22]

When challenged on witnesses' evidence that this was not happening in BCUHB, the Minister stated that this had been picked up by the Delivery and Support Unit and corrective action was being taken.

The Committee's view: It is a matter of concern to the Committee that, nearly 18 months after the Government's published expectation, access to TIA services is not uniform across Wales. We would welcome further detail about what corrective action is being taken in North Wales to address the delays in the Betsi Cadwaladr area, and seek detail from the Minister – as part of the timetable requested in our letter above – about when services will be available across the whole of Wales within target timescales. Furthermore, we seek an indication of what action the Minister will take if Health Boards fail to meet these targets by the deadlines outlined in his forthcoming response to this letter.

[21] National Assembly for Wales, Health and Social Care Committee, ***Record of Proceedings [para 225]***, 23 October 2013 [accessed 2 December 2013]
[22] Ibid ***[para 242]***

5. Carotid surgery

The Welsh Stroke Alliance reported that there were still delays in getting access to timely carotid intervention, including delays between symptom onset and referral, and from referral to surgery.

The Minister agreed with witnesses that insufficient progress has been made in improving adherence to clinical guidelines relating to carotid endarterectomy. Additionally, Welsh participation rates in the Royal College of Surgeons' carotid endarterectomy audit[23] have been disappointing.

Dr Chris Jones, Deputy Chief Medical Officer, noted that the audit report may not provide an accurate picture of performance:

> "… the largest vascular surgery unit, in Cardiff and Vale, was not contributing to this audit at the time, which was a problem, and its performance is excellent. I am pleased to report to the committee now that they are all online and engaged and uploading their data. So, the true situation is better, I can tell you in truth, than it appears in the publications to date."[24]

Dr Jones also described work underway to improve participation in national clinical audits, including the setting up of a national clinical audit advisory group responsible for overseeing Health Boards' engagement in the audit process.

The Committee's view: The Committee concludes that insufficient progress has been made in improving adherence to clinical guidance relating carotid endarterectomies since the Committee reported two years ago. The Committee would welcome clarification from the Minister of the target timescales within which he expects patients to receive carotid intervention, and confirmation of the deadline by which he expects Health Boards to meet these targets. The Committee seeks an indication of what action the Minister will take if Health Boards do not meet the expectations he outlines in this regard.

[23] Royal College of Surgeons England, ***Carotid Endarterectomy Audit***, October 2013 [accessed 2 December 2013]
[24] National Assembly for Wales, Health and Social Care Committee, ***Record of Proceedings [para 246]***, 23 October 2013 [accessed 2 December 2013]

6. Atrial fibrillation

Written evidence received by the Committee suggested the lack of a consistent approach to manual pulse checks and detecting atrial fibrillation (AF) in primary care, and a need for clear guidance on professional responsibilities remains. It was not clear in oral evidence exactly what progress has been made in identifying and treating AF in Wales.

Witnesses referred to the 1000 Lives plus primary care programme for AF, although it was noted that participation is voluntary and wider use should be encouraged.

Dr White and Dr Jafar (BMA) described how there are two different types of AF, only one of which might be detected through a manual pulse check. Dr White highlighted difficulties in accessing five day 'holter monitors' in North Wales, which can be used to detect paroxysmal AF.

Nigel Monaghan (PHW) made the point that although NICE recommends opportunistic screening, the UK National Screening Committee (UK NSC) is currently considering whether screening for AF should be carried out. At the time of writing, it is understood that the UK NSC will publish its draft review and recommendations for consultation in December 2013.

On screening for AF, the Minister stated:

> "… for anybody going into a GP surgery with the telltale signs that put them in an at-risk group for stroke, pulse checking should be a routine matter. After that, our belief, and I think the committee's conclusion last time, is that you have to try to do it on an opportunistic basis. You have to take all the chances that there are in the system for this to happen, rather than to have a pulse-checking screening programme."[25]

Paul Underwood of the Stroke Association highlighted that such an approach will not capture all those at risk:

> "GPs are fully aware of their registered population and are incentivised to manage the co-morbidities of their registered populations. The challenge is members of the population who do not attend their GPs

[25] National Assembly for Wales, Health and Social Care Committee, ***Record of Proceedings [para 265]***, 23 October 2013 [accessed 2 December 2013]

and are walking around with high blood pressure, irregular pulses and AF risks."[26]

The Committee's view: It is not clear what progress has been made in the identification, treatment and management of AF. Furthermore, it appears that a consistent approach to providing manual pulse checks in primary care is lacking. A more strategic and coordinated development of methods to identify and treat AF in line with published NICE guidance, across primary and secondary care, is needed – this should include consideration of those who cannot be identified by a simple pulse check alone. The Committee awaits the outcome of the UK National Screening Committee's review of screening for AF.

7. Public awareness

Evidence received during the follow-up inquiry highlighted the need for improved public awareness of the risk factors for stroke, including lifestyle factors as well as AF and TIA.

Ana Palazon from the Stroke Association referred to the FAST campaign[27] (which identifies the most common symptoms of a stroke) as one of the most successful UK health campaigns ever, but noted that this is not maintained throughout the year:

> "FAST and TIA should be prominent in the public domain and across the age spectrums, in education, schools, universities et cetera – they all have a role to play in this. It is not just the NHS."[28]

Examples of other public awareness campaigns cited included:

- joint work between the Stroke Association, the Welsh Stroke Alliance and the Welsh Ambulance Services Trust looking at displaying key messages relating to FAST and TIA on the side of ambulances.

[26] National Assembly for Wales, Health and Social Care Committee, ***Record of Proceedings [para 85]***, 23 October 2013 [accessed 2 December 2013]
[27] Stroke Association, ***Act FAST: Recognise the symptoms of a stroke*** [accessed 2 December 2013]
[28] National Assembly for Wales, Health and Social Care Committee, ***Record of Proceedings [para 115]***, 23 October 2013 [accessed 2 December 2013]

- a small Stroke Association pilot in partnership with a pharmacy chain to encourage people to go into pharmacies for a blood pressure and pulse check.
- the nationwide stroke awareness campaign delivered through community pharmacies in Wales in May 2013. Pharmacies provided advice on lifestyle changes to reduce risk of stroke, and prioritised medicines use review (MUR) consultations for people taking blood pressure or anticoagulant medication.

Questioned on the value of the national public health campaign, the Minister said:

> "… a lot of it was about consciousness raising and awareness raising – it had some good coverage in the media and so on during that week. It was of direct benefit to those 10,000 and more patients who came forward for an MUR during that week."[29]

The Minister stated that it should be possible to carry out further analysis to assess whether MURs themselves have an impact on the risk of stroke.

The Committee's view: There remains a need to increase public awareness of stroke risk factors, including AF and TIA. The value of community pharmacy campaigns in raising awareness and identifying people at risk of stroke is something the Committee has previously highlighted and the need for successful campaigns (such as FAST) to be sustained is clear. The Committee would welcome an indication from the Minister as to what plans there are for further action to increase public awareness of stroke risk and prevention (as well as the symptoms of stroke), and whether any specific work is underway to target young people as well as older generations.

Next steps

The Committee would welcome a response from the Welsh Government to the key issues raised in this annex. Furthermore, given the lack of clear progress identified in some areas covered by our original inquiry, the Committee recommends that the Welsh Government publish a timetable clearly setting

[29] National Assembly for Wales, Health and Social Care Committee, ***Record of Proceedings [para 276]***, 23 October 2013 [accessed 2 December 2013]

out when it expects to fully deliver the Committee's recommendations, all of which it accepted – at least in principle – in December 2011. Following the publication of the recommended timetable, and the provision of the additional information requested in this annex, the Committee will return to this subject to ensure that progress continues to be made in relation to stroke risk reduction.