



Cynulliad Cenedlaethol Cymru **The National Assembly for Wales**

Y Pwyllgor Iechyd a Gofal Cymdeithasol **The Health and Social Care Committee**

Dydd Iau, 22 Medi 2011
Thursday, 22 September 2011

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Cofnodir y trafodion hyn yn yr iaith y llefarwyd hwy ynddi yn y pwyllgor. Yn ogystal, cynhwysir cyfieithiad Saesneg o gyfraniadau yn y Gymraeg. Mae hon yn fersiwn ddrafft o'r cofnod. Cyhoeddir fersiwn derfynol ymhen pum diwrnod gwaith.

These proceedings are reported in the language in which they were spoken in the committee. In addition, an English translation of Welsh speeches is included. This is a draft version of the record. The final version will be published within five working days.

Aelodau'r pwyllgor yn bresennol

Committee members in attendance

| | |
|-----------------|---|
| Mick Antoniw | Llafur Labour |
| Mark Drakeford | Llafur (Cadeirydd y Pwyllgor) Labour (Committee Chair) |
| Rebecca Evans | Llafur Labour |
| Vaughan Gething | Llafur Labour |
| William Graham | Ceidwadwyr Cymreig Welsh Conservatives |
| Elin Jones | Plaid Cymru The Party of Wales |
| Darren Millar | Ceidwadwyr Cymreig Welsh Conservatives |
| Lynne Neagle | Llafur Labour |
| Lindsay Whittle | Plaid Cymru The Party of Wales |
| Kirsty Williams | Democratiaid Rhyddfrydol Cymru Welsh Liberal Democrats |

Eraill yn bresennol

Others in attendance

| | |
|-----------------|---|
| Lowri Griffiths | Pennaeth Cyfathrebu a Materion Allanol, y Gymdeithas Strôc Head of Communications and External Affairs, the Stroke Association |
| Jo Jerome | Cyfarwyddwr Cynorthwyol, y Gymdeithas Ffibriliad Atriaidd Assistant Director, Atrial Fibrillation Association |
| Ana Palazón | Cyfarwyddwr Cymru, y Gymdeithas Strôc Director Cymru, the Stroke Association |
| Paul Underwood | Dirprwy Cyfarwyddwr Cymru, y Gymdeithas Strôc Deputy Director Cymru, the Stroke Association |

Swyddogion Cynulliad Cenedlaethol Cymru yn bresennol

National Assembly for Wales officials in attendance

| | |
|----------------|---|
| Stephen Boyce | Gwasanaeth Ymchwil yr Aelodau Members Research Service |
| Llinos Dafydd | Clerc Clerk |
| Catherine Hunt | Dirprwy Glerc Deputy Clerk |

Victoria Paris
Naomi Stocks

Gwasanaeth Ymchwil yr Aelodau
Members Research Service
Ail Glerc
Second Clerk
Dechreuodd y cyfarfod am 9.30 a.m.
The meeting began at 9.30 a.m.

Cyflwyniad ac Ymddiheuriadau **Introduction and Apologies**

Mark Drakeford: Bore da. Croeso i'r cyfarfod cyntaf o'r pwyllgor hwn ar ôl yr haf. Croeso yn enwedig i William Graham, sydd yn y Pwyllgor Iechyd a Gofal Cymdeithasol am y tro cyntaf. Fel y gŵyr pawb, yr ydym yn gwneud popeth yn ddwyieithog yn y pwyllgor hwn, ac mae clustffonau ar gael i dderbyn gwasanaeth cyfieithu ar y pryd o Gymraeg i Saesneg ar sianel 1. A yw pawb sydd eisiau gwranddo ar y cyfieithiad yn gallu ei glywed? Diolch yn fawr. Atgoffaf bawb i ddiffodd eu ffonau symudol cyn inni ddechrau. Mae hwn yn gyfarfod cyhoeddus, ffurfiol, felly nid oes rhaid cyffwrdd â'r meicroffonau. Nid oes dim ymddiheuriadau; felly mae pawb yma.

Mark Drakeford: Good morning. Welcome to the first meeting of this committee after the summer. Welcome in particular to William Graham, who is attending the Health and Social Care Committee for the first time. As you will all be aware, this committee is held bilingually, and headsets are available to hear the interpretation from Welsh to English on channel 1. Can everyone who wants to receive the interpretation hear it? Thank you. I remind you all to switch off your mobile phones before we begin. This is a public, formal meeting. So, you do not have to touch the microphones. There are no apologies; everyone is here.

9.31 a.m.

Ymchwiliad i Leihau'r Risg o Strôc—Tystiolaeth gan y Gymdeithas Ffibriliad Atrïaidd **Inquiry into Stroke Risk Reduction—Evidence from the Atrial Fibrillation Association**

Mark Drakeford: I am pleased to welcome Jo Jerrome, the assistant director of the Atrial Fibrillation Association—we shall say AF, as we will all stumble over it otherwise. Thank you for providing a paper in advance.

Pwrpas cyfarfod heddiw yw clywed tystiolaeth gan sefydliadau yn y trydydd sector ar gyfer ymchwiliad y pwyllgor i leihau'r risg o strôc. Yn gyntaf, bydd yr ymchwiliad hwn yn canolbwyntio ar effeithiolrwydd y gwasanaeth a ddarperir ar hyn o bryd i leihau'r risg o strôc. Yn ail, bydd yn canolbwyntio ar effeithiolrwydd y camau a gymerwyd i roi'r cynllun gweithredu i leihau'r risg o strôc ar waith ac ar y problemau a gafwyd wrth geisio ei roi ar waith. Yn drydydd, bydd yn edrych ar y dystiolaeth o blaid cael rhaglen ar gyfer sgrinio am ffibriliad atrïaidd yng Nghymru.

The purpose of today's meeting is to take evidence from organisations in the third sector for the committee's inquiry into stroke risk reduction. First, the inquiry will concentrate on the effectiveness of current stroke risk reduction services. Secondly, it will concentrate on the effectiveness of the steps taken to implement the stroke risk reduction action plan and the problems that arose during the process of implementation. Thirdly, it will look at the evidence in favour of establishing an atrial fibrillation screening programme in Wales.

Jo, please give us a brief introduction, because Members have questions and things that they want to discuss with you. Just before the end of this part of the agenda, which we are aiming to finish at 10.30 a.m., I will probably ask you whether you want to summarise any key points that you think we should take out of the discussion. So, we will come back to you right at the end.

Ms Jerrome: Thank you for inviting the Atrial Fibrillation Association here this morning. AFA is a charity that is focused on providing information and support with regard to atrial fibrillation and atrial flutter. We are dedicated to working with patients, carers, physicians, policy makers, service providers and all stakeholders in the care pathways, to improve services and understanding, and therefore patient outcome in relation to atrial fibrillation and flutter. In our work, we provide patient-approved and medically-approved forms of supporting information: booklets, factsheets, compact disks and websites—all of which are endorsed by the Department of Health. We run educational meetings for clinicians and patients and carers, and some of these have accredited points for their improvement services and are also linked to further professional studies. We also raise awareness among the general public, through campaigns such as Know Your Pulse, and we promote research into the management of atrial fibrillation.

Mark Drakeford: Thank you; that is a useful summary of what the association does. I offer the floor to any Members who want to indicate to me that they would like to begin. Any Assembly Member who has a question will probably ask you two or three questions, if they need to, in order to pursue their points. Darren is first.

Darren Millar: Thank you, Jo, for the evidence that you have provided. I was astonished to read about the prevalence of atrial fibrillation in the general population and the significant proportion of people who go throughout their lives with this condition undiagnosed. I was interested in some of the evidence that you provided in your paper to do with the role of general practitioners, the quality outcomes framework and the points that they are awarded when they diagnose AF patients. I felt that 12 points, which is the number of points that they get when they diagnose, was quite generous. Why do you think GPs are not diagnosing many more people than they ought to be, particularly given the generosity of the system in terms of the number of points awarded? How does that number of points compare to other conditions that GPs are asked to diagnose?

Ms Jerrome: Atrial fibrillation is a complex condition, and it can present as symptomatic, with a few symptoms, or with symptoms that can easily be considered for other disease areas. For example, fatigue and breathlessness can easily be passed off as old age or the side effects of certain drugs, just as a fast heart rate or palpitations in middle age can be put down to panic attacks. So, it is often missed because other things are considered first. It may also be missed as a hereditary condition because, until more recent times and greater research, the risks involved with atrial fibrillation were not fully understood, or not understood as well as they are now. It was therefore seen as a condition of old age—benign and nothing to worry about—and perhaps did not elicit such urgency during an examination.

The QOF points reflect data from 2005 and the National Institute for Health and Clinical Excellence guidance at that time, in which it was deemed that there was a stroke risk. You had points for diagnosing, but you also had points for offering some kind of antiplatelet or anticoagulation therapy. There is no differentiation at the moment. So, what I believe is happening within many primary care practices is that, if they are not quite aware of the risks, or if they are considering the risk of a bleed, perhaps in an elderly or frail population, they may make a decision that is not taken in the full light of current guidance and evidence.

Darren Millar: Do you think that there is a need to refresh the guidance to make it clearer about the treatments that should be offered to someone who is diagnosed with this condition?

There is talk about the process for diagnosis, and from speaking with the AF association in the past, it appears that while it is relatively easy, this diagnosis is still missed by many practitioners, such as GPs and nurses. Could you pick up on the treatments that are available and specified for GPs to offer?

Ms Jerrome: In general, the treatments are a vitamin K antagonist, of which the most commonly used is warfarin, or an antiplatelet, of which the most commonly used is aspirin, although clopidogrel is sometimes used. In recent years, a schema has been developed, called CHADS2, and this has been further refined to CHADS2VASc2, which assesses the individual's risk of stroke. Atrial fibrillation is the greatest risk for stroke, increasing an individual's risk up to fivefold. However, other factors increase that risk. CHADS is a simple scale that looks at congestive heart disease, hypertension, age—at this point it says 75 and above—whether the individual has diabetes and whether they have had a stroke or a transient ischaemic attack previously. In the assessment, you get a point for each risk identified, unless you have had a previous stroke or TIA, which would give you two points. If you score two or more, the recommendation is that you consider anticoagulation—warfarin, most likely. If you score one point, the current NICE guidance notes that as a moderate risk. You then have to decide whether to go for anticoagulation or antiplatelet. Anticoagulation, by its very nature, will increase the risk of a bleed, and it can be very fearful for many, because, for the older population, there are concerns of falls and the difficulty of maintaining the time in therapeutic range. However, evidence has shown that warfarin, a vitamin K antagonist, can significantly reduce the risk of stroke by 60 per cent to 70 per cent, whereas an antiplatelet such as aspirin can reduce it by about 22 per cent at most, so there is a massive difference. However, aspirin is perceived as being easier to take and safer. In fact, recent Birmingham Atrial Fibrillation Treatment of the Aged trials showed that the bleeding risk of aspirin and warfarin were almost identical, but that the protection that warfarin gives a moderate to high-risk patient is far greater.

Darren Millar: I have one brief question in closing. New and emerging evidence seems to point to the fact that the guidance needs to be refreshed or updated. Is one of the factors in prescribing aspirin rather warfarin the difference in cost?

Ms Jerrome: To my understanding, warfarin is far cheaper in pence than aspirin—I believe that warfarin is about 4p and that aspirin is 16p, but there are monitoring issues that must be adhered to with warfarin, as it is much harder to predict and manage. That is why it is often not a preferred choice.

Darren Millar: So, it is about the whole treatment cost rather than the drug cost.

Ms Jerrome: Yes, it is about the whole package, and perhaps there is currently some fear and a lack of understanding and education surrounding it.

Mark Drakeford: Jo, while you have been answering those questions, almost every member of the committee has indicated that they want to ask you a question as well, so we will have to try to keep things moving, if we can. I will take questions from Lindsay Whittle, Mick Antoniwi and Lynne Neagle next. William, Vaughan, Kirsty and Rebecca have also indicated.

Lindsay Whittle: Thank you for your evidence, Jo. You provide an excellent service in highlighting this issue—I am of an age when I need a six-monthly MOT. Is there anything that we can do to raise public awareness of this issue? Are there any self-assessment procedures that the public can do? I do not know what I am really looking for when I am taking my pulse. I thought the recent advertisement about stroke, in which the brain seemed to catch fire, was excellent; I think that we should do more of that.

I have lots of other questions. How can we roll out the good practice that seems to have

happened in the Wrexham primary care model? Do you think that we should spend more on prevention, and how can we encourage GPs to undertake screening in their surgeries and clinics? I have many more questions, but I do not think that I could get away with asking them.

Ms Jerrome: On your first question, there is a very simple test that will at least detect atrial fibrillation—an electrocardiogram will diagnose it. However, with regard to knowing your pulse, which is something that we can all do as easily as we weigh ourselves or go to a pharmacist to have our blood pressure taken, we provide free medically-approved information on an A4 factsheet on why it is important to know your pulse and how to take it. This is being used in many thousands of centres throughout the UK during awareness weeks and then during the year. This is done to help engage with patients and the general public so that, if you feel an irregular pulse that is more Morse code in rhythm than the regular ticking of a clock, monitor it regularly for perhaps a week, in the morning and evening. If you still have a concern, go and talk to your doctor.

This policy is also being made available on information sheets for schools, because it very comfortably fits into the health and care curriculum in science. It has a twofold benefit in that it informs and educates the population for the future, and they then take it home and share it with their families, in particular the older members of the families who are perhaps more at risk of this.

9.45 a.m.

On your next question, about rolling out good practices, we are very engaged in that, and we highlight successful models. For instance, the successful models in the Wrexham clinics could greatly benefit other practices or health boards in Wales. They could then be adopted under local guidance, because it has to fit into the local setting. The Wrexham nurses have shown that they are engaging with GPs and are helping to share the burden. Over the past three years, prevalence is known to have risen from 1.3 to 1.7 per cent, and in some areas it is well over 2 per cent. So, it places a substantial burden on the general practitioner. In 2008, almost 50,000 GP appointments were directly attributable to atrial fibrillation. That is a large number of appointments, and some of those could have been avoided through earlier intervention and prevention. The model used by the nurses in Wrexham shows that you can not only detect more cases but look at those who have already been diagnosed and reassess their risk reduction appropriately, and you can then enable practices to better manage the patients in their care.

Mick Antoniw: The 2007 study seemed to show that, if you have AF, the risk of stroke is similar to that of the general population, unless you face a number of risk factors. You have identified some of those, such as smoking, alcohol, high blood pressure and a whole series of other issues. Are we concerned with only those people who have AF for whom those other factors are relevant? What happens and what treatment is given to those who have AF if those additional risk factors are not relevant for them?

Ms Jerrome: They are relevant for the majority. Although a growing number of younger patients are diagnosed, the prevalence is still far greater in an older population. One risk factor is just being older; another is being female. So, there are two things that you cannot escape from, unfortunately. If you are younger or do not face those risk factors, and are looking at reducing your risk of stroke, you would need an annual review, because the risk factors may change. If there is little or no risk, you do not need anything to reduce your risk. You may need treatment for your atrial fibrillation, in the form of drug therapy or intervention therapy, but to reduce your risk you may not need anything at that point.

Mick Antoniw: To move on to the pilot project at Wrexham Maelor Hospital, I looked at the

paper, and I was unclear about whether the pilot project targeted people in certain age categories and so on. Secondly, I presume that hundreds or thousands of people were assessed, but only seven new AF cases were identified. The biggest problem that seemed to arise from the project was that a fairly large number of people—60 or 70—were identified who were either not on medication or who were receiving inappropriate medication. I do not know how successful the Wrexham Maelor Hospital pilot project was, but is it the case that the biggest problem is the doctors' understanding with regard to the medication and the levels of medication and so on? Or is it still your view that the biggest problem is identifying people who have AF and who face risk factors?

Ms Jerrome: I think that both are true. I do not have the details in front of me, but the initial project at Wrexham Maelor Hospital ran for six months, and is continuing. It had two main focus points. One was to risk assess the high-risk population, which comprised generally people over 65 years of age and who perhaps attended clinics for chronic disease such as diabetes, hypertension, flu jabs and so on. They were targeted because other trials, such as the screening for atrial fibrillation in the elderly trial, had highlighted that that was a very effective and efficient manner of trying to find AF in the community.

The second part of the work was to look at registers. In England—I know that you have had evidence offered to you on this—there is now a tool available called GRASP-AF. It is a computer tool that will look at an existing AF register within a practice and highlight all those AF patients on the register who have a CHADS score of two or more but who are not anticoagulated. The Wrexham nurses looked at the practice registers for AF patients and reassessed those people. That threw up quite a number of patients whom it was wise to call in in order to reassess them and talk with them about the possible benefits for them of anticoagulation.

Mick Antoniw: Is it your view that the Wrexham Maelor study is sufficient to draw clear conclusions as to doctors' practice? It is also clear from the paper that GPs have not been complying with even the existing guidelines on AF and risk factors. There seems to be confusion in the GP service, or even a lack of experience, with regard to what to do. Is it your view that the Wrexham Maelor study is sufficient, or is a larger more controlled pilot study needed to come to clear conclusions? Are those conclusions already sufficiently empirically sound?

Ms Jerrome: I think that that project, along with other projects that have been undertaken, are sound enough for us to believe that there are undiagnosed and insufficiently managed patients for stroke risk prevention. The GRASP-AF tool, which has raised prevalence from 1.2 to 1.7 per cent, also reflects this.

Lynne Neagle: Thank you for your evidence this morning. You said in your evidence that it is not just that adherence to guidance is weak, but that the guidance itself is poor. You have mentioned the cost, but can you say a bit more about exactly what guidance clinicians are working to? If it is poor, how should it be strengthened, particularly by Government? My other question relates to the UK national screening committee, which I understand is looking at screening for AF as part of its regular cycle of reviews. Are you feeding into that? Is there any information that you would like to share with the committee?

Ms Jerrome: The guidance that most people are working to at the moment does not include opportunistic screening. Where it is done, it seems to be very successful and effective, but it is not taken up widely; it is an option. The guidance referring to anticoagulation is too broad. Yes, that is under review, and we have made a submission to seek a further review of, for example, the quality assessment framework standards of care so that people are assessed against their risk and it is decided whether they need to be anticoagulated, whether they do not need anything, or, if anything, aspirin, instead of aspirin being on a par with a vitamin K

antagonist or any other anticoagulant. It is being left to general practitioners to manage this. They have a huge workload covering all disease areas. It is, therefore, very important—although it can be quite challenging—to stay up to date on all current guidance, such as the most recent European or American guidance on how to treat atrial fibrillation. That also goes down to how you treat the patient with symptoms and when to refer them.

In more recent years, more specialist centres have opened. An example was in Llanelli, where Dr Izzat was aware of a massive AF population. They were going into every clinic, but not their own, and demanding so much time. Without any guidance, other than what they could see, the multidisciplinary team there worked together to develop their own AF clinic. When they looked at the patients referred there, only 22 per cent of those were sufficiently anticoagulated. That has now risen to 40 per cent and there are aims to increase that further. However, it has taken someone to identify the problem locally and then work with the team, without any extra finances, to begin to address it. So, it is a complex condition and issue. As for the opportunistic screening, we have not, as yet, worked with the committee that you mentioned, but we would welcome the opportunity to feed in the evidence that we have.

Lynne Neagle: The UK national screening committee is looking at opportunistic screening, which means that if someone goes to the doctor about one thing, the opportunity would be taken to screen them for AF. So, it is not general screening for the whole population.

Ms Jerrome: That is right. Opportunistic screening is usually for patients over the age of 65 who, more often than not, come to the centre at least once a year, and often far more frequently—it is not unusual for them to be in other clinics. Indeed, just by being in those other clinics, they are a higher-risk population as well.

William Graham: Moving on from Lynne's question, would you support this being one of the campaigns that the Government takes on?

Ms Jerrome: Yes, we would welcome a campaign for AF. If there was a general awareness and understanding of the importance of knowing your pulse, we believe that it would support primary care in bringing it to the attention of those who may not otherwise have presented. Another population within which it is quite common to find AF is the young and extremely fit, which is a population that is not opportunistically screened. So, by knowing their pulse, patients such as those would be able to present and go forward for an electrocardiogram and so on. So, a campaign would be beneficial for the general population, along with a more targeted approach with opportunistic screening within practices to support general practitioners. I emphasise that that needs to be followed up by an ECG, which can be interpreted by a cardiologist or GP with a special interest in this, and then assessed against current approved schemes, such as CHADS or the CHADS₂VASc₂, so that the appropriate decision can be made by the clinician with the patient.

William Graham: My second question is linked to that, with regard to guidance given to GPs. Those who were privileged to attend the cross-party group this morning heard that aspirin, for example, is much more a palliative for the dispensing position than for the patient, because they feel that they are giving them something, even though it is not particularly good or useful. So, should the follow up be a fairly automatic thing?

Ms Jerrome: We are now familiar with the 'aspirin myth' term, because aspirin is so much easier to give, it is often prescribed for other things as well, and it is much easier to manage. However, what has not really been recognised by some practices is that aspirin has, in other ways, a greater risk of bleeds and does not protect the individual patient who has a CHADS score of two or more nearly as much as other things that could be offered. Unfortunately, people fear a bleed, but for almost everyone, the fear of a stroke must be catastrophic.

William Graham: My last question also arises out of that meeting this morning. One contributor at the meeting questioned whether the name should be changed. Most small children understand what a heart attack is, but would not necessarily understand what a stroke is. Therefore, should we perhaps move towards the American idea of calling it a brain attack?

Ms Jerrome: We can use lots of terms for conditions, and, providing there is good education behind this, they can be accepted and taken on board by a young person or an older person, or by middle-aged people, adequately and safely. It is important to use the terminology that is used by clinicians, because, first, if I thought that I was having a brain attack and then someone mentions a stroke, would I put the two together? Secondly, if I had access to the internet, would I find the right information by Googling one term and not the other? A perfect example of that is that I do not know what 'HIV' stands for and I cannot pronounce what 'ME' stands for, but I can tell you the symptoms and some of the risks. So, education is critical. We can use lots of terms, but sometimes the clinical term also has to be in that.

10.00 a.m.

Mark Drakeford: That was an interesting last question.

Vaughan Gething: I want to clarify, for my own mind, some of the points that you have made already. When you are going through the CHADS2 score and trying to assess and identify risk, are you saying that medication should still be considered for people who have a score of ≥ 1 , as opposed to medicating them anyway at that point?

Ms Jerrome: The more recent research, which was published last year by the European Society of Cardiology, presented the CHADS2VAsc2, which evolved because CHADS2 was very good, but it was recognised that a slightly younger population of AF patients, aged between 65 and 75, was suffering a disproportionate amount of stroke. It looked into that and now advocates that, although CHADS2 is good, if someone has a CHADS2 score of ≥ 1 , you should go to the CHADS2VAsc2 and further assess them. CHADS2VAsc2 also considers vascular events, sex—if you are female—and age from 65. Those are the three main extra parts to it. If, at that point, someone has a CHADS2VAsc2 score of ≥ 1 , the authors of CHADS2VAsc2 would suggest that you consider anticoagulation or nothing, but it should be anticoagulation, really, because there is a risk, which will increase every year, if only with age, but possibly also because of other factors.

Vaughan Gething: The conclusion that you seem to be fairly inevitably driving towards in terms of some of your other evidence is that there should be greater consideration of using medication and greater use of medication. Just so that we are clear about how many people we would then expect to take this medication fairly regularly—you talked about the aspirin myth—would we then get into a situation in which most over 75s and, particularly, most women aged over 75, would end up being advised to take medication?

Ms Jerrome: Only if they have atrial fibrillation.

Vaughan Gething: That is helpful. That leads me on to my other point, which is about how we assess atrial fibrillation in terms of other risk factors. You have spoken about other risks, picking up on Mick's question about lifestyle choices. I understand that one in six stroke victims are likely to have atrial fibrillation, but that the stroke is likely to be more severe. How do you set that against the other risk factors and what are the most common other risk factors that you would assess with atrial fibrillation?

Ms Jerrome: Atrial fibrillation is by far the greatest risk factor for stroke and it is also, usually, a risk factor for the most severe type of stroke. With AF, 30 per cent of people do not survive a stroke. When you have atrial fibrillation, the upper chambers of the heart beat

irregularly and, in doing that, provide an opportunity for the blood to pool and therefore form small clots. Being in the heart, they can break off and go to the brain. So, it is an ischaemic type of stroke. Almost a third of people die within the first week, a further third die in the first year, and only about a quarter are able to return home following a stroke induced by atrial fibrillation. Many of those are still disabled in some way. So, it is a very severe, debilitating and costly type of stroke.

Vaughan Gething: There are other questions about the clinicians and prescription, but that is it for now.

Mark Drakeford: Kirsty, croeso yn ôl.

Mark Drakeford: Kirsty, welcome back.

Kirsty Williams: Good morning. Your evidence, both in written form and this morning, has focused greatly on the need to change guidance and the quality and outcomes framework and to focus heavily on education for clinicians. Can you outline for us whose job it is to do that? We would not necessarily have any influence over NICE and getting it to change its guidelines, but QOF is for the Government. Does the Government have a role in the education of clinicians or is that the role of the royal colleges? Whose job is it to address some of these issues that you think need changing?

Secondly, in paragraph 6 of your paper, you talk about how even if a person is lucky enough to be put on warfarin or another anticoagulant, they are not managed properly, so the benefit of the drug is negligible; it does not do them any good at all. Have you carried out an assessment of the capacity for ongoing monitoring that would be required if everybody who should be on warfarin in Wales was on warfarin? Have you done any assessment of what that would mean for capacity within GP surgeries, or secondary care, if that monitoring were to be done properly? There is no point in us getting everybody on to warfarin if it is not doing them any good.

Ms Jerrome: First, on education, we believe that the education of clinicians, but also of patients and the general public, is critical. The decision to go on to an anticoagulant, or an understanding of any risk factors in atrial fibrillation and the disease itself, has to come from a two-way conversation, with both parties understanding the disease. We advocate education for all parties involved, and we provide education and booklets and so on, but we would also welcome work with local health boards, as we have in the past. Just last week we were in Carmarthen running a cardiac update course with local clinicians, presenting to the medical fraternity—mostly GPs and practice nurses—and the greater part of the day was spent on atrial fibrillation, in terms of detecting, diagnosing, managing, and then anticoagulation as well. That was across the board, and we would advocate far more of that, possibly linked in to a general, annual or regular appraisal event within a surgery, so that somebody is aware and up to date. In some areas in England we have worked with practice nurses, and that has been very successful, because quite a lot of the monitoring afterwards can go through to the practice nurse and healthcare officials. As to the monitoring and an increase, we have not run a survey to find out about the pressure that this would apply. At the moment there are a number of choices; obviously, there is warfarin, although it will not be suitable for some patients, and there are devices that are becoming available to cover the left atrium appendage, which can reduce the risk of stroke. That is obviously a small percentage. There are new oral anticoagulants moving towards coming to market that do not require as much monitoring. They will possibly require a monitoring point at three months or six months, but that is yet to be decided. So there are other options coming to market.

Anticoagulation testing takes place in so many different types of centre—some in general practices, some in clinics and hospitals, some through drawing blood, some through prick tests, and some people self-monitor at home on approved devices and then talk with their clinic or their centre. It is very varied. I am not aware of any issue about the number of

patients added, but I do not have any evidence on that, I am afraid.

Rebecca Evans: This is rural health week, and, like other Members, I will be really keen to ensure that this committee always pays regard to rural communities in our discussions. I was wondering what particular issues you see relating to stroke prevention in rural communities. Are rural issues addressed adequately by the stroke risk reduction action plan? If not, what more do you think needs to be done?

Ms Jerrome: Over and above the comments that we have already discussed on awareness, detection and diagnosis, one of the challenges in rural communities is adequate and regular monitoring, if the patient is on an anticoagulant. An anticoagulant such as warfarin interacts with almost everything, from everyday food to alcohol to other drugs. It is also very patient specific, so it requires regular monitoring. That can be an expensive challenge, both for the patient and the clinicians involved. Sometimes, in rural monitoring, a clinician will do home visits, sometimes people will travel in, or, in a very small number of cases, home monitoring will be offered. That is an issue that still needs consideration. The therapeutic range for warfarin in a patient with AF is between 2 and 3. When it is lower than 1.7, the risks are not addressed and if it is higher than 3.5, the patient is at an increased risk of a bleed. So, it is quite a tight therapeutic level, and that is one of the challenges for rural communities.

Rebecca Evans: Community pharmacies play a key role in many rural communities. You might be aware that this committee is also looking into the role that community pharmacies can play in public health. There are some actions within the stroke risk reduction action plan relating to community pharmacies, but is there a role for them in diagnosis and monitoring? For example, could at-risk groups receive a manual pulse check when they attend a community pharmacy to receive their medication or when they receive their flu jabs and so on? Is there a role for them in monitoring and diagnosis?

Ms Jerrome: Yes, very much so. When people are collecting medications or visiting the pharmacy for whatever reason, the pharmacist could take part in that monitoring. There are also blood pressure devices available that have gone through trials to see whether they would be suitable for use in pharmacy and general practice, because they detect atrial fibrillation. So, it provides a simple double check. We all go to the pharmacy and can often use different devices there to check, for example, cholesterol levels; that could easily be made available and it would be very helpful. Equally, hand-held monitoring devices can do a single lead or three-lead electrocardiogram if someone presents at the chemist and says that they do not feel very well. They are very easy to use. They are not invasive, but can detect a problem and the person can then be referred.

Rebecca Evans: So, monitoring and diagnosis is possible within community pharmacies, but it is not happening yet.

Ms Jerrome: Not widely, no.

Another service where there are some examples of this but it is still not happening widely is the 999 service, the emergency services. They routinely take a pulse, but it is not always the case that something happens with that information. One of the problems with AF is that, if you have paroxysmal AF, it means that it can come and go at any point. So, someone may call out the services, an irregular pulse may be detected and may even be monitored on the ECG, but it might have gone by the time that the person arrives at the hospital. Some emergency service areas, particularly in the south-west, have put in place a procedure whereby the pulse is taken and the information is passed on to the clinician when someone goes to hospital. That has made a significant difference. So, the information is there, but it is a matter of improving what we have and increasing the use of it.

Elin Jones: In your evidence, you have provided us with figures showing the costs to the NHS in Wales of treating strokes. Do you have any figures on the savings that could be made by introducing your version of an appropriate diagnostic and treatment system through GPs and the NHS in general? What savings could the NHS make, or what would be the difference in costs between the model for the treatment of strokes and the model that focuses more on preventive work?

Ms Jerrome: I have costs for one example at the moment, which is based on information from a doctor in north-east Essex called Shane Gordon. Three years ago, he grouped with a number of practices—37 out of the 40 practices in his area—during the flu inoculation to do screening. Over a period of six weeks, they took pulses while giving the flu inoculation. In the six weeks 34,201 patients were screened, and 3,154 patients were found to have an irregular pulse, which is about 9.2 per cent—these are his figures. Following an ECG, 189 patients were found to have atrial fibrillation, which is 0.55 per cent, and 342 patients were found to have other arrhythmias, including two with complete heart block. He then looked at those 189 patients, and he said that of those, because they were in a higher-risk category, 10 would have suffered a stroke in the next year. A locally enhanced payment was offered in this system of £2 per pulse taken; in some systems, there has been no payment and in others it has been 10p, so it varies. In his system, the payment was £2.

10.15 a.m.

He said that the treatment of AF to reduce the risk of stroke was 50 to 70 per cent, and he felt that by finding, treating and managing the 10 patients suitably, five strokes would have been prevented. So, his analysis was that the initial outlay was almost £68,500 for the diagnosis of 189 patients, so it cost £362 per patient diagnosed because of the local enhanced services payment. However, he looked at the Saka data on the cost of a stroke, the healthcare services and wider community data, which puts the cost of stroke at £44,000, and because of the five strokes prevented, they had made a cost saving of £220,000. In their practices, they had made a return on their investment of 322 per cent. They have continued with that model, and others have followed.

Other models have shown that finding patients and diagnosing them adequately has been cost-effective, whether there was a local enhanced service payment of £2 or less, or in counties such as Surrey and Buckinghamshire, where no locally enhanced service payment was offered, or if there was, it was a minimum payment of 10p.

There is also Dr Izzat's model in Llanelli in which no extra moneys were available for the service at the clinic that they set up. While they did not find more patients, because the patients were already diagnosed and being referred in, they almost doubled the appropriate anticoagulation levels within the first year, which is very good.

Mark Drakeford: We have five minutes or so if anyone has an urgent point to take up as a result of the other evidence that they have heard. Darren and Lynne have already indicated.

Darren Millar: It is not so much of an urgent point. As a charitable organisation, who funds you? Is it a collective of other charities that all contribute to the pot? I have never been to a fundraiser for the AFA in my constituency, for example. However, I am regularly invited to fundraisers by the Stroke Association or the British Heart Foundation. Where do your resources come from?

Ms Jerrome: We were set up with a Department of Health grant and we still benefit from Government grants. We also do fundraising—we had a fundraising event in the midlands at the weekend. We also receive annual sponsorship from members and donations are high. We run events that help to sponsor us, and we also sometimes receive sponsorship from allied

professionals.

Darren Millar: In terms of the Department of Health funding that encouraged and promoted your establishment, was a contribution made by the Welsh Government towards your resources in order to highlight the focus of your work?

Ms Jerrome: No, we have not received any funding support from the Welsh Government.

Lynne Neagle: I want to clarify something that you said in response to Rebecca. You said that some people—I cannot remember the term that you used—had a type of AF that comes and goes. How many AF sufferers have that type of AF, and how would that affect the efficacy of any opportunistic screening programme, as that could apply to anyone if they go for screening and it is not happening at that moment?

Ms Jerrome: In general, atrial fibrillation tends to beget atrial fibrillation, and it is not unusual for someone to start with what is termed as paroxysmal AF. AF is very loosely and not particularly very clinically divided into three sections. Paroxysmal means that it comes and goes. Most people start with episodes of paroxysmal AF. They may find triggers, which could be exhaustion, food or exertion, or they may not be aware of or able to find those triggers. It is not unusual after a period of time—this can vary individually—for that AF to persist. Paroxysmal AF normally self-terminates within seven days, but it will often terminate within 48 hours without any intervention.

Persistent AF will continue running for more than seven days and it will need some kind of intervention—medical or electrical—for it to revert to the normal rhythm. After about seven or eight days, it is then seen as persistent AF that needs treatment. If a point is reached where the doctors and the patient agree that they cannot easily revert the rhythm back into sinus rhythm, it is called persistent or long standing.

Some people may go straight into one type of AF, and others may stay in one type, such as paroxysmal AF, for many years. This can be linked to age and to other general health issues, but it varies as much as the variation in how symptomatic a person can be. The risk of stroke remains the same regardless, and the risk of stroke is not just when you are in AF. If you have paroxysmal AF and you are not in it at the moment, you are still at risk of a stroke. This is why screening is challenging, and why opportunistic screening has been trialled and seen as the most effective and efficient, because you are beginning to look at the higher-risk population. This is also why we would advocate a general awareness campaign, because we can all take part in this, along with pharmacists and so on. We may not see the AF, we may not even feel it as we walk around, but we can certainly detect it in our pulse.

Mick Antoniw: With regard to the Wrexham Maelor pilot, who funded it and who co-ordinated it?

Ms Jerrome: To my understanding, it was funded locally. It was co-ordinated by the arrhythmia nurses and Michelle Bennett, along with the hospital.

Mick Antoniw: Was it health board funding?

Ms Jerrome: I believe so, yes. When the nurses were appointed, part of their remit was to work with primary care, and one of the nurses appointed had come from primary care. So, that is how it developed.

Mark Drakeford: Thank you for sharing your expertise with us this morning, Jo; it has been helpful for us all. I am going to offer you a few minutes if you want to re-emphasise any points or pick up any that you think we ought to have asked about. There have been some key

themes around the table; there is the issue of detection in the first place, and there is the issue of what you do when detection services have been put in place. You have been asked a series of questions about how robust the evidence base is so that we would know what we would do if we were to move down a particular path. You have been asked questions about costs and how confident we can be that, if we were to suggest that the Government move in a particular direction, some of the cost savings would be realised—almost everyone we meet tells us that the savings would be realised if only we did what they are particularly interested in. How confident can we be that they would be realised in this case?

Ms Jerrome: Thank you for giving us the opportunity to present to you today. Atrial fibrillation is a complex condition and addressing the issues that arise from it is equally complex. I have drawn together a summary. The evidence that has been presented this morning seems quite robust and it is being endorsed and highlighted across the UK and the world to prevent avoidable strokes and much suffering and misery, and to save costs. Costs may not always come directly back to the initial diagnoser, but they do come in to the healthcare budget and then into the wider social care services budget.

I have written a few lines so that I do not lose my train of thought, if you do not mind. Stroke is a disaster, and surviving stroke can seem worse than death, with victims facing an uncertain future and a life that may be severely damaged by disability. The financial burden of stroke is staggering and its costs are set to increase dramatically due to a predicted increase in atrial fibrillation in an ageing population, which survives far more conditions than ever before. Currently, anybody above the age of 40 has a one in four chance of developing atrial fibrillation. With emerging medicines and with people surviving for longer, those younger than 30 have closer to a one in two chance of developing atrial fibrillation in the future. By taking simple actions now, which are quite complex, but include a general awareness of atrial fibrillation and how we can detect it, improved opportunistic screening of higher risk patients and appropriate diagnosis through a well-read ECG and assessment of risks, the suffering and cost can be avoided, and we believe that there are enough international data to support that.

Poor understanding of this complex disease means that, unfortunately, AF goes too often unrecognised. Greater awareness, opportunistic pulse screening and an ECG will make inroads. There is strong evidence and many examples of successful practices that achieve improvements in standards of care and patient outcomes. Equally, support in addressing and changing the QOF, and enforcing a quality of standard for AF, is also important to achieve patient outcomes at relatively little cost, while giving consideration to NHS costs. We thank the committee for inviting us here today and we urge you to press for the adoption of opportunistic screening for AF within a framework of guidelines that would improve detection and diagnosis and, subsequently, lead to the appropriate management and review of all AF patients.

Mark Drakeford: Diolch yn fawr am ddod y bore yma. **Mark Drakeford:** Thank you for being here this morning.

Jo, I am sure that you already know that you will get a transcript of the evidence that you have given and of our discussion. There will be an opportunity for you to ensure that we have accurately transcribed the points that you wanted to make.

*Gohiriwyd y cyfarfod rhwng 10.27 a.m. ac 10.31 a.m.
The meeting adjourned between 10.27 a.m. and 10.31 a.m.*

Ymchwiliad i Leihau'r Risg o Strôc—Tystiolaeth gan y Gymdeithas Strôc Inquiry into Stroke Risk Reduction—Evidence from the Stroke Association

Mark Drakeford: Croesawaf y tystion, sef Ana Palazón, cyfarwyddwr Cymdeithas Strôc Cymru, Paul Underwood, y dirprwy gyfarwyddwr, a Lowri Griffiths, pennaeth cyfathrebu a materion allanol y gymdeithas.

Mark Drakeford: I welcome the witnesses, who are Ana Palazón, the director of the Stroke Association in Wales, Paul Underwood, its deputy director, and Lowri Griffiths, the head of communications and external affairs.

Gofynnaf ichi wneud cyflwyniad byr ar y dechrau; bydd cyfle wedyn i Aelodau ofyn cwestiynau. Pan fyddwn ar fin gorffen, mewn oddeutu awr, down yn ôl atoch i weld a oes unrhyw bwyntiau yr hoffech eu gwneud, fel y gallwn fod yn siŵr ein bod wedi clywed popeth sydd gennych i'w ddweud. Diolch am ddod y bore yma.

I would ask you to make a brief presentation at the start; Members will then ask questions. When we are approaching the end of the session, in about an hour, we shall come back to you to see whether there are any points that you would like to make, just to make sure that we have heard everything that you have to say. Thank you for coming this morning.

Over to you, therefore, for a brief introduction before we hand over to Members for questions. Ana, did you want to start?

Ms Palazón: I thank Members for inviting us to give oral evidence. Our evidence is based on what we submitted in writing, but we also have additional points to make that we would be grateful to be given the opportunity to expand on. To give a bit of background, the Stroke Association in Wales is part of a UK and international organisation, and we have close links with partners in Europe.

With regard to our operations in Wales—to give a bit of context—we have four departments. One of our largest departments provides direct services to stroke survivors who have been through the medical and social care system, and those who may not have. That department is led by Paul. We also have a communications and external affairs department, which undertakes all our awareness raising and campaigns. That is led by Lowri. Awareness of stroke and stroke prevention is a key area of the work that we do through that department. We also have a fundraising department that works closely with partners across the four nations and specifically on fundraising in Wales, for Wales. We also have support services such as human resources and so on. So, we are part of a UK organisation, but are very well cemented in Wales.

The work of the Welsh Government with regard to the stroke risk reduction action plan is a step that we very much welcomed, and we have partnered with the Government in order to implement its recommendations. We believe that prevention is crucial. It is obvious that prevention avoids human tragedy, but it also avoids unnecessary expenditure in what is already a fragile economy. So, there are a number of reasons why we are very keen that prevention is given the important status it deserves. We do not believe that, to date, that has happened.

As I am sure you have been hearing lately and as has perhaps been said in your discussions this morning, stroke is the third major cause of mortality and is predicted to become the second. It is also the leading cause of long-term adult severe disability. So, I do not think that it is something that can continue to be underestimated or overlooked. We are very conscious that the previous Welsh Government, and indeed this present Government, have made stroke prevention and services a priority. That is something that we truly welcome and we want to

continue to be partners in the process.

We have obviously come to committee to respond to the questions that you have for us, but I am not sure how you want to deal with those.

Mark Drakeford: I think that we should probably pause there, following that introduction, which was very helpful. Thank you. I am sure that we will pick up those questions as we go round the table. Darren, who has obviously been on some sort of course on this over the summer, has managed to get in first again. He will start off and then we will have questions from Rebecca, Kirsty and Lindsay.

Darren Millar: I would like to thank you for your paper and congratulate you on your good work across Wales. We all have good examples of the Stroke Association doing great work in our constituencies and I certainly appreciate that. One thing that all Assembly Members recognise as not being good enough is the fact that Wales is at the bottom of the league table of outcomes for stroke patients. The former Health, Wellbeing and Local Government Committee produced a report on stroke services in Wales, published last year, to which you contributed significant evidence. There were recommendations in the report that the Minister agreed to take forward, including one on bringing the risk reduction strategy together. That is what the Minister committed to do, and I know that she made this a priority in her department.

However, one thing that surprised me in your evidence was what you said in paragraph 2.1, that following the publication of the report and the Minister having agreed to take it forward,

‘we have not had any further correspondence regarding implementation despite being attributed as an organisation to deliver key actions in partnership with others.’

Can you tell us a bit more about that? Have you been contacted since the publication of this evidence document, for example? Why do you feel that there may not have been the progress that you—and everyone, including the Minister, to be fair—would have liked to have seen? You give a hint as to what I think your answer might be in paragraph 3.1, where you talk about the ownership issue—who actually owns the implementation. Could one of you speak to that please?

Ms Palazón: If I may, I will start to try to answer your question, and then I may hand over to Paul. I think that we may not be speaking about the same report. I think that you are talking about the report I have here—

Darren Millar: Yes, and the acceptance of the recommendations by the Minister.

Ms Palazón: I think that we were making a more specific reference to the risk reduction action plan that was launched by the then Minister, Edwina Hart, in June last year—

Darren Millar: That plan was launched in response to the report last year.

Ms Palazón: Yes. So, we are trying to say that we welcome the clear commitment to translate some of the report’s recommendations into practice and concrete action. However, we do not feel that there has been a comprehensive co-ordination of this plan to make it a reality. The plan has a number of sensible, well-thought-out, well-planned and welcome points to follow, with a timetable; however, many organisations that were attributed with actions were not necessarily consulted, so some of them may not even be aware that they are expected to deliver on this. The initial implementation of this plan was, coincidentally, launched at a difficult time—at the closing of the previous Assembly Government, and in readiness for a new Government. So, that brought some pressure to bear; it was, politically, a difficult time to

launch it.

The way that we became partners is specifically interesting. We have not delivered on some of the actions that were attributed to us as a lead organisation, and we have not had the conversations that we need to have, partly because some of the officials changed roles during that change of administration. There is also one area where we were not seen as the contributing lead organisation, but we became the lead organisation in the delivery of the Ask First campaign, and the atrial fibrillation and blood pressure campaigns. The relationship worked well with our partners in the Welsh Government, but we have not yet had an overall, step-by-step evaluation of how this is going and how we see these campaigns changing perceptions. For example, through the evaluation that we carried out as part of the campaign, we know that individuals who have already had atrial fibrillation have become more cognisant of what it means, but cognisance has not increased within the general public. So, while there has been validity to the campaign, we believe that its impact has been quite limited. It is therefore about understanding what that means for future campaigns.

Kirsty Williams: You acknowledge in your paper that the Welsh Government has funded a number of stroke prevention publicity campaigns and they are listed here—the most recent was the AF one. I am concerned to hear you say that when you carried out the evaluation of that campaign, the people who are already affected might know more about their condition, but the people we need to get to are those who do not have any idea that they may be at risk and need to take action. How do we therefore evaluate the impact of the money already spent by the Government on stroke prevention public health campaigns, and whether the money and the messages have resulted in better outcomes?

Ms Palazón: The last thing that we would want to say is that there is no value to public education campaigns; we believe that they are incredibly helpful and valuable, but it is about how you deliver them. For example, we have evaluated the FAST campaign and seen that it was a very effective campaign and has saved lives. The AF campaign was delivered differently; it did not have the same mass-media approach. We had radio broadcasts—which were, of course, bilingual messages—on commercial radio stations across Wales over a period of two weeks. We also had posters in bus shelters, and literature and posters were given to I do not know how many GP surgeries to be displayed prominently. That work was done in partnership, but, due to the one-off approach, we did not reach the parts that we needed to reach.

Ms Griffiths: What we are saying is that we welcome the opportunity to work in partnership with the Welsh Government, and although that campaign was successful, we want to see some kind of longevity to campaigns so that they can continue to have that impact, so that they are not just one-off two-week campaigns—we need to think about how they progress. We would also like to look at having more lead-in time in terms of delivery. You are asked to deliver a campaign with a 10-week lead-in to delivery, whereas months are probably required to be able to integrate that kind of campaign into other areas, so that we can mainstream it so that it becomes a rolling thing that continues beyond a period of, say, a couple of months—I am talking about years even.

10.45 a.m.

Ms Palazón: It is also about targeting the audiences that we need to target, because we believe that we are missing a big element of the audience, namely younger people, and doing that through the education system.

Darren Millar: May I go back to the fundamental point about the ownership of taking forward the necessary change? I am concerned about this, because we are all of the opinion that we need to improve our stroke services, and the Minister set out a clear programme for

delivery, but it is not being delivered. The last thing that we want is more recommendations to be accepted by Ministers that then sit on a shelf and are not being implemented. How do you think that we can improve that, who should be taking the lead on implementation within the NHS, what role should the Stroke Association and others have, and who should be monitoring the delivery?

Mr Underwood: The association is well placed. We sit on all seven stroke boards—they are called different names: the stroke forum, the stroke steering group or the stroke board, but they all have the same level of priority. We can be independently objective and critical as an organisation at those fora and those meetings, and we are, because the stroke reduction action plan is an agenda item at the meetings and discussed there. We are vocal about it and we can be and have been critical of what is happening. We are finding that there is a good take-up and recognition of the priorities from a health perspective, but there is little emphasis on the requirement for local authority attendance. Stroke is a tragic medical event, but it is preventable, as we know, and if you look at the life after stroke pathway, you will see that the majority of interventions and costs associated with stroke are not the actual clinical interventions, but the community involvement thereafter. We are bringing these things up and, sometimes, we hit a brick wall. Health boards need to look at other priorities, for example, the acute pathway and the intervention of thrombolysis and 24/7 treatment, but maybe something is being lost whereby the prevention agenda is hidden behind the money that has primarily gone into the acute service. I feel that we can be critical and objective, and we can review and make comment on that.

Darren Millar: So, you are saying that regular reporting by you might help to nudge things along on outcomes, are you?

Ms Palazón: We work closely with Public Health Wales and we believe that there is an important leading role for it to co-ordinate this. We are members of the Wales Stroke Alliance and, only this morning, we had the first meeting of the cross-party group on stroke. We believe that there are some important strategic groups that should be taking ownership and having a watchdog approach to ensuring that these actions are being delivered as intended.

Mark Drakeford: Thank you very much for that. With three witnesses and everyone wanting to ask questions, we will have to organise ourselves to ensure that we make the best use of our time. So, I plan to go to Rebecca, then Mick, then over to Kirsty, in case she has a follow-up question, and then to Lindsay. Everyone else will have their chance, but that is the next run of questions.

Rebecca Evans: Apart from the issue of ownership, do you have any other areas of particular concern regarding the action plan? I am thinking specifically of actions that should have been in the plan but were not.

Ms Palazón: Our main concern with the plan is that it seems to have gone silent. Whether it is comprehensive or not, it does not feel as if it is a live plan. The problem lies in communication. If we do not monitor and evaluate what has already been delivered and communicate that, we will not have a sufficiently objective and informed view on what should be there and what the next step should be. So, we need to know whether this is working. If it is, let us carry on, but, if not, where should we go from here?

I still believe that we should also be working with a wider segment of the population, and that we should make better use, as intended, of the various networks, in the third sector as well as in the statutory sector, to make sure that we are getting to those who can make a difference. This morning, at the meeting of the cross-party group, we had some discussions around ignorance with regard to atrial fibrillation, and there was an example of a 73-year-old woman who had been to her doctor at least eight times during the course of the year, and not once had

her pulse been checked, yet she had atrial fibrillation. There is plenty of anecdotal evidence that GPs may not even know about atrial fibrillation. We need to be much more targeted and much more specific about the result that we want from these actions. We have not captured what success looks like in this plan.

Rebecca Evans: You might have answered my next question there. I know that the Stroke Association is very keen on having a stroke strategy in place for Wales, and I was wondering what you think this stroke strategy could offer, in terms of prevention, that the action plan does not. I am assuming, from what you have been saying, that it would be about co-ordination, targeting, performance indicators, and that sort of thing. If you could give us more information about your vision for a stroke strategy, that would be very helpful.

Mr Underwood: I am sure that we can very quickly look at the English model and what happened there with the development of the strategy and the investment that was made. If you look at the Royal College of Physicians' clinical audit results, they showed that England had taken a massive leap forward in the development of stroke services and the outcomes thereafter. To bring in the terminology, the word 'strategy' brings with it the invisible word 'commitment', and the recognition that people need to move to make a difference and to improve outcomes. There was significant investment in England. Having said that, even with a lot less investment in Wales, over the last 12 months in particular you could clearly see the impact of prioritisation and action plans—albeit associated with one particular area of the pathway. If you are asking why we need a strategy, and why that might be important, at the highest, strategic level it does make people move, and it does ensure that actions get acted upon. Achievements have been made in England. Achievements are now coming forward in Wales as well, but maybe a strategy would take that forward further.

Ms Palazón: It is about basing this on the evidence—from England, yes, but from other countries as well. Also, it is about ensuring that we do not lose sight of the fact that, although there have been some significant and very welcome improvements in stroke services at the acute end of the pathway, when stroke survivors stop receiving the medical interventions that they need, when they go home, that is when the feeling of abandonment comes in. It is not just a feeling; the reality is that we have plenty of examples of people who have just been left to deal with a complete new reality: severe disability, loss of communication, loss of personality, loss of identity, loss of job, loss of income, and so on. The list goes on. It is about bringing all of that together. It is not just a medical matter, but also a social matter. It is to do with employment, education and citizenship, and we need to move the focus of the approach in Wales so that it is not so heavily concentrated on the medical aspect—which is critical, but is not the only aspect that we need to address. As Paul said earlier, we have in Wales what I think is an unacceptable and embarrassing situation in that social services are not participating in any of the strategic groups that are working to address the issues around stroke prevention, awareness and services.

Mick Antoniw: The thrust of what you have been saying is that, despite the best of intentions and a reasonable plan, this has been largely ineffective in Wales. One of the themes that seems to appear in a number of the papers is the fairly significant inadequacy in the training, take-up or focus of GP practices around Wales, either in complying with existing guidelines or even taking up any new campaigns that are launched by the Assembly Government. That seems to be a barrier that has been almost impossible to break through. Given that many of the causal factors that increase the likelihood of a stroke are associated with health conditions and lifestyle—smoking, alcohol consumption and so on—are there particular hotspots in Wales? Are we saying that this is a much more significant problem in certain communities than in other, more affluent communities perhaps? Rather than having generic campaigns, would it be better to have more focused screening programmes that target those hotspots in order to achieve the most immediate effect? My concern is that, with all of the information that comes out about health, we are, to an extent, scaremongering and the information largely

goes over people's heads unless they have the condition that is being highlighted. What are your views on strategy? Should it be a different and more focused strategy and one that incorporates GP training and so on?

Ms Palazón: First, I would like to say that we believe that this plan is a very positive step. The problems have been in co-ordination, ownership and project management. That is perhaps part of why this is not working as well as it could or should. Having said that, I completely agree: there is irrevocable evidence that stroke is linked to wider health inequalities. In Wales, we have plenty of hotspots, if I may put it that way. We know of some lifestyle choices and of the lack of employment opportunities and other socio-economic factors that impinge upon people's lifestyles. Part of what we need to do is to ensure that we use the correct language to encourage people at all levels in a more popular way, and not to scaremonger. We all know that, if you ask someone how severe a heart attack is, people understand that; when you talk about stroke, all sorts of myths surround the term.

People might understand its importance better if we were to use the correct term, which is 'brain attack'. Anecdotally, when you tell people who have, for example, a brain haemorrhage that it is a stroke, they do not want to accept that, because they see a stroke as something that is demeaning or that perhaps happens only to older people. We have ageist preconceptions, so we do not want to identify with that. So, it is important that the language that we use is inclusive and makes people realise the urgency of acting and preventing this. If we could work with specific communities where we know that health inequality is more prevalent and do that through community development approaches, we can get people to recognise what is needed for change and needs to come from within people. This paper recommends working closely with Communities First communities, but we do not have evidence that that has happened.

Mr Underwood: You mentioned certain demographics or certain areas that might benefit from being targeted, and there is a benefit in doing that. If you do not mind me mentioning names, if you look at public health data, Welshpool and the Welsh Valleys have significant deprivation levels that are also linked with co-morbidities, which link to coronary artery disease and stroke. They are very similar in their presentations. However, that is too late. We all need to be looking at primary prevention. Where it has already been identified that there are very large areas of health demographics that are a cause for concern, that is secondary prevention; the damage has already been done. Of course, you will want to limit that; you do not want them to have the second transient ischaemic attack or the second stroke. As Ana said earlier, we are missing something here. We have to start at school age—we have to prevent obesity, diabetes and high blood pressure and keep cholesterol levels down, but how do we do that when we sometimes target our actions at the wrong level? We need to do both; where there are problems and challenges, we need to get in there to prevent a first or second stroke, but we must also work generically across the whole pathway and at the youngest age to prevent deterioration of condition.

11.00 a.m.

Mick Antoniw: Does that not miss the point? We know that there are communities where there is already high incidence of stroke, but the successive generations within those communities are equally susceptible to the same conditions that cause stroke. So, in terms of focus and targeting, the fact that the community already has a high incidence of stroke means that it is ongoing, and it is about the education within the community. What I am concerned about is not achieving results by being so generic across the board with everyone, but by targeting to have the most impact.

Ms Palazón: An example of where we have tried to target is a service that is funded by the Big Lottery Fund in Ceredigion. We are rolling it out in Carmarthenshire, and we hope to do

similar work in north Wales. We have been working in partnership with the National Farmers Union in Wales, because evidence demonstrates that men in the farming community may not be engaging with their GPs or health services as readily as they might. At the risk of sounding stereotypical, we have been working with the female members of the farming community to help us to support their husbands or partners to engage with health services. By working with the National Farmers Union, we have been able to hold events to target what we know is a segment of population that does not take the prevention messages as well as it might by doing blood pressure checks. We have been able to target what we know is a segment of the population that otherwise would not have engaged.

We have been doing similar work in Ceredigion by holding surgeries in partnership with GPs, which has allowed us to reach the people who would perhaps not have engaged in the same way, because they know that we are not the medical profession. We are perhaps a friendlier face, and this can also enable them to talk about the condition and their fears. So, the approach that you take is as important as wanting to be there.

Mick Antoniwi: What, then, is the main failing in terms of the GP practices? There seems to be a theme running through this, if it is correct, to do with their training or their capacity to absorb the tests, or whatever. Where is the failing in achieving improvement in the consciousness and the capacity of GPs?

Mr Underwood: I think that the consciousness is always there—it is about what they are measured on and their compliances with QOF. Very simple interventions that take very little time can make a big difference, but they are not measured and therefore not paid for, or not rewarded, should I say—such as taking a pulse. I heard Jo mention it earlier. You can very easily detect atrial fibrillation with a 15-second pulse check. That very early identification can prevent years of medication, unnecessary treatment and death.

I do not mean to be critical, but it is how the system is. GPs will operate based on the reward system. Unless that is changed so that there is more of an emphasis on what they need to do of a specific nature with stroke and AF, I do not think that things will change. We know that GPs get a basket of enhanced services each year for extra-curricular things that make a difference in their local area. Why cannot some of those additional funding opportunities be targeted towards some of the primary interventions that need to happen? It could be an opportunity that would offer a carrot, because if primary care is not involved and it does not want to be involved, we are not going to be making any change. We could be knocking on that door for years and years. However, they are essential, powerful and influential people that we need to engage with. Yes, a part of that is training and education, but they are trained and educated; it is just that we want them to take a pulse and offer basic screening that will prevent stroke and AF. I think that that is achievable very quickly.

Ms Palazón: And very cheaply.

Kirsty Williams: Your argument seems to be that the only way of bridging the gap between guidance and practice is via the QOF, because, as we have seen in previous evidence, GPs are aware of the guidance and are supportive of what it says; it is just that it seems to be a different matter when it comes to doing it. Given that, what discussions have you had with the Government about including the additional QOF requirements? You are specific in your document about the two QOF requirements that need to be added, so what discussions have you had, if any, with Government about having them included?

Ms Palazón: We are awaiting a meeting with various departments. We have asked the Minister to meet us and she has referred us to meet Chris Jones next Friday.

Ms Griffiths: It is one of the things that we want to bring up.

Mark Drakeford: [*Inaudible.*]

Ms Griffiths: Yes. We have not had the discussions yet, but this is an area that we want to start work on.

Ms Palazón: One initial discussion we have had was with Tony Jewell, the chief medical officer, and that led from the Ask First campaign to a fibrillation campaign. With regard to partnership in these programmes, we have had some initial discussions, but not specifically about QOF; that is to follow.

Mr Underwood: The challenge with that, even though I think it is achievable, is the fact the QOF is for the UK and not Wales specific. I do not know whether, through us as the Wales representatives, there would need to be representations to press for that change on a UK level or whether there could be a specific mandate from the Welsh Government down that would make those changes happen in Wales first.

Ms Palazón: On the issue of the UK versus Wales, we have a body of leading experts in Wales in the field of stroke. For example, if we focus on thrombolysis, we know that it saves lives when applied within a certain time frame, but because of the guidance issued by NICE—Paul will be able to say more on this—many people are prevented from receiving a life-saving treatment, when leading experts and practitioners in the field in Wales are saying this can and should be done differently. In Scotland, they have their own way of determining that time frame without having to follow NICE, and in Wales, there is a body that can advise in that respect. Therefore, it is important that we look at ways in which the Government can support breaking out of the straitjacket that some of the guidelines issued by NICE are imposing.

Mark Drakeford: Paul, I might have to ask you to pick that point up later on. To get through the number of questions, we have we will have to ask for one answer per question for a little while. Kirsty, do you have any further comments?

Kirsty Williams: No; that is fine.

Lindsay Whittle: Thank you for your evidence. We have got to stop pussyfooting around here. All the evidence I am hearing at the moment is that there is something wrong with our health improvement plans and we are not getting it right. If this were America, I believe that we would be open to litigation—thank goodness it is not America. Tell us, in all honesty, what is wrong with the Government's health promotion campaign? How can we improve it? How can we get local health boards, local authorities and the 50-plus fora that exist in Wales on board? I think that we all agree that prevention is better than cure. I have been discussing this since 8.15 a.m., and three people will probably have died from a stroke today as a result of this issue, and all we are doing is talking about it. I think that we need action, and we need it fast. We have got to start persuading people that prevention is better than cure, and a greater percentage of budgets must go towards prevention to stop these terrible traumas from happening to people.

My main question—and I am sure that you agree with everything that I have said; I hope that you do—is this: what about the aftercare? I do not mean this as a joke, but I recall that, when I was a boy, my grandfather had a stroke, and his speech was badly affected. I genuinely thought that he was speaking to me in Welsh, because I could not understand a word he was saying. He was an angry man as a result of his stroke. I am an angry and impatient man, and it must be extremely frustrating indeed. That does not help your recovery. I heard a reference in the meeting of the cross-party group this morning to the psychological effect and how there are only three people in Wales who are dealing with that. How are we doing on speech

therapy to help the victims? It is great for us to talk about prevention, but we also have to realistically address the issue of how we can assist those people who have had strokes in becoming involved in their communities again.

Mark Drakeford: There are one or two basic questions. The first is: can you tell us about the effectiveness of current programmes and how those can be improved? Secondly, could you tell us something about post-stroke recovery services?

Ms Griffiths: I just want to say something about the effectiveness of Health Promotion Wales for everyone who is tasked with delivering parts of it. It is easy to be critical, and we can be critical of ourselves in that we do not do as much as perhaps we would like to. It is not for us to sit here and be critical of how things have been implemented. We should draw a line under that and, moving on, say, 'Let's do it differently. Let's own it and drive it, and all work together to make this happen.' It would be helpful to review what has happened. I am sure that if we put all the parties who are responsible for certain action points together and asked, 'What have you done against this?', there would probably be a lot of ticks there, but nobody knows about it. So, as a starting point, we need to sit down and ask, 'Where have you got on this?', and then we can move on from that. It is not for us to criticise the Welsh Government on its implementation; it is for us to say, 'Can we now look at this? It's timely; there is an inquiry into it. Let's get moving on it.' It is all there, and it is still all relevant; it is just that we need to see where we are and how we can progress from there. We are not here to criticise Government in any way; we are here to nudge things in order to get them moving.

Ms Palazón: A fundamental problem is the timetable by which the plan was drawn up and implemented. It was done at a time when one Government was about to cease existing and another come in. Perhaps it has fallen between the two in that process. We know that the Minister is putting together a new plan to ensure that things are better co-ordinated. This is perhaps the opportunity for us to say what has to be part of that plan.

Mr Underwood: I would like to be slightly critical, if I may. I mentioned earlier that I get frustrated, sitting on stroke boards at the lack of representation from local authorities. Maybe that can be driven downwards more centrally by saying that there needs to be a 50:50 partnership, or maybe a three-way partnership, involving organisations in the health, social care and voluntary sectors, in driving things forward, as Lowri was saying. Things are lost in translation sometimes, in that, where does stroke fit? In many places, it fits into the chronic conditions management framework. In Gwent, it fits in with the clinical futures or frailty agenda. Does it fit into the primary and community care work that came from Chris Jones's model, which looked at the community resource teams throughout Wales? Is that where community stroke services should fit? I do not think that the organisations know. Without being critical of them, I think that they think that they are doing the right thing. Things are progressing, but in Betsi Cadwaladr University Local Health Board, Aneurin Bevan Local Health Board, and in Abertawe Bro Morgannwg University Local Health Board, it sits in different places.

Without meaning to be too critical of the programme and the detail, I do not think that there is full ownership, which Lowri referred to. If it is not being driven by all parties, it will not go anywhere. So, a lot of work could be done without any investment that could move this on quickly.

Mark Drakeford: Could you say something on Lindsay's second question, which was to do with post-stroke recovery services? You have already touched on it, I know, but could you make some points?

Ms Palazón: I have a few points. Despite what we hear day in, in day out about austerity measures and the problems of the global economy, services need to have a level of

investment. Having said that, what we need to do first is to get an overview on how we are investing in stroke services. As was said this morning at the cross-party group, this is realigning the deckchairs so that the ship will float and keep going.

11.15 a.m.

We need to strategically analyse what we have invested and look at where we need to move funding in the pathway for life after stroke services. They are not being funded properly, and we do not have the engagement of the appropriate practitioners, even at a strategic level—although, as part of the Wales Stroke Alliance there is a sub-group, on which we are representatives, to look at the life after stroke pathway, and how that needs to be delivered. It is being driven by clinicians, but as Paul said, life after stroke is primarily in the social care/social justice domain, really; clinical intervention finishes at one point and social intervention needs to start. We do not have the resources, or engagement with the right bodies in terms of the partnership where the medical and the social sides come together. The clinical psychologist example is clear. Neuropsychology is a specialism of the three practitioners that we have working on stroke in Wales, but they are all based in south-east Wales, for starters, and one of them is moving out, so we only have two in reality. They will not only be dealing with the emotional and psychological support needs, which are critical, but also with cognition, which sometimes other medical professions cannot detect.

Mark Drakeford: Darren has one very specific question, then for the last 10 minutes I will go to Lynne, William and Vaughan.

Darren Millar: I have one very brief question. The purpose of this inquiry is to look at stroke risk reduction rather than rehabilitation issues, which you have touched on. To what extent does the lack of focus by social services departments in local authorities—which you mentioned earlier, Paul—contribute an extra risk factor for further strokes?

Mr Underwood: The health, social care and wellbeing strategies mean that all local authorities, in conjunction with local health boards, should really be prioritising this within their plans, as well as within the full health plans. If the full structure of community services is not in place—in the health, social care and voluntary sectors—then people will not be pulled out of hospital appropriately; they will be staying in secondary care and costing more money. I referred earlier to the Gwent frailty project and the pump-priming investment that Aneurin Bevan LHB has had there, ensuring that appropriate community services are in place. I am not saying that that investment needs to happen across the board, because I know that there are comparator sites such as Bridgend where they are trying to do things on a lot less money. However, without the commitment from social services, and without a review of the invest-to-save perspective, other organisations can do things differently and more cheaply, and we will have the same problems. There needs to be a drag from secondary into community care, and we need the buy-in of all sectors to ensure that that happens.

Darren Millar: Will that reduce risk? That is the issue.

Mr Underwood: Hopefully, yes. The problem at the moment is that organisations are trying to appropriately—I used the word ‘push’—transfer care into the community, but if the appropriate services are not there, readmission rates will increase, and there is compromise in the community because care cannot be provided.

Lynne Neagle: To be honest, that was my question—on the local government side. I just wanted to make one point. I thought that the evidence was clear and focused, but also worrying, in terms of the big implementation gap that we have, yet again. You are clearly in the dark about how this stroke risk reduction plan is working, and I also now feel in the dark. I would like to ask, Chair, if we could maybe have a paper from officials. I know that we are

hearing from the Minister in November, but it would be helpful at this stage, so that we can scrutinise this as we go on, to hear from Government on how this is being taken forward, and where it believes the ownership lies, so that we can pursue that with other witnesses.

Ms Palazón: Yes, because this is a huge opportunity.

Mark Drakeford: We will do our best to acquire that.

William Graham: Without wishing to labour the point, I must tell you—I am sure that this goes for all Members—that a portion of our postbag is about exactly what you describe, namely a feeling of abandonment on the part of elderly people who have suffered a stroke, and, of course, secondary and third strokes come after that. How do you suggest we may be able to introduce some realistic plan for engagement on the part of social services? That seems to be the best way to ensure at least some continuity after release from hospital.

Ms Palazón: One of the problems that we face with social services—which is perhaps not what you want to hear me say in response to your question—is that the eligibility criteria have been set so high, because of the cost, that prevention and long-term rehabilitation are not looked at. Fundamentally, the problems are the eligibility criteria and the capacity that local authorities may or may not have to address the population we are concerned with. Another area is to do with age discrimination. Going back to the issue of thrombolysis, we know that the majority of strokes happen in people aged 65 and over, but thrombolysis cannot be applied to anyone over the age of 80 because clinical trials exclude older people.

William Graham: That is dreadful.

Ms Palazón: So, we have a situation where life-saving interventions are denied to people on the basis of their age, and that goes back to clinical trials. So, it is a bigger picture than that. Another area is our own services. At the risk of being caught in a conflict of interest—I am declaring it—we are in a contractual relationship with all of the LHBs across Wales and with a tiny minority of local authorities to provide services to stroke survivors. However, we are touching only the tip of the iceberg. We are not appropriately resourced to be able to deal with all of the referrals that come our way, nor are many other partners in the third sector.

Mr Underwood: If I may, I would like to come in on that. You mentioned the second and third strokes. Those are the individuals we are serving as a by-product of being funded by statutory organisations. On the idea of the thresholds of care being lowered, it is the maintenance of the lower-level need that prevents the exacerbation to the problems that cause admission and further strokes. We know that, not only the Stroke Association, but many organisations, can enable lower-level support. We are even talking about things such as simply having individuals to check pulses or carry out basic-level health checks who could make a referral to a doctor or another service to stop the risk occurring again. So, there are many ways it can be managed very cheaply. I am not saying that we are the only organisation that can do that; of course we are not. It is about ensuring that statutory organisations are aware of what is around them so that they can do things to increase the value added. I think that we can do that while reducing costs.

William Graham: Should we, therefore, be asking for evidence from social services on eligibility, the care plan and so on?

Ms Palazón: Yes, I would agree with that. I would also reiterate that preventive action is not just about preventing a second, third or fatal stroke, but the decline in mental health and in other aspects of health that inevitably come as a result of people not having the support services that they need. They end up being readmitted into the medical system for depression and for falls and other aspects associated with having had a stroke and a lack of support.

Ms Griffiths: To respond very quickly to your question about how we target local authorities, the local government elections next year will be a key opportunity for us as an organisation to lobby councillors and chairs of health and social care committees. We will keep banging on the door, because, as a voluntary organisation, that is one luxury that we have—we can go in there and make a bit of noise. I hope that we can do that next year.

Vaughan Gething: I will not go back over some of the things that have already been said, but something was said in the closing remarks of the previous evidence that we received that I did not have a chance to ask about. The assertion was made that people under 30 years of age have a one in two chance of developing atrial fibrillation. Do you recognise that statistic? If so, where is the evidence that supports it and what are the factors? Is it more than simply having an ageing population?

Ms Palazón: Congenital factors as well as lifestyle factors can lead to atrial fibrillation, and we know that it increases with age; that is a fact. However, we not only have people who have AF at a younger age, but strokes as well, which is why the challenge of the awareness-raising work is to break all the myths and misconceptions. Yes, it is a condition that primarily affects older people, and as we are an ageing population, particularly in Wales, it is of extreme relevance. However, we also have a significant number of people under the ages of 50 and 40 who experience strokes, many of whom we are targeting with our awareness-raising campaign. This is, again, something that was highlighted at the cross-party group this morning. Surgeons and physicians used to say that it affected people at 60 or 70 years of age, but it is now people aged 45 or 50 who are presenting with strokes and symptoms of stroke.

So, the situation is changing because of lifestyles, health inequalities, smoking and drinking in particular. We were at a public health conference yesterday, and one of the statistics that the chief medical officer presented to us was quite interesting—which is something that we already knew anecdotally, but is now proven through the research—namely that drinking, for example, in terms of the stratification of social class, is affecting professional and affluent people. There is a lifestyle change that is not to do with health inequality, as such, which signals a big problem with regard to that cohort that will very soon be in hospital beds. So, it is becoming complex in that respect as well.

Vaughan Gething: What I was asking was whether the evidence base for that assertion is robust. It is quite a stark statistic to say that one in two people who are under the age of 30 today will have AF. That is a huge additional risk, not just for more strokes but for more serious ones, presented by your very clear evidence and the evidence this morning. So, I am interested in the source of the evidence, because if that is a real statistic that we can trust and rely on, it will have an impact on our recommendations.

Ms Palazón: Those statistics are taken from UK studies. We do not have a sufficiently robust evidence base from within Wales, and one of the problems that we have, which was acknowledged by this report—I know that some work is beginning to be done—was about having a register for Wales. We also know that the older people and ageing research and development network has a stroke research group, but we do not have a sufficiently robust evidence base from within Wales about Wales. The evidence, therefore, comes from UK studies.

Ms Griffiths: I will speak to Jo Jerrome about the statistic that you are talking about to find out where it has come from and come back to you.

Mark Drakeford: That would be helpful. Thank you. It will not be Welsh-specific, in that instance; if there is a pattern, it will be well beyond Wales.

We have more or less come to the end of our allotted time, but I would still like to give you a few minutes at the end to raise any points that have not emerged in our discussion that you want to ensure that the committee is aware of and takes into account. Who would like to round off for us?

Ms Griffiths: As far as I am aware, we have addressed every single one of our key points.

Mr Underwood: I have one point to make. Someone mentioned the cardiac networks earlier on, and I know that a lot of work is going on for them to now be recognised as vascular networks. Ana mentioned the changing of the term ‘stroke’ to that of ‘brain attack’. You have all heard of ‘heart attack’ and you have all probably heard of the terminology ‘MI’—myocardial infarction—which is the same thing. When you hear people talking about stroke, maybe even at primary school age, not a lot of people know what it means. Maybe we need to change the way that we refer to stroke as a brain attack and then the education and the prevention agenda could focus on it, which could make people think, ‘This is a hard-hitting name to be classified under.’

11.30 a.m.

Ms Griffiths: We have not really addressed the AF screening issue much. AF strokes are more debilitating and prove more fatal than other strokes—not to lessen the impact of other strokes. AF screening can also be carried out in existing settings. We have not really covered that, but I am sure that Jo talked about it.

Mark Drakeford: We had a reasonably good opportunity to rehearse those things with Jo.

Ms Palazón: I am not sure whether Jo covered the role of the specialist nurse.

Mark Drakeford: Do you want to give us one or two sentences on the role of specialist nursing? I do not think that we discussed it.

Ms Griffiths: As part of an AF campaign event that we held in July with the Royal College of Nursing, one thing that we talked about with the RCN was the need to have someone in local health boards who has knowledge and training not just about AF—of which I am sure that there are some—but about AF and its link to stroke. We need some training in that area; AF is a heart condition, but it can lead to stroke, which is a brain condition, and they need to be joined up.

Ms Palazón: A specialist nurse will focus healthcare more effectively.

Mark Drakeford: We are taking oral evidence from the RCN in two weeks, so that is helpful and we will be able to pursue those points with them.

Diolch am fod yma y bore yma.

Thank you for being here this morning.

Thank you for that; it has been very helpful to us. I am sure that you already know that you will get a transcript of what you have said to us and what we have been asking you. You will get a chance to correct anything that needs to be corrected in terms of its accuracy. We will be grateful for your further help on that. For this morning at least, thank you very much.

We are moving on to a set of housekeeping items, for us to plan ahead and see what we are going to do next. Rebecca, do you have something specific arising from what we have already heard this morning?

Rebecca Evans: I was wondering whether we could write to all parties in the action plan to

find out whether they are aware of their responsibilities, what actions they have already taken, and what more support or resources they may need to deliver. It mostly includes local health boards, local authorities and so. That is my first suggestion. The second is this: within the next two weeks, the chief pharmacists will meet to decide which six public health campaigns they will take forward in 2013. I was wondering whether the committee thinks it is too early, at this stage, to recommend that they look into stroke prevention. I do not think that it is, given the fact that it is the third biggest killer of people in Wales.

Darren Millar: We will have to ask the Minister to ask one of her officials to update us on the implementation, so I suggest that we wait until we receive that before we write to the other partners. It will be a bit of mish-mash otherwise and there could be glaringly obvious inconsistencies, which we may find interesting afterwards, but I think that that may be a better approach.

William Graham: Having said that, the second point is much more relevant because it could be fairly soon.

Kirsty Williams: On the second point, we have had some evidence this morning that seriously questioned the effectiveness of current public health campaigns with regard to whether they actually make a real difference. We need to hear what evaluation has been carried out on the effectiveness of those campaigns. From the evidence that we have had this morning, it seems to me that the more generalised one that had a much bigger media exposure was successful, as opposed to the AF one, where all it had done was raise awareness among people who already had the condition. I do not think that I could recommend a public health campaign and further expenditure on a public health campaign unless I had robust evidence that that was going to make a difference.

Rebecca Evans: I was thinking in particular about the public health campaigns in community pharmacies, because they have already been funded for the next three years. So, it is already a funded programme. It is not so much about television public health campaigns, but the community pharmacy campaigns, such as the diabetes one, on which all evidence has suggested that that has been a positive campaign.

Mark Drakeford: Here is my suggestion: I am reluctant for us to start recommending things without having completed our inquiry, but we should write to those who are responsible for making that decision, drawing their attention to the fact that we are holding an inquiry and ensuring that they have a chance to look at the evidence that we have had so far. So, we will at least ensure that they are thinking about it. If they have come to the conclusion—because they will have other evidence as well as what we have heard—that this should be a part of it, we will have done our job in that way. It is probably a bit early to move from what we have heard this morning straight to saying to people, ‘This is what we think you should be doing’.

On the first point, which I think was useful, Darren is right. We should think about how we can collect some evidence from the people charged with the implementation of the stroke action plan to enhance the evidence that we have heard already this morning about how it is being done. We will have a think about it.

Lindsay Whittle: I am sorry, Chair, but does that mean that we will take that further? It will mean liaising with the health boards, probably—

Mark Drakeford: The point was well made that we heard quite compelling evidence this morning about some gaps in the way that the plan is being implemented and that we need to augment the information that we have by hearing directly from some of those who are responsible. We will give it some thought, given what Darren said about other evidence that we will get, and come back next week with some suggestions as to how that would best be

done.

Diolch yn fawr am hynny.

Thank you for that.

11.36 a.m.

Craffu ar Gyllideb Ddrafft 2012-13—Ystyried y Dull Gweithredu Scrutiny of Draft Budget 2012-13—Consideration of Approach

Mark Drakeford: There is a series of housekeeping issues for us to think about. Those of you who have done this many times before will know that the budget scrutiny by committees is always a matter of timetable jamming. In the paper that you have, you can see what the timetable looks like this year. As far as the health committee is concerned, we know that the Ministers are available to come to give evidence in a budget scrutiny session on 20 October.

The timing of this is so condensed that we have had to do a bit of thinking ahead, and so I have some suggestions to make to you, rather than our normal approach, which I would have preferred, which would be to hear from you first. My suggestion is that we hold a session on 12 October in advance of our session with the Ministers that will not be quite like the conventional sessions that we hold. We would have a roundtable discussion in which we would invite a small number of experts in the field to come in, not to give us evidence so much as to help us to think of the sorts of things that we want to pursue when we have the Ministers in front of us. It would be a session to help us to develop our thinking so that, when we have a chance to scrutinise the Ministers on the budget, we would be tuned into the issues that we would want to pursue and the types of questions that would help us to get to the information that we want in the sorts of areas, particularly in health, in which there are policy and practice issues to pursue. Lindsay and I went yesterday to a useful session with the Research Service on the budget at which six different areas on which committees might want to concentrate during budget scrutiny were suggested. We could ask the people who would come to a roundtable session with us to give us some help in getting below those headlines and to think of it in a health-specific context.

I am slightly anxious in that, this year, we are doing it on a wing and a prayer in relation to the people whom we can ask in to help us. There is also a suggestion in the paper that, thinking ahead to next year, we might quite soon identify a couple of people whom we might ask to keep in touch with the way that budget matters work out over the coming year, so that, this time next year, we will have some expert advice from people who have made it their business to keep track of the way that these things work out over the next 12 months. That would put us in a better position to do the job that we all want to do when we see the Ministers this time next year.

Darren Millar: May I respond to that? I welcome the paper and your thoughts. Having a roundtable discussion this year is a good idea, and I have no problems with that. Historically, there has always been a challenge, because the window of opportunity to comment is very limited, so I think that that will help. I am not so sure about the idea of an expert adviser to the committee in the future. To be fair, we have plenty of expert advice from the plethora of organisations out there that are representing their sections of the health and social care industries. They lobby us on a regular basis and make their priorities clear in terms of spending. I assume that there would be a cost involved in an expert adviser, so to spend unnecessarily on that might be unwise.

Kirsty Williams: I welcome the approach that you have outlined, Mark, and I agree wholeheartedly with your suggestion regarding a roundtable discussion. Building capacity within the non-governmental side of this institution is crucial to its ongoing credibility. There is nothing more important that we can do as scrutinisers than to look properly and carefully at

the budgeting process. In the past—and I have been here since the beginning, so this is not a criticism of anyone in particular—the budget has been looked at very quickly over a couple of weeks, and then, to all intents and purposes, it is forgotten until we go through the same rigmarole the following year. I personally think that Darren is right: there is a plethora of organisations with views, but they are their views, influenced by their role within the system in which they work. Having some advice, help and guidance for this committee that is independent of the pressures where that person sits within the health service would be a helpful tool in building capacity in this institution—not just to do justice to the budget scrutiny that is coming up in the next couple of weeks, but to the ongoing work. There is no aspect of our work that is more important than health, because it is the biggest-spending department. If that part of the budget cannot be spent properly, and if it is not looked at carefully, it will have an impact on all the other services that the Welsh Government is able to provide and which we scrutinise in this National Assembly. So, I wholeheartedly support you in that approach.

Mick Antoniw: I agree absolutely with Kirsty because health takes up something like 40 per cent of our budget and it is such a complex and specialist area that the sort of ongoing support that we will require has to be strategic, has to provide an overview, and has to be independent of all the lobbying pressures that we become subject to. Without that sort of support, I will find scrutiny difficult, and the coming years will probably be the most difficult since devolution. There are experts and experts, as we know; the key is identifying those who really have the nous to understand what we need, and are prepared to give that impartially and independently to us. Then, what we make of it is a matter for us. However, I would envisage that, periodically, we would be presented with a review of what is happening—a state of the service report as we go along.

Lindsay Whittle: Would a witness from the Welsh NHS Confederation give us impartial advice, or would they say that we need to spend more on the NHS? Would a witness from social services give us impartial advice or say that we need to spend more on social services? The same goes for areas such as adult mental health, for example. They will all have very good arguments, and we will agree with them all. I do not see why we would want an academic here; it frightens me to death, to be honest. I thought that it was our job to scrutinise the budgets. I would be quite happy for us to have quarterly reviews of the budget so that we can look at any overspends and underspends to prevent this scrabbling at the end of the financial year, as I said yesterday. If money is being spent in areas where it is not needed, then we need to be monitoring the situation throughout the year. I thought that that was this committee's job. I may be wrong, because I am quite new here. I appreciate that the figures are not with us yet, because they will be published in October, when the budget goes before the Finance Committee, but we can look at those figures—we do not need these people from outside. We employ researchers, and there are enough accountants here: more than you could shake a stick at. They could do the job for us; that is their job, is it not?

11.45 a.m.

Lynne Neagle: I disagree with Lindsay. I agree with the approach that you are setting out, Chair. I have one plea, which is not to forget about the social care side of it. I am not at all convinced that the protection that the Welsh Government intended to afford to social services in this financial year has been delivered. We need to keep a close eye on that. I would certainly welcome the input of expert advisers.

Darren Millar: To respond to some of those points—[*Inaudible.*—]—in the last Assembly we tried to do more of that, as Kirsty Williams has mentioned, by having Ministers in on a more regular basis to hold them to account for what was going on in their departments at the time. That gave us an opportunity. However, regarding appointing a special adviser, we do not know what the costs would be, and we should not commit to things if we do not know what

the potential costs are. We must have clear information regarding the role of a special adviser. I am not saying that I want to rule it out, but I question whether it would add significant value to the process. We already have all these organisations with their areas of expertise, and, within the timeframe of when the budget is produced to the time we have to scrutinise it, these organisations drill down into the details in ways that one person could not. They can then arm us with the information. If you had a single expert adviser, that person would not be able to do what those organisations can.

Kirsty Williams: Darren is right that there are people who have a great deal of expertise in specific areas. I do not think that we are ruling out hearing from these people; that has been an important part of the budget scrutiny process in the past, and will continue to be in future. What I am interested in is building capacity within the non-governmental side of this institution to really hold the Government to account. Given that Darren has legitimate concerns and wants to have further details, I suggest that we agree to look further into the matter and flesh out paragraphs 11 and 12 so that any concerns that Darren has about the cost, role and job description are addressed. That might be the way forward.

Vaughan Gething: [*Inaudible.*]*—*this is what we want to do. I agree that we need to have objective assistance, rather than assistance from the more partial campaign groups. For good reasons, they are deliberately more partial in the way that they go about things. I would welcome assistance in providing effective scrutiny. So, it would be good if we could have that paper. We could review it after a year to see how effective it has been.

Mark Drakeford: I think that we have a way ahead on that. We will learn something over the next three weeks. Darren's view is that we already have all of the help that we are going to need. We will see how that works out. At the end, we will see whether that is the case. While we are learning from that experience, we can work up the idea that we had this morning. If we were to get independent advice we would want it to be good and to do the right job. So, there is a bit more thinking to be done. We would also need to know how much it would cost.

Darren Millar: I have one further comment to close, which is that the biggest obstacle to scrutinising the budget is the very limited information that comes from the Welsh Government. It is far more limited now that the Executive has split from the Assembly.

Mark Drakeford: So, for this year, we are happy to go with the plan that is in the paper, which is a round-table session, which will help us to tune ourselves up to have the scrutiny session with the Minister. Do you want the round table to be held as a public committee session, or do you think that we might get more out of it if it were less formal?

Mick Antoniw: I am happy for it to be open; the worst thing we could do would be to have too many closed sessions. There might be a need for an opportunity to also have a number-crunching, head-scratching informal session as well, with some expert advice.

Mark Drakeford: We might not be able to have both, Mick, that is the problem, because of the timetable.

Lynne Neagle: I wonder whether people might be more frank in a private session. When we did it with the Children and Young People Committee in the last Assembly, I think that it was in private.

Mark Drakeford: I see that you have done this before.

Kirsty Williams: As Lynne said, we might be more assisted by a very frank discussion under the Chatham House rule. I do not think that you would ever get a finance director of the NHS

to talk about £1 billion in the same way again if the discussion were held in public.

Mark Drakeford: Okay, this time, then, we will do it that way. It will be a session for us on 20 October: a session to inform Members to allow us to do the job that we need to do. Therefore, this time, we will do that as a private session.

11.50 a.m.

Ymchwiliad i Ofal Preswyl i Oedolion—Papur Cwmpasu Inquiry into Adult Residential Care—Scoping Paper

Mark Drakeford: This comes to us as a result of the discussion that we had before the summer recess and the subsequent session with Rob Pickford that some of us were able to attend. The feeling that we took from those discussions was that the committee was interested in holding a relatively substantial inquiry into the area of residential care services for older people, which would not be confined simply to what happens after people arrive in residential care, but would also look at the pathway that took them there, whether there were services and decisions along the way that might have been done differently had other things been in place.

The paper that you have before you is a scoping paper that has been deliberately drawn on that broad basis. You will see that there are seven potential strands to the inquiry. I would like to draw to Members' attention the advice that I have received, which is that, if this is the work that we decide to do after Christmas and if we want to do it on the scale noted in the paper, it will dominate our work for quite some time. I am sure that you have all met all sorts of organisations over the summer that have said, 'If only the committee could do an inquiry into this or that', but an inquiry of this size would reduce our opportunities to do that. We will not be able to do all of those things as well as this, and some of the other things may have to wait. So, we can narrow the scope of the inquiry to allow a bit of room for something else, but it has been drawn up in this way because I felt that the weight of opinion before the summer was that we wanted to do something that we thought would be substantial and had a fighting chance of making a difference to the way that policy will be made.

Kirsty Williams: It is an unenviable position for you to be put in as the Chair. You are quite right; this could dominate our work for many months to the exclusion of everything else. I am happy, if the committee is happy, to do a large-scale inquiry, but if we were to focus it down it would give the committee greater flexibility to respond to events as they arise. I am particularly interested in quality and regulation and inspection, because those are the areas that have the greatest impact on people who are entering the care sector: the quality of that provision and the way in which we ensure that quality is maintained and people's wellbeing is safeguarded by appropriate inspection. We have seen some horrible examples over the border—not in Wales—where organisations that have been inspected have been found not to be failing, only for the most horrendous examples of abuse to come to light subsequently.

Mark Drakeford: Lynne, do you want to say anything?

Lynne Neagle: I take what Kirsty has said. If I had to prioritise, issues of quality would be the priority, because of the constituency experiences that I have had. However, I see some value in looking at all of these issues. I am particularly interested in the alternative funding and ownership models, because the way that services are run at the moment has a massive impact on the ability to deliver a quality service. I would not be unhappy to focus on something as significant as this to the exclusion of other things.

Darren Millar: I agree with what has been said about quality. We have to have a sharper focus, because we will have so much work to do—especially when the social services

legislation starts coming through—that we will want to sharpen up our timetable to focus on the areas on which we can have the biggest impact. However, in addition to the quality issue, I agree with Lynne that we need to look at the alternative models. Also, under point 4, the capacity of the sector, there is a real shortage of beds in the sector in some parts of Wales, and we need to include that. So, I would be happy if we could concentrate on capacity, alternative models and quality.

William Graham: [*Inaudible.*]

Mark Drakeford: In some ways, the issue touches on it. It is a running theme.

William Graham: I support what you suggest, Chair.

Lindsay Whittle: If we are to have an inquiry, whenever the inquiry takes place, we should involve all of the providers, including the Wales Local Government Association, registered social landlords—the whole kit and caboodle. That is vital.

Mark Drakeford: Even with the slightly narrower focus that we have discussed, this is still going to be a major inquiry. Even concentrating on the four things that we have highlighted, and taking Lindsay's point about needing to take comprehensive evidence, this is going to be the single biggest thing that we do as a committee in this Assembly year. However, by narrowing it down in the way in which we have suggested, it might give us a little bit of elbow room. I am anxious that we do not tie our hands so much that when legislation comes our way, we struggle to find time to scrutinise it.

Mick Antoniw: On the funding impact, there will almost certainly be UK legislation, which will be beyond our remit to some extent, that we will have to have regard to.

Mark Drakeford: Future funding models for social and residential care will form the context in which all of this is discussed.

William Graham: In terms of adult residential care, is it intended for that to also encompass mental health provision? That is a large part of it at present.

Mark Drakeford: I do not see how we could avoid talking about elderly mentally infirm care, as it described, because that is a very big part of the sector, but you are right to highlight it.

Darren Millar: A good way of truncating an inquiry is to have panels of organisations presenting evidence at the same time so that they do not repeat the same points. That might be something that we can think about.

Mark Drakeford: We have agreed on a focus on older people, because we could look at a wider age range, but that would just open up the scope even wider. I will outline the timetable then. I think that we have a good sense of what the scope of the inquiry is likely to be. We will give you some draft terms of reference, based on today's discussions, at next week's meeting on Wednesday, 28 September. We said before the summer recess—and I am keen that we should try to live up to it—that we wanted to give organisations out there that have an interest in this inquiry a chance to comment on the terms of reference. If you are happy for us to do that, we can let them know that today so that they will be alerted to the fact that, on Wednesday next, we will agree draft terms of reference. That will give them two weeks to comment before we finally confirm the terms. We want people out there to know that we are keen to learn from and listen to them, and I want to give people a chance to let us hear their voice.

Darren Millar: They will just recommend a much wider inquiry.

Mark Drakeford: You are absolutely right, and maybe we need to get a message out there that we are not looking for organisations with special interests to write in and say, 'But you haven't thought about x'. We are not going to be able to do very much with that sort of comment, but I want people to look at the terms of reference, think about what we have said today and tell us whether it could be shaped a bit more sharply, or done in a way that would shine a better light on the issue that we want to talk about. Those are the kind of comments that we are definitely interested in learning from.

Mick Antoniw: In terms of the timetable, could we have an indication from the Government about its legislative timetable, as that will determine a lot of our work?

Mark Drakeford: We can certainly ask. One reason why we said before the summer recess that we thought that this inquiry was especially worthwhile for the committee was that, by immersing ourselves in these policy issues, when the social care Bill that the Government has indicated it is bringing forward comes our way, as individual Members, we will be that much better prepared to understand those issues and do the job we want to do on legislation. So, we will try to get that indication if it is available, Mick.

12:00 p.m.

**Ymchwiliad y Pwyllgor Plant a Phobl Ifanc i Iechyd y Geg mewn Plant yng
Nghymru—Llythyr gan y Cadeirydd
Children and Young People Committee Inquiry into Children's Oral Health—
Letter from the Chair**

Mark Drakeford: You will have seen a letter that has come to us from Christine Chapman, as Chair of the Children and Young People Committee, which has embarked on an inquiry into children's oral health. There are inevitably overlaps between committees' responsibilities. As a children's committee, it has prioritised this issue. However, it is extending an invitation to any member of this committee who has a particular interest in that from a health perspective to sit in on the oral evidence that it will be taking. We know that there can be complications with diaries and clashes of committees and so on, but I am sure that the offer is genuinely made. Lynne, given that you are a member of that committee, I think that we are well covered.

Lynne Neagle: I will be your mole, yes. [*Laughter.*]

Mark Drakeford: That is excellent, Lynne. Thank you for that. Christine also offers to ensure that the evidence it takes is available to us. So, if, near the end of that inquiry, we want to spend half an hour thinking about whether there is anything we want to contribute, we will have the opportunity to do that.

Darren Millar: There will also be a letter coming to you from the Public Accounts Committee with regard to a recent update report by the auditor general on mental health services in Wales. The committee felt that it was appropriate to write to this committee to see whether it wants to consider that report.

Mark Drakeford: Thank you very much.

12.01 p.m.

Papur i'w Nodi: Blaenraglen Waith y Pwyllgor—Hydref 2011
Paper to Note: Committee Forward Work Programme—Autumn 2011

Mark Drakeford: Finally, I am quite keen that we should publish our forward work programme so that organisations that want to know when we are taking evidence and on what can prepare themselves, not necessarily to give evidence, but to follow the evidence we are taking. It is inevitably subject to change. It includes a session on 6 October when we, as a committee, will be scrutinising the annual report of the Commissioner for Older People in Wales. I think that that date is fixed, but, otherwise, the timetable is a bit more fluid. Are Members happy that we publish it so that people are aware of it? I see that you are.

William Graham: We were encouraged in this morning's session to ask for some evidence from social services. It is not in this programme, but, even if we were to ask for written evidence only, it would be something for us to be able to look with regard to those criteria, particularly with regard to trying to prevent strokes.

Mark Drakeford: Yes, we will certainly ensure that we ask for written evidence. If we can squeeze someone in, we might want to take oral evidence.

William Graham: I appreciate the timescale.

Darren Millar: One thing that I think all Members found extremely useful was an open session with the appropriate Ministers, which used to take place once a term in the former Health, Wellbeing and Local Government Committee. We might be able to see whether we could slot that into the timetable before December.

Mark Drakeford: I think that we are in discussion with the Minister's office about exactly that sort of open scrutiny session before Christmas.

Darren Millar: Great. Smashing.

Mark Drakeford: Diolch yn fawr iawn.

Daeth y cyfarfod i ben am 12.03 p.m.
The meeting ended at 12.03 p.m.